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ORIGINAL ARTICLE

How communication between cancer patients and their specialists affect the quality and cost of cancer care

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Abstract

Purpose Communication in cancer care is multidimensional and may affect patient treatment decision-making and quality of life. This study examined cancer patients' perceptions of the communication with their cancer specialists and explored its impact on the care they received and the financial burden they experienced.

Methods Semi-structured telephone interviews were conducted with 20 rural and 20 outer metropolitan Western Australians diagnosed with breast, lung, prostate or colorectal cancer. Thematic analysis using a phenomenological approach was undertaken to derive key themes regarding the communication experiences of the participants.

Results Four main themes emerged: information context, communication about treatment options and treatment providers, communication about costs of treatment and impact of communication on continuity of care. The quality of the communication experienced by participants was variable and in many cases sub-optimal. This affected their ability to undertake well-informed decisions regarding treatment and providers and led to substantial out-of-pocket expenses for several participants. Whilst participants differed in their information needs and expectations, most participants trusted clinicians' treatment recommendations.

Conclusions Our results raise concerns about the quality of communication cancer patients receive during treatment and the repercussions for their treatment decisions and out-of-pocket expenses. Clear treatment and cost communication could empower patients in choosing treatment and providers. However, these findings suggest patients must remain vigilant during consultations and discuss available treatment pathways and their financial dimension to avoid costly treatments or missing out on available financial aid.

Keywords Cancer · Communication · Supportive care · Qualitative study · Western Australia

Introduction

Patient-centred health care recognises the importance of patients' engagement in their care and the value of this engagement for patient outcomes and quality of care [1]. Cancer patients have unique needs, and clear patient-centred communication is essential for good clinical practice in cancer [2, 3]. Poor communication in cancer care is multidimensional and exerts a negative influence on treatment decisions, symptom management, psychosocial experience and quality of life, with further ramifications for patient out-of-pocket expenses (OOPE) [4, 5]. Research suggests that health professionals need to discuss the financial consequences of diagnostic and treatment choices in the same way that they disclose treatment side effects [6], because financial distress caused by cancer treatment has been identified as a mortality risk factor [7, 8].

In Australia, with increasing cancer incidence and prevalence [9] and escalating costs for health care [10], the burden of cost is shifting to the patient [10]. Patients are reporting increasing financial burden from cancer care and associated direct and indirect OOPE [11–14]. Limited work has explored the relationship between communication and patient's experiences of cost and OOPE [15]. Research suggests that conversations about treatment costs in clinician–patient interactions

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are rare and clinicians are often hesitant to initiate the conversation [16–18], whilst patients want to have the conversation [16, 19]. Cost discussions promote shared treatment decision-making and may lower OOPE, improve patient satisfaction and could facilitate more informed treatment decisions [15]. Clear cost communication has been endorsed in reports released by patient advocacy bodies, voicing the concerns of cancer patients [11, 20].

This study explored rural and outer metropolitan cancer patients' perceptions of the communication with their cancer specialists, its impact on the quality of the care they received and the financial burden they have experienced.

Methods

Setting

WA's health system

Western Australia (WA) is Australia's largest state, spanning 2.5 million square kilometres. It has a population of just under 2.6 million [21], of which 80% reside in the Perth metropolitan area. The health system is a mix of services provided by the Federal and State Governments and private health care providers. Whilst tertiary hospitals in WA are located in the capital city, Perth, some densely populated outer metropolitan suburbs and large regional towns have hospitals with specialised cancer units. All Australians have universal access to primary care, and the right to receive public hospital services, for free either as a public patient or as a private patient with extra costs. People with private health insurance (57.1% of the Australian population [22]) have varying levels of cover for access to private hospitals and ancillary health services.

Cancer patients' treatment pathways

Prior to diagnosis most symptomatic cancer patients present to a GP or a hospital emergency department. Access to a cancer specialist requires a referral usually initiated by a GP or a hospital clinician who has performed initial diagnostic tests. An individualised treatment plan is then developed, usually by a multidisciplinary team, and the treatment options are discussed with the patient.

We conducted a larger multimethod study that explored Western Australian cancer patients' experiences during diagnosis and cancer treatment, which focused on patients' experiences of their health care and associated OOPE. The current study is a secondary analysis of these data. Whilst not explicitly targeted in interviews, the emergence of strong themes surrounding communication with service providers prompted this secondary analysis.

Participant recruitment

Participants were recruited from the patient sample who took part in the Out-of-Pocket Expenses Study (OOPES), an ambidirectional cohort study investigating rural and outer metropolitan cancer patients' OOPE as described elsewhere [23]. Eligible participants were recruited via the WA Cancer Registry and offered to opt-in to being contacted for a telephone interview regarding their OOPE experiences following completion of treatment. A purposive convenience sample of 40 respondents (20 participants from each of the OOPES primary regions of interest—outer metropolitan and rural) was selected to participate in semi-structured, in-depth interviews. This sample has been recommended as a size for phenomenological studies at which thematic saturation should be achieved [24, 25]. Eligible participants were selected based on region, diagnosis, age, health insurance status, employment status and a range of experiences (as reported in the questionnaires) (Table 1), with participant selection prioritising under-sampled characteristics as the interviews progressed.

Ethics

Ethics approval was obtained from the WA Country Health Service Ethics Committee (#2014:10) and the Department of Health WA Human Research Ethics Committee (#2014/26).

Data collection

Semi-structured telephone interviews were conducted in 2016 and 2017 and audio recorded. They explored the patient experience throughout their diagnosis and treatment, with particular attention to the impact of costs following their cancer diagnosis and treatment. Interviews were on average 37 min long and guided by an interview schedule. Once all interviews

Table 1 Participant demographic characteristics

Characteristic	Number	Characteristic	Number
Age		Area of residence	
≤ 50	< 5	Rural	
51–65	12	South West	10
≥ 66	24	Great Southern	< 5
Sex		Midwest	< 5
Male	22	Goldfields	< 5
Female	18	Outer Metropolitan	
Cancer diagnosis		Peel	6
Breast	11	Joondalup	< 5
Prostate	11	Wanneroo	6
Lung	7	Rockingham	< 5
Colorectal	11		

were completed, they were transcribed verbatim by a third party (RS).

Data analysis

We adopted a phenomenological approach, as we did not want to constrain the analysis with preconceptions and potentially overlook important aspects of participants' experiences [26]. Transcripts were read initially by project personnel (NSA, HH, JN). Preliminary line-by-line coding of each transcript was undertaken using the constant comparison method and NVivo, version 12, to identify and manage the codes. Thematic content analysis consisted of rereading the transcripts, identifying units of meaning, grouping those units into clusters and identifying a theme that expresses the essence of each cluster [27]. The codes were exported from NVivo into a Word document and NSA repeatedly read the transcripts to identify and consolidate the codes relating to communication into overarching themes and identify patterns between participants to connect main themes. JN reviewed the identified themes and their representative quotes to confirm their credibility. Any discrepancies were discussed and resolved. This cross-comparative approach facilitated the confirmation and validation of conclusions.

Results

Sample characteristics

Forty interviews were undertaken with 20 rural and 20 outer metropolitan participants diagnosed with breast ($n = 11$), prostate ($n = 11$), colorectal ($n = 11$) and lung ($n = 7$) cancer (Table 1).

Four themes were identified regarding participants' communication experiences: information context, communication about treatment options and treatment providers, communication about costs of treatment and impact of communication on continuity of care. There were no notable differences between the themes that arose for outer metropolitan and rural participants; however, rural participants noted difficulty with transition of care between tertiary and rural health care providers.

Information context

The information context surrounding a cancer diagnosis encompasses the delivery, time, place and health professional providing the patient with information relating to their diagnosis and prognosis, as well as the quality and the quantity of the information provided the format, the clinical setting and the time allowed for the consultation. Disclosure of a cancer diagnosis was viewed as a norm by cancer patients; however, one rural participant reported that their doctor was reluctant to inform them of their diagnosis (Table 2, Q2.1).

Broadly, participants revealed that they were provided with plenty of oral and written information about their disease, treatment options and available support. Some found the information packages informative, explained in a way they could understand and a good reference resource (Table 2, Q2.2–Q2.6); others were overwhelmed by the information provided (Table 2, Q2.7–2.11). The need for a support person to be present at the appointments to assist with processing all the information provided was emphasised (Table 2, Q2.8). The complexity and intricacy of the information were a particularly strong sub-theme for participants who talked about the scary and unfamiliar terminology that they needed to “Google” or ask about, which some patients found to be “too much to handle” (Table 2, Q2.7, Q2.9, Q2.10). A participant treated in both the public and the private sector found the private sector more comprehensive when it came to delivery of information (Table 2, Q2.12).

Communication about treatment options and treatment providers

All participants were involved in making decisions about their treatment, and there were varying levels of trust placed in the recommendations of health professionals, friends and family or personal research. Many trusted the professional knowledge and personal recommendations of the referring clinician to help them choose a specialist and type of treatment (Table 3, Q3.1–Q3.3). However, several participants relied on friends or relatives for advice with treatment choices (Table 3, Q3.4) or on their own research into treatment options available locally, nationally and internationally. In some instances, this meant going against their specialists' initial treatment recommendations (Table 3, Q3.5).

It was very important for participants to be well-informed about their treatment and the possible side effects.

They reported conflicting sentiments regarding the clinicians' treatment planning and rationale. Whilst some were pleased with the care they received, others felt that they had not been well-informed about their treatment, its aim or rationale (Table 3, Q3.7–Q3.9). Lack of clarity about the importance of the timing of treatments was raised as an issue (Table 3, Q3.10).

Participants were concerned about communication practices regarding treatment options and side effects of treatments (Table 3, Q3.11–Q3.14). Some identified a reluctance by their specialist to discuss side effects and attributed this to the health providers' lack of awareness about the importance of this information for the patient, unwillingness to acknowledge that some treatments can cause harm (Table 3, Q3.11–Q3.13) and lack of personal experience with the treatment (Table 3, Q3.14).

Table 2 Sample quotes about patient experiences of communication content related to their diagnosis and treatment

Sub-themes	Quotes	ID
Disclosure of cancer diagnosis	Q2.1 … the doctors beat around the bush a bit—they do not like to tell you that you have got cancer, but we told them we wanted to know what was wrong and then the CT scan showed that I had cancer so she told us and that was it, sort of.	R-19
Satisfaction with communication content	Q2.2 When I first was diagnosed … .they gave me booklets and pamphlets and told us where the support groups were and you could go in there you could come back to the hospital. It was really good.	R-08
	Q2.3 … we were given loads of information and loads of help, and if we were stuck at all, we were guided through it, so, you know, we were given so much help and so much guidance, it was really good.	M-01
	Q2.4 Yeah, no it was just all done so well, and I always felt comfortable with the people that I was with. Everything was explained in a fashion that I could understand I think. You know there was nothing scary about it.	M-16
	Q2.5 Everything was helpful because they give you a lot of information about it, sometimes you do not want to read about it but if you need to know anything or are worried about anything you can go and get your information and you can ring them up (the breast care centre) and ask questions and they are always prepared to answer them for you.	M-02
	Q2.6 I got plenty of information etc.	M-20
Complexity of information	Q2.7 To have someone right there in the initial stages, that's where the shock happens and that's where people get confused and they walk away with a book that they do not understand half the language of, or be told that they should access this website well that's fine but when your head is spinning around and you do not know what you are doing and you are looking at all of this medical terminology and percentages of outcomes, it's—that's not what we should be doing as patients. That is I think too much to handle.	R-14
	Q2.8 But for anyone who is in that position with cancer I would always recommend that they have another party come along with them because basically your mind blanks out and you do not really absorb what's being said.	M-13
	Q2.9 … at the beginning, all the terminology, it was all scary and everything, but, you know, you realise you are one of many.	R-06
	Q2.10 I write a lot of things down when I take my book in to the doctors. If I get words I do not understand, I either ask for them to explain them or I bring them home and look them up.	R-05
	Q2.11 A lot of it is, yeah it's all here in writing, but its certainly up to the individual, I just go through things and, as it happens it happens.	R-04
Delivery of information	Q2.12 The particular surgeon that I saw, (Name), she has a nurse who sits with you beforehand when you go in there and she explains everything in detail and then they give you a booklet to take away so that you really go in there really well informed. With the public system, they did some explanation but probably not as detailed as what (Dr's Name) did.	M-03

The importance of self-advocacy to ensure that patient needs were clearly expressed was acknowledged (Table 3, Q3.15–Q3.18). In some instances, this meant that participants needed to undertake extensive reading and be prepared for the consultation (Table 3, Q3.16). In other instances, it was a question of common sense and intuition to negotiate and navigate optimal care (Table 3, Q3.17–Q3.18).

Other sub-themes that arose included the importance of communication about available treatment providers, differences between treatment in the public and the private sector, the impact of private health insurance and availability of local services. Being offered a choice of treatment providers, including at a local level, and being in control of their treatment pathway was valued by participants (Table 3, Q3.19–Q3.21).

Participants with private health insurance expressed disappointment with providers who did not make the option of receiving care as public patients known to them (Table 3, Q3.22). Furthermore, the notion of fair access to free health services was discussed together with the lack of information regarding the available public and private treatment pathways and their associated costs (Table 3, Q3.23).

Communication about cost of treatment

Patients valued discussions about treatment options, providers and the associated costs, because such discussions increased participants' control over their decision-making and financial situation (Table 4, Q4.1–Q4.3). The role of health professionals to help their patients navigate the health care system in the most cost-efficient manner was acknowledged. Having a doctor cognisant of the extent of patients' treatment expenses, financial circumstances and attitude towards OOPE proved beneficial for some participants (Table 4, Q4.4). Being involved in the decision making process empowered patients to be in control of their finances whilst ensuring that they receive the best treatment (Table 4, Q4.3).

Conversely, several participants treated in the private sector acknowledged that cost of treatment had never been discussed and expressed disappointment with the lack of price transparency and cost-related discussions. Unexpected post-treatment bills were seen as an unnecessary surprise that could have been avoided if treatment costs had been discussed prior to receiving treatment (Table 4, Q4.5, Q4.6). The need for transparency regarding the costs of health and/or support services

Table 3 Sample quotes of patient experiences of communication about treatment options

Sub-themes	Quotes	ID
Trust in health care professionals	Q3.1 And I obviously did not have a clue as to what is the best option or what should be done, so I sort of mentioned this to him and he said well obviously I cannot recommend anything particular—that is your choice, but if it were me I would do this, and what he would do was the robotic prostatectomy so I said ok fine …	M-12
	Q3.2 His cancer was really quite aggressive and you know he was told that you really had to have surgery and we were told that the robot was the best way to do it …	R-15
	Q3.3 So I was just happy to go with their (doctors') recommendations because I did not know anyone, y'know it's not like for example when you have a baby and people are like 'oh I know this good gynaecologist' or 'this good obstetrician'—I knew nobody so I was happy to go with the medical professional's recommendation. … I did not really make any decisions, I just went where they told me to go *chuckle*, so I was happy with that.	M-05
	Q3.4 … a friend of ours met this lady who had had it [the cyber knife] and got everything off her and told us [to get] our doctor to … refer us …	R-19
	Q3.5 Yeah, well my main doctor, he put me on to a specialist in (a secondary hospital), which I had a biopsy done there and then he wanted to go on with the treatment and just rip my prostate out but I chose other options. I did not want to be cut open like a sheep and have everything taken out and he did not give me any options of nano—not nano-knife, robotic surgery or anything like that, just at the last minute he gave us an option to get radiation. So but we had already done a lot of research into nano-knife over in Sydney and I saw another specialist up in (a different hospital) and he wanted to do the same thing—take it out as soon as possible … .	M-08
Communication about treatment rationale and timing	Q3.6 They told us everything. They came in and explained why I had to have the bag and everything when I woke up, but they really explained everything great to me and they rang when I got home to say that I had to have chemo and then they got hold of the chemo.	R-07
	Q3.7 The other thing, too, is, with all the treatments I wasn't given options, I was just put on a treatment and then modified according to the way the doctors felt would be the best way to go. Now, it's not that I do not believe in the doctors—I think they are doing a fantastic job—but I was only informed on the day as to what was going to happen. It was like, so we have got you on Docataxel—and I am going "Docataxel? What the … 's that?" And I had to look all that up on the net: where does it come from, why does it work, you know all this sort of stuff …	R-16
	Q3.8 … at some point, I need to know what's the rationale for my treatment—is it just a blind faith thing? … I need to know why am I undergoing this particular form of treatment. It's not explained initially that this is the newest stuff, unless I ask questions and then look it up on the net.	R-16
	Q3.9 And I tried to get more information about using tablets as a chemotherapy treatment and I spoke to the Cancer Council and I got varying answers depending whether I talked to the Bunbury office or the Perth office and some people said yeah, sounds as though the tablets are a good idea and when I posed that question to my oncologist, they said they felt that there had not been enough research done on the tablet for rectal cancer as against bowel cancer. And that is why they would not recommend it.	R-11
	Q3.10 So when I went from the surgeon, and to be fair to the surgeon he said 'look I think you need to be there at the chemotherapy sooner rather than later', and after my operation I said well cannot we come back in six months and do it then and he said 'I do not advise it, get it done sooner rather than later'—now he never explained why I should get it done sooner rather than later.	R-11
Communication about side effect of treatments	Q3.11 I feel that the specialists are a bit flippant on when it comes to dealing with side effects from things, and you know 'you'll get over this' and I think there needs to be a bit more explanation on their behalf.	R-11
	Q3.12 … oh radiation oncologists were alright but probably the medication oncologists, the chemotherapy, because they never give you the real story about side effects and they I guess they do not want to. you are basically being administered poisons so *laughs* I do not know how you would tell anybody the real story or they'd never be part of it, but I guess that's really common to everyone.	M-13
	Q3.13 … there wasn't enough information about the post treatment inconvenience, the pain, the stitches, the bits and pieces. I am keen to think that some professionals providing services, they become a bit um … so aware of the service that they do not pass some of the messages on to the patients.	R-10
	Q3.14 … a lot of the health professionals can sort of talk the talk but cannot sort of walk the talk because they have never had the problem.	M-13
Importance of self-advocacy	Q3.15…Well we knew what we wanted and it was up to us to tell them what we wanted and if they did not want to do what we wanted that was too bad, they had to do what we wanted.	R-19
	Q3.16 Each visit I go to, say with my radiation oncologist, or medical oncologist, or even when I go and get a CT scan and stuff like that, unless I am armed with a lot of questions, it's incumbent on me to Google stuff on the internet or read copious amounts of material that they have got.	R-16
	Q3.17 The only problem I had was before my diagnosis was with a doctor who treated me like a hypochondriac. … And really everyone—if it happened again you'd go with your gut instinct or get a second opinion but you learn these things.	R-06
	Q3.18 … I just kept pushing, because I said, look I am not driving the 400kms to Perth to have a mammogram to then have to come back and get another referral from you to go back down again.	R-18

Table 3 (continued)

Sub-themes	Quotes	ID
Communication about treatment providers	Q3.19 Yes, I came up to (a tertiary hospital) and they diagnosed it in at (the hospital's) Breast Centre and then they gave me the option, they said "You can come through the private health stream if you have got private health cover you can go private" and I said "I am happy to do either because the (hospital) reputation is so good with breast care and the public service" and I asked what the difference would be and they said that you get moved to the top of the list with breast cancer in public anyway, but if you have got private cover you can go there. And I said "well then I want the best breast surgeon possible" and I am really happy with who I got. So then I went to the private system for my chemo and surgery and went back to the public system for radiotherapy.	R-02
	Q3.20 I was offered a choice to go to public health, the public health system with the urologist who diagnosed how bad it was … ..and he turned around and said the earliest I can do you is in three months. That was in January, in February I had the operation (Privately) and a fortnight after the operation I went back and saw the specialist and he turned round and said well everything's gone.	M-09
	Q3.21 The questions after that was 'are you privately insured by the way' and they want you to say yes and they say 'ok, go to (a local rural) private hospital etc.' but they do not make any allowances to maybe if you want to have it done locally, and you do not have to go privately.	R-11
	Q3.22 … nobody ever offered me the public option because I had private health cover so it was never offered to me or if it was I cannot remember it being offered, but I never asked to go down that path anyway.	M-20
	Q3.23 Since I have had my operation I have come across numerous other men who have had prostate cancer and had a surgery and quite a number of them had it done under Medicare, where it did not cost them a cent. And in a way, their treatment and everything else was as good as what I have had and I think well you know, it's not quite so fair that I have to pay $10,000 and they get away with it for nothing. Maybe I should have gone in as a public patient rather than a private patient. But this is with everything that you have in the hospital system.	M-12

after discharge from the hospital, medications, gap payments and financial support available was evident (Table 4). The lack of awareness of services and costs prevented participants from accessing financial assistance (Table 4, Q4.7), lead to treatment non-adherence (Table 4, Q4.10) and caused unnecessary stress to patients and their families (Table 4, Q4.8, Q4.11).

Communication and continuity of care

Participants were aware of the role that health professionals at all levels of care had in their cancer journey (Table 5, Q5.3–Q5.8). Many credited their care providers for the smooth transitions between health providers within and between the public and the private sector, as well as between tertiary and secondary and rural services (Table 5, Q5.1, Q5.2).

The importance of local and hospital based cancer nurses in helping patients to navigate the health system was widely recognised. Nurses were considered a primary point of contact for health related issues and a reliable source of information when needed, whose emotional support was greatly appreciated (Table 5, Q5.15–Q5.20).

Navigation through the different interfaces of the health system proved challenging for some, particularly rural participants. Issues identified include lack of timely communication between health professionals involved in the patient's care and gaps in communication between cancer specialists themselves, between specialists and patients and between specialist and rural health providers (Table 5, Q5.9–Q5.12). Participants acknowledged that their continuity of care and information needs had been impaired by the lack of connection and clear communication between specialist and primary care providers (Table 5, Q5.12, Q5.24–Q5.25). Additionally, some participants perceived limited continuity of care in the public sector (Table 5, Q5.13, Q5.14) that was attributed to the change in staff and system organisation (i.e. the appointment being with the consultant but being seen by a registrar).

Another sub-theme was patient dissatisfaction with the decreasing level of support as they transitioned from active treatment to survivorship or other types of care. Once the patient's condition was under control, the number of appointments reduced and the connection with cancer specialists weakened. Participants felt abandoned and left to navigate their ongoing health issues in a health care system they perceived as complex and costly (Table 5, Q5.21–Q5.23).

Discussion

Clinician–patient communication emerged as a prominent issue in interviews that explored patient experiences of the cost of a cancer diagnosis. Participants' communication experiences were variable and in many cases did not meet their needs. Communication problems, described by some participants, affected their ability to undertake well-informed and unbiased decisions regarding treatment and providers—a fundamental right for cancer patients outlined in existing guidelines [1, 2, 28, 29]—and resulted in substantial OOPE.

Table 4 Sample quotes of patient experiences of communication about cost of treatment

Sub-themes	Quotes	ID
Satisfactory cost communication	Q4.1 … that was all laid out, yes from day one really and the information packs we got from there and you know, the face to face in the meetings explained the options and the different sorts of therapies.	R-14
	Q4.2 I did ask about the radiotherapy if I had to pay and they said it was covered. I asked at the chemo, they said that was covered. The only thing I had to pay for were the visits to the oncologist—a portion of the visits. So yeah, I had a good run really.	R-06
	Q4.3 No, I think each time I went to an appointment I was told, up front, how much it was going to cost and how much my Medicare rebate was going to be. I actually found that really quite helpful—so that I was prepared…	M-05
	Q4.4 … my doctor was the one who said 'we will get the best care for you at the right price for you so that we do not leave you short, you do not have to pay money out.' They were really good, so they saved me a lot of money …	R-12
Unsatisfactory cost communication	Q4.5 Ah, there wasn't a lot of help or assistance given, I found out, as I went, and the amount of costs attached to everything, were absolutely horrendous, and, if we had not been able to pay, I do not know what woulda happened.	R-04
	Q4.6 So you know, it was very quick and the cost wasn't mentioned at any stage. I did not think it was going to be cheap, I knew there was going to be some form of gap *laughs* I did not realise until after the operation, I found out then that it was going to cost $10,000 …	M-12
	Q4.7 … we did not know that we could have got financial assistance. That was the biggest shock that came out—that we could have got financial assistance. Nobody told us ….	M-09
	Q4.8 … I ah, I may, have been told about it but I do not think I was fully aware of what the costs were going to be and how for how long, because the ah, the medicines she gave me six months, you know, ah, six prescriptions, or a prescription and five repeats, um, but that was $180 a month, and ah, that just floored me that ah it was such an expensive um medicine.	R-03
	Q4.9 When it came to gap payments, we did not have many gap payments. The hard part was knowing what was a gap payment and what wasn't.	R-11
	Q4.10 Ahh, we'd share, like I said I just could not afford, I just had to sort of take half of em, and, miss a couple of weeks, and take a few more, and miss a couple of weeks, and that sort of thing, and sort of spin it out.	R-03
	Q4.11 … then they said OK you are allowed three weeks and that will come under the hospital thing and you will not have to pay [for at home support around the house] … But then I got a bill in from [a care provider] for when they had been coming in. … I rang to query it … and she said no, none of this comes under the hospital. So obviously there's a lack of communication somewhere along the lines, because as I say I was definitely given that information.	M-19

In response to the growing body of recommendations for clear clinician–patient communication in the literature and from consumer organisations, clinician communication guidelines and training programs have been developed [30, 31] to support clinicians' communication skills and improve cancer patient experiences [32, 33]. In Australia, both Medical and Surgical Oncology trainees have mandatory communication training; however, how this is implemented in clinical practice remains unclear. Despite these measures, our findings indicate that clinicians continue to avoid cost discussions and suggest that current communication practices and clinical guidelines have little impact on patient experiences and associated costs [34, 35].

We found that participants differed in their information needs and expectations, and most participants trusted clinicians' treatment recommendations. This is consistent with previous research [36]; however, a minority faced medical paternalism and expressed a sense of disappointment in their treating clinicians' refusal to respect their treatment preferences (Table 3). Sub-optimal communication has a detrimental impact on the quality of the decisions patients are able to make in relation to their treatment, and can increase the use of alternative and/or unnecessary treatments, lead to psychosocial distress, decrease patient satisfaction and may exert significant cost burden upon the patient [4].

Whilst all participants were involved in the decision making process, their level of involvement varied. Participants who were not informed about different treatment options and their possible side effects did not feel empowered to navigate their care. The lack of price transparency affected a number of participants. This disconnect observed in some clinician–patient interactions calls for clinicians to ensure they are sufficiently engaging patients in their care, understand their expectations and respect their needs [37, 38].

Optimal cancer care pathways (OCPs) have been endorsed in Australia and are being implemented nationally [39]. Although they promote quality cancer care and aim to ensure that all people diagnosed with cancer receive the best care, regardless of where they live or receive treatment, their implementation requires collaboration and communication between health professionals at all levels and with their patients. OCPs do not incorporate details about communication regarding options for care providers, quality and cost of care and patient experiences. These shortfalls could be addressed through systematic collection of standardised outcome metrics [40] and measuring outcomes that are important to patients, including cost experiences to empower patients to make informed decisions based on provider health outcomes [41]. Consequently, the need for optimal communication between doctors and

Table 5 Sample quotes of patient experiences of communication and continuity of care

Sub-themes	Quotes	ID
Continuity of care	Q5.1 Helpful has been the support from regional all the way through to Perth—it's almost seamless the way everything falls into place and the transition from public to private back from private to public. There's no problem with that.	R-02
	Q5.2 I was a total private patient so I did not go through any of the public sector, I did not have any dealing with the public sector side of things with my treatment at all, and the hospitals and the health professionals that I was sent to were all very good. I have no complaints.	M-20
	Q5.3 Um, the general cooperation between surgeons, nursing staff, the hospital and my personal doctor was excellent.	M-10
	Q5.4 Yeah, um, after the treatment of 2016–2017, coming in to 2017, my oncologists, my cancer doctor at [hospital] had me transferred down to [hospital in region of residence] so getting to [hospital in region of residence] was—the oncologist was—I never had to ask for anything, he just told me what was available, and sent letters out to explaining things, …	M-04
	Q5.5 … once I found out what we had to do, all the dates were locked in and the treatment was locked in and uh, yeah we went and did it …	M-14
	Q5.6 … we had three urologists there that were treating me, the service is excellent, the backup is fairly good there from the cancer nurse who deals with preliminary or pre-op situations and then post-op situations. Counselling type things I guess or information more than counselling on what's available and other treatments, other roads to go down.	R-14
	Q5.7 …. I did not have a problem at all. They just seemed to shuffle me around and go in the right direction and come out the other end, they had it all organised there which was nice. No problems in that.	R-01
	Q5.8 I think the whole team at (a tertiary hospital) really helped me with whatever problem occurred, they always had someone there who can help you. I talked about the financial help with someone as well, but yeah it just came out pretty quickly that I am not eligible.	M-17
	Q5.9 Yeah because you were sort of dealing at the time with two doctors, like an oncologist and a physician and they did not always work together very well.	R-17
	Q5.10 There was a lot of messing around, and that wasn't good at all. He (a local/rural surgeon) finally needed to get an opinion from another group of surgeons in Perth, and I am just sort of hanging and wondering what's going on, until eventually I referred to this particular surgeon, there was no problem, he said "this is what you have got, I think it's got to come out" bang, bang, bang, and that was it.	R-09
	Q5.11 The other problem I had was when I developed my lymphedemas after my treatment in Perth and had to come back with them. The hiccup between the hospital and home here and the link to the surgeons in Perth. did not have it. So next time I would make sure that they first contact our local doctors in the hospital in the home, because I had to come and get it drained. … .what about those people who chose to go to Perth for their op but they are not linking in here for the follow up.	R-02
	Q5.12 To be honest, it's nothing to do with—they themselves are collaborators—I am pretty sure the oncologists spoke about my case with the urologist and they are definitely collaborating, but they are not communicating to me.	R-16
	Q5.13 … in the private system, I, it was brilliant, because I had my own surgeon, that was all very well explained, … the hospital were extremely supportive, um, with the radiotherapy, I went in to a public hospital, and the staff were brilliant, and all of that, but that's a lot more complex to navigate	M-03
	Q5.14 Basically, you have an appointment to see someone, and you do not necessarily see that person, I probably saw four or five oncologists, where … my appointment was with one … I'd made an appointment with [treating oncologist] and I only saw her once, each time I saw other people …. So, you see all these different people, and that's probably … you kind of do not know whether … there's a continuity that's all.	M-03
Role of cancer nurses	Q5.15 At (a tertiary hospital) they have a few nurses who lay—they um … they sort of like help ya. They put you in the right part.	M-07
	Q5.16 I am amazed at the health system, I am amazed at the nursing staff, at the women that work, or the nurses that work in oncology, in theatre. And I guess it's been a bit of an education for me … So I have been very impressed with the health system.	R-05
	Q5.17 Just whichever stage of treatment I was at, I got a—no. You just ring the breast care centre and they have nurses there who answer your questions.	M-02
	Q5.18 It was actually quite simple because my doctor was very informative and everything like that and I had contact with one of the Cancer Council people down here and the McGrath Nurse down here, so if my doctor could not answer it then these other people could answer it and put me in the right direction and tell me everything I needed to know, so that was really good to have that back up.	R-12
	Q5.19 …. I had a major operation—it took 3.5 h because they did it keyhole and I was out of hospital on the third day, and the Cancer Nurse visited me both days when I was in hospital and was ringing me every day for the first week to see how I was coping. And that made it a whole lot easier, yes.	R-01
	Q5.20 The nurse practitioner who was attached to the oncologist and the chemo probably saved my life. She was absolutely amazing. I could not have done without her … …. sat me down and talked to me and reassured me that I was managing alright despite it being difficult, and it was particularly difficult for me. So that was particularly helpful.	M-15
Roles of health care providers	Q5.21 Now, they do have nurses who provide you with initial guidance and things like that, which is fantastic, but along the process that tends to drop off.	R-16
	Q5.22 Because once they kick you out of hospital you are sort of on your own well, let me put it this way, when I was diagnosed the frequency of seeing the specialists and the doctors were more frequent, but because the treatment has	M-11

Table 5 (continued)

Sub-themes	Quotes	ID
	taken such a long time and we are put on to a longer duration so maybe once in three months we get to see the doctors or the specialist or something …	
	Q5.23 There's nowhere you can go, like a one stop shop, there's nowhere you can walk in to, and it does not cost you an arm and a leg, to get some advice and help. Nowhere like that. (???)So much on your own.	R-04
	Q5.24 So if we go to the GP and ask him for some help, he has to you know, ring the doctor and find out which means you have to have a couple of visits before that can happen.	M-11
	Q5.25 Yeah, so there's no local, or, central, point of information, you gotta figure everything out yourself as you go along? You keep running, to GP, or back to the surgeon ….	R-04

patients and between health professionals regarding treatment options, providers, outcomes and costs becomes increasingly important [42]. In Australia, leading cancer organisations have developed a Standard for Informed Financial Consent, which encourages greater commitment and transparency from doctors and health care providers to inform patients of the costs. This includes providing full financial disclosure and an accurate fee estimate with updates to help patients navigate the financial implications of their diagnosis [43].

Informative and well-timed clinician–patient communication conducted at an appropriate level would empower patients in choosing treatment and providers, help health professionals to objectively assess patient's needs, assist with the decision-making process and ensure smooth transitions of care across the care continuum. Our findings indicate that to facilitate the delivery of coordinated cancer care and to ensure prompt referral to specialist, allied health and supportive care services, health professionals should routinely undertake comprehensive assessment and screening of cancer patients for clinical, psychosocial and supportive care needs.

Finally, several participants in our study acknowledged the role of nurses in their care. The cancer nurse coordinator (CNC) service has been available in rural and metropolitan WA since 2006 and encompasses a broad range of psychosocial support and assistance with the coordination of care [44]. The role that CNCs play in patient care could be further explored, as greater accessibility could benefit patients who experience sub-optimal care coordination when transitioning between services and after the completion of active treatment.

This study has a number of messages to all health providers who care for patients with cancer. Building on a number of recommendations from the Breast Cancer Network Australia in their State of the Nation report [20], which are applicable to other cancers, we recommend that health providers ensure that:

1. The level of engagement in treatment decision making is ascertained at each step of the patients' journey.
2. Rural patients are provided with information about diagnostic and treatment services available locally.
3. Patients are well informed and given choice between public and private treatment providers.
4. There is cost transparency for tests, procedures and treatments.
5. Patients are fully informed of the treatment cost prior to treatment commencement.
6. All patients have access to a cancer nurse.
7. There is timely communication between all health providers involved in the patient's care and continuum of care.

Strengths and limitations

Our findings and conclusions should be considered within the limitations of the overall study. Although we utilised a purposive sampling strategy to ensure that a diverse range of participants were represented in the data, lung cancer patients are underrepresented in the sample as they became progressively ill and many had passed away by the time of the interview. Due to the existing relationship between the interviewers and participants from previous follow-up in the OOPES study, social desirability bias may have emerged; however, this was deemed to be outweighed by the benefit of the rapport participants had with the interviewers. A particular strength of the study is that it reports on the experiences of rural and outer metropolitan cancer patients with four different cancer types and, thus, offers novel insight into the experience of these under-researched groups. However, we identified that there were no specific differences in the experience of these participant groups other than those reported regarding transitions of care.

Conclusion

Whilst a system-wide approach is needed to improve communication and transparency in cancer care, an open dialogue that incorporates patient values and personal circumstance with particular attention to financial standing should guide treatment discussions. Health care providers should regularly assess how the patient is travelling through the disease continuum and assist with referrals and coordination of care. This must be coupled with initiatives to successfully monitor and sustain improvements in patient communication and care; to ensure that patients' information needs are met, the care they have received is of high quality and at an affordable cost.

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Author contributions CJ and CS designed the study; JN and HH conducted data collection; JN, HH, and NSA conducted the qualitative analysis; JN, NSA, HH, CJ, and CS contributed to the analysis and interpretation of the data; NSA and JN wrote the manuscript. All authors read and approved the final manuscript.

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Compliance with ethical standards

The authors declare that they have no competing interests. Study participants provided written informed consent. The study was undertaken in accordance with relevant ethical standards and guidelines and was approved by the WA Country Health Service Ethics Committee (#2014:10) and the Department of Health WA Human Research Ethics Committee (#2014/26). The authors have full control of the primary data and are able to provide access upon request if deemed appropriate by all investigators.

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