

TRIPLE NEGATIVE BREAST CANCER AUSTRALIAN STUDY 2021



Section 1



Introduction
&
Methodology

This is where you can read about the PEEK methodology, information about the recruitment period and approach.

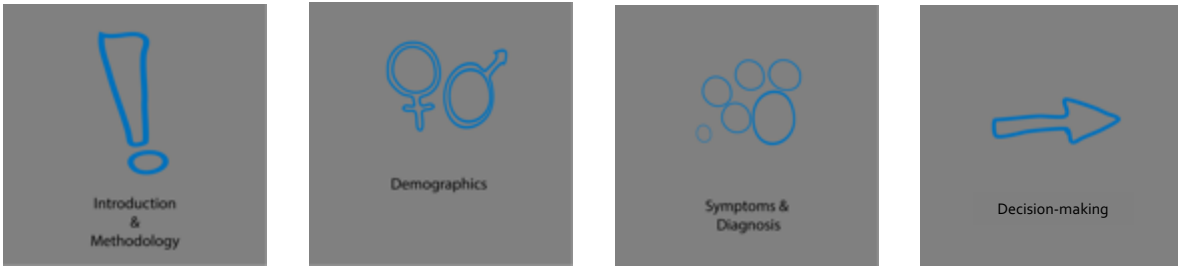
There is also a review of other mixed methodology studies in the field to identify the position of the PEEK study in the context of other literature. PEEK studies are often the largest of their kind in depth and participant numbers.





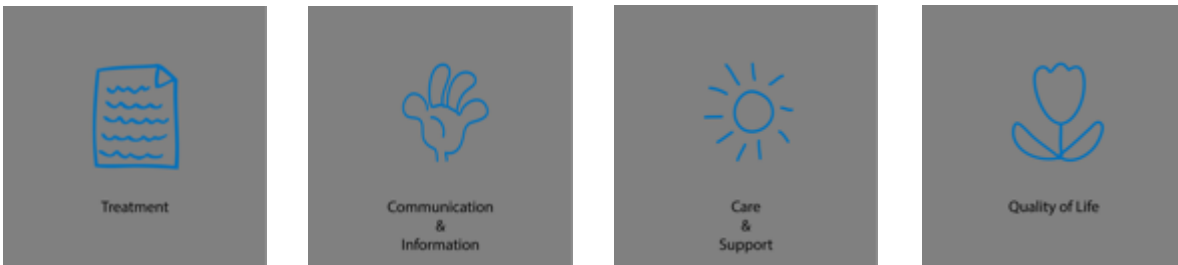
The Centre for Community-Driven Research team for this study included:

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Thank you to each and every person that participated in this PEEK study.

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Gilead Australia provided arm's length sponsorship for the Centre for Community-Driven Research to report on the PEEK protocol data for people who have been diagnosed with triple negative breast cancer. The sponsor had no input into the methodology, data collection, data analysis or reporting.



There were 12 studies identified of between six and 902 participants. There was only one study identified that interviewed participants or used qualitative methods, this study was focused on African Americans diagnosed with triple negative breast cancer (Bollinger).

A comparison of studies is available in Section 1.

A PubMed search was conducted to identify studies reporting patient experience, patient reported outcomes, and quality of life studies in the triple negative breast cancer community. Studies conducted more than 10 years ago were excluded, and studies that included multiple types of breast cancers that did not report triple negative breast cancers separately (as a subgroup) were excluded.

There were 11 studies that collected patient experience/patient reported data by questionnaire. The two largest studies of 902 and 190 participants with triple negative breast cancer respectively, were multi-national drug clinical trials (Adams, Rugo). There were three other clinical trials identified that collected patient reported outcomes, two were conducted in USA, and had between 37 and 38 triple negative breast cancer participants (Anders, Filho), one trial conducted in Spain with 73 participants (Manso).

There was one study conducted in China focused on patient activation with 121 participants (Shen), and one study conducted in the USA focused on health-related quality of life of 83 participants (Vadaparampil). There were two studies conducted in North America that focused on clinical trial participation that included between 15 and 74 participants (Jacobs, Kuderer). One study was focused on lifestyle changes, conducted in the USA with 23 participants (Swisher), and one USA study of 13 participants focused on coping (Watkins).



Section 2



Demographics

The demographic section is where you can find information about the study cohort. This is also where the sub-groups used throughout the study are described and where the baseline health of the cohort is described, using the SF36 questionnaire.



Demographic	Definition	Number (n=50)	Percent
Age	25 – 34	4	8.00
	35 – 44	15	30.00
	45 – 54	22	44.00
	55 – 74	9	18.00
Location	Major Cities of Australia	34	68.00
	Inner Regional Australia	13	26.00
	Outer Regional Australia	2	4.00
	Remote Australia	1	2.00
State	New South Wales	14	28.00
	Queensland	14	28.00
	Victoria	11	22.00
	Western Australia	9	18.00
	South Australia	1	2.00
	Tasmania	1	2.00
	Australian Capital Territory	0	0.00
	Northern Territory	0	0.00
Socio-Economic Indexes for Areas (SEIFA)	1	2	4.00
	2	6	12.00
	3	3	6.00
	4	2	4.00
	5	5	10.00
	6	2	4.00
	7	6	12.00
	8	4	8.00
	9	9	18.00
	10	11	22.00
Race/ethnicity	Caucasian/White	47	94.00
	Other	3	6.00
Education	Less than high school degree	0	0.00
	High school degree or equivalent	12	24.00
	Some college but no degree	11	22.00
	Trade	1	2.00
	Associate degree	4	8.00
	Bachelor degree	14	28.00
Graduate degree	8	16.00	
Employment	Currently receiving Centrelink support	2	4.00
	Disabled, not able to work	1	2.00
	Employed, working full time	27	54.00
	Employed, working part time	14	28.00
	Full/part time carer	2	4.00
	Full/part time study	1	2.00
	Not employed, looking for work	2	4.00
	Retired	2	4.00
Currently on sick/maternity leave	5	10.00	
Carer status	I am not a carer	24	48.00
	Children	25	50.00
	Other	2	4.00



Other conditions	Number (n=50)	Percent
Anxiety (Self or doctor diagnosed)	27	54.00
Anxiety (that you diagnosed) yourself	25	50.00
Anxiety (that a doctor diagnosed)	11	22.00
Sleep problems or insomnia	22	44.00
Chronic pain	13	26.00
Depression (Self or doctor diagnosed)	19	38.00
Depression (that you diagnosed yourself)?	14	28.00
Depression (that a doctor diagnosed)	10	20.00
Arthritis	9	18.00
High cholesterol	7	14.00
Hypertension	4	8.00
Atrial fibrillation or arrhythmias	4	8.00
Diabetes	3	6.00
Cancer (other than breast cancer)	2	4.00
COPD (Chronic obstructive pulmonary disease)	1	2.00
Have you had a stroke?	1	2.00
Chronic heart failure	0	0.00
Angina	0	0.00
Other	28	56.00

Number of other conditions	Number (n=50)	Percent
No other conditions	6	12.00
1 to 2	18	36.00
3 to 4	8	16.00
5 to 6	14	28.00
7 to 8	4	8.00



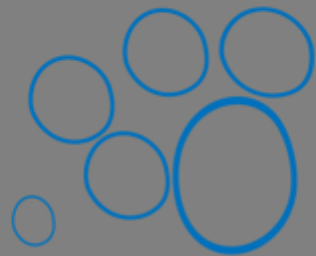
Subgroup	Definition	Number (n=50)	Percent
Breast cancer stage	Early breast cancer	23	46.00
	Advanced breast cancer	27	54.00
Physical function (n=44)	Poor physical function	19	43.18
	Good physical function	25	56.82
Year of diagnosis	Diagnosed before 2020	26	52.00
	Diagnosed in 2020 or 2021	24	48.00
Education	Trade or high school	24	48.00
	University	26	52.00
Location	Regional or remote	16	32.00
	Metropolitan	34	68.00
Economic status	Mid to low status	20	40.00
	Higher status	30	60.00
Age	Aged 25 to 44	19	38.00
	Aged 45 to 54	22	44.00
	Aged 55 to 74	9	18.00



SF36 scale (n=44)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	71.36	23.36	77.50	36.25	0 to 100	4
Role functioning/physical	55.11	41.96	75.00	81.25	0 to 100	4
Role functioning/emotional	77.27	34.31	100.00	33.33	0 to 100	5
Energy/Fatigue*	41.93	19.39	45.00	26.25	0 to 100	3
Emotional well-being	70.91	14.13	74.00	21.00	0 to 100	4
Social functioning	69.60	26.61	75.00	40.63	0 to 100	4
Pain	63.92	26.23	67.50	37.50	0 to 100	4
General health*	51.93	18.02	55.00	35.00	0 to 100	3
Health change	51.14	34.92	50.00	50.00	0 to 100	3



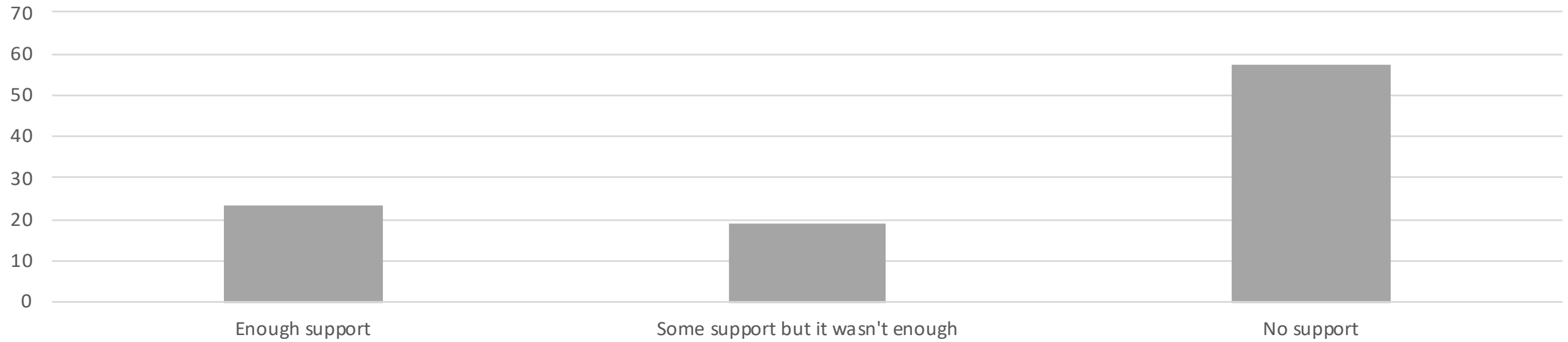
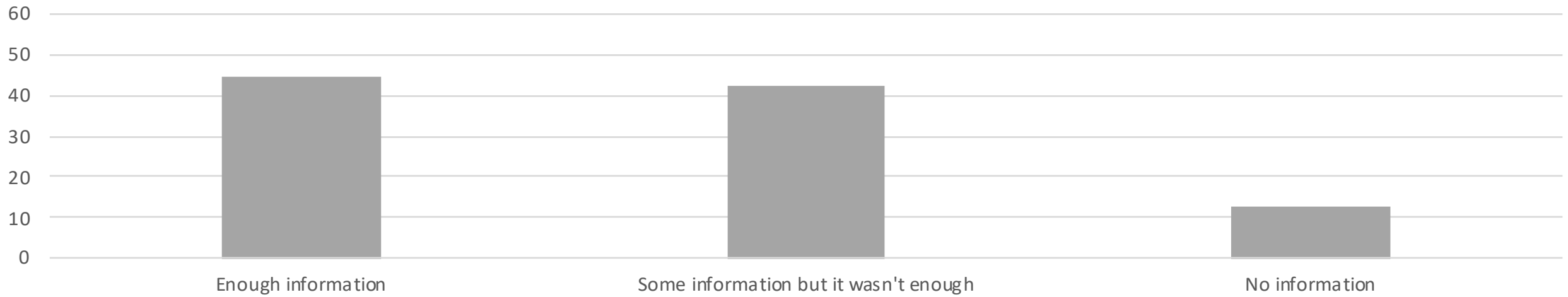
Section 3



Symptoms &
Diagnosis

The symptoms and diagnosis section is where you can find information about experience of symptoms before diagnosis, as well as the symptoms that led to the diagnosis. There is information about the diagnostic tests that were performed, where the tests were conducted and the time from tests to diagnosis. In this section, there is also information about the participant's understanding of their condition and their understanding of their prognosis.

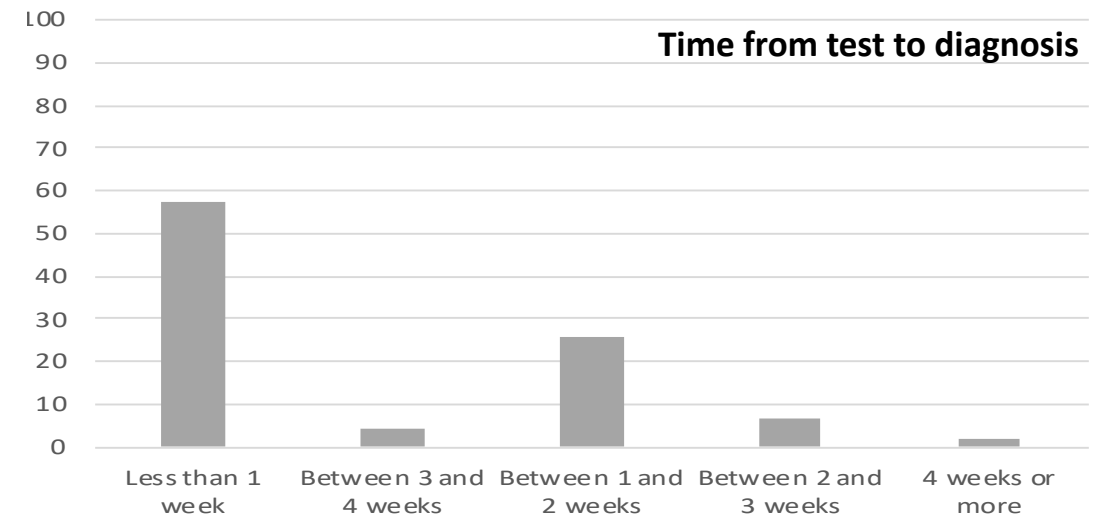
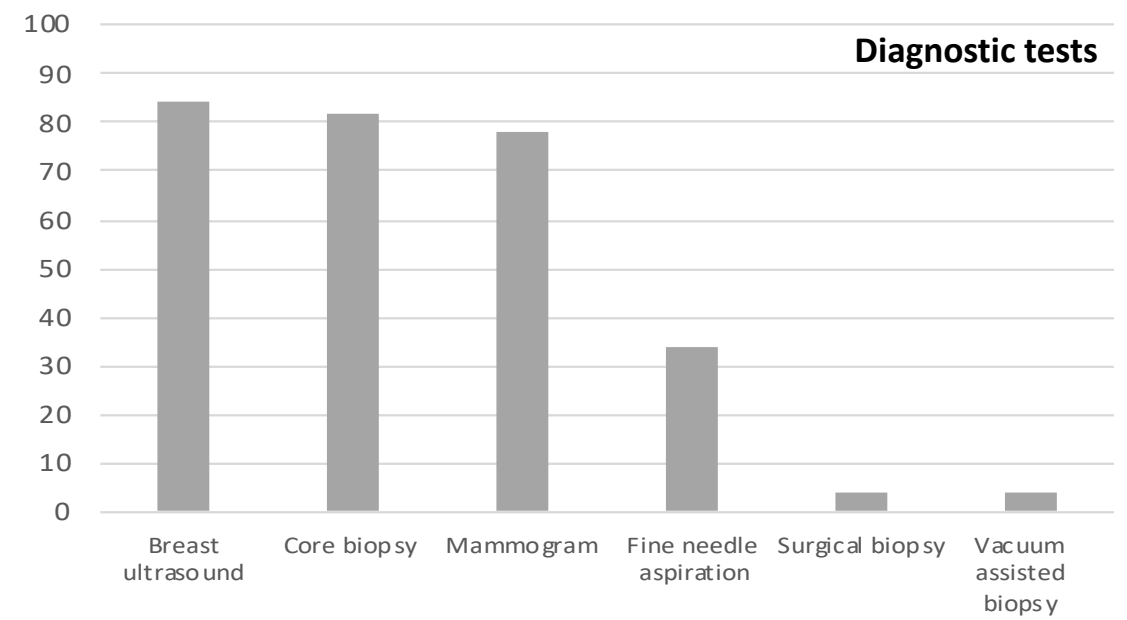
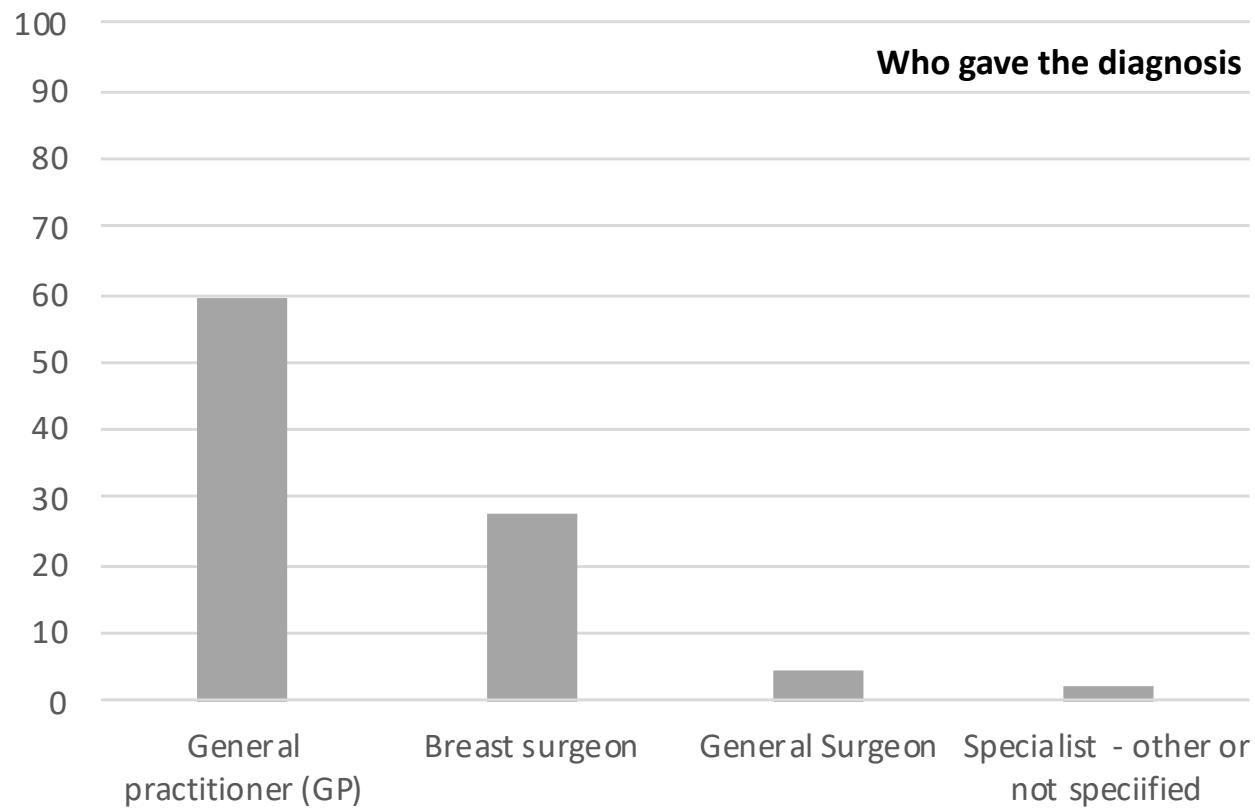


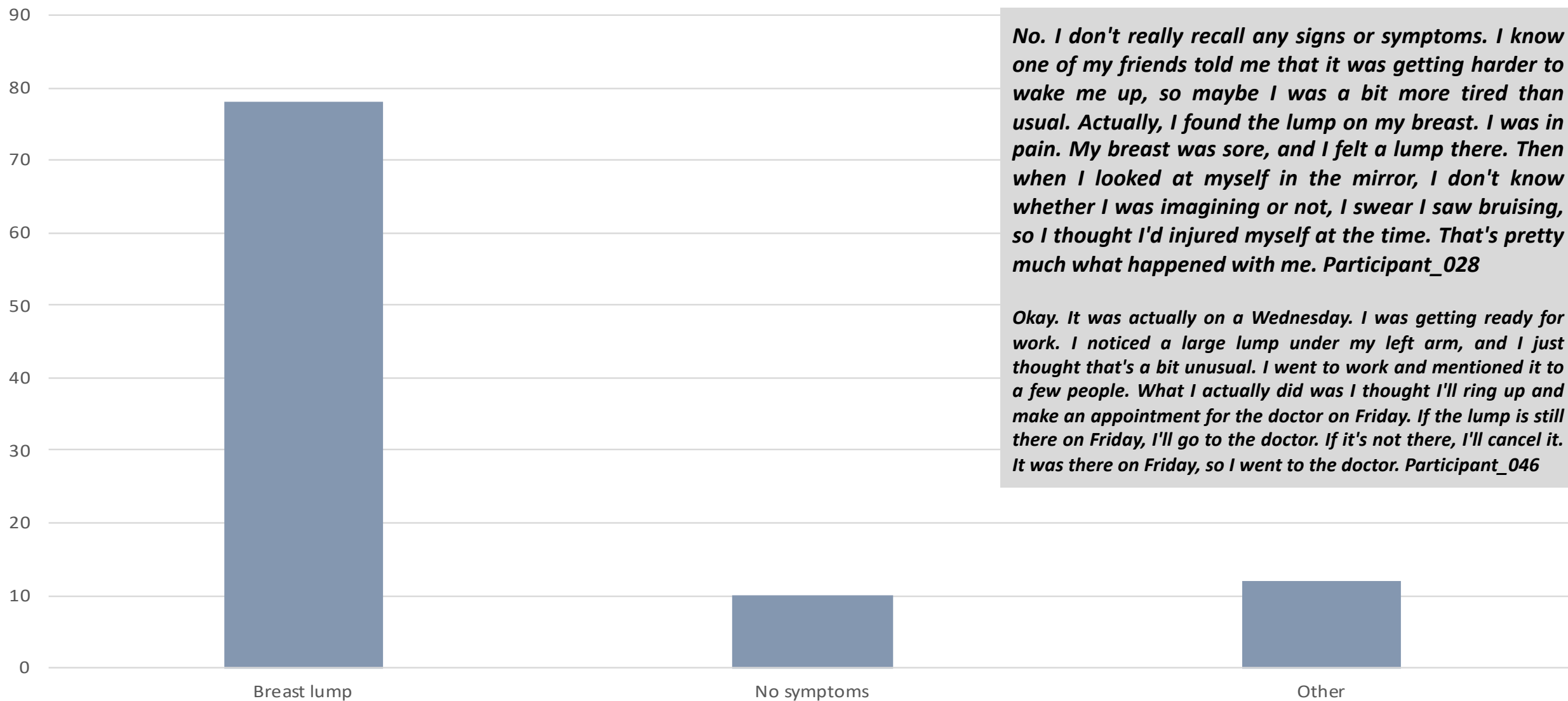


Information + support at diagnosis



Number of diagnostic tests per participant	Number (n=50)	Percent
1 to 2	11	22.00
3 to 4	38	76.00
5 to 6	1	2.00



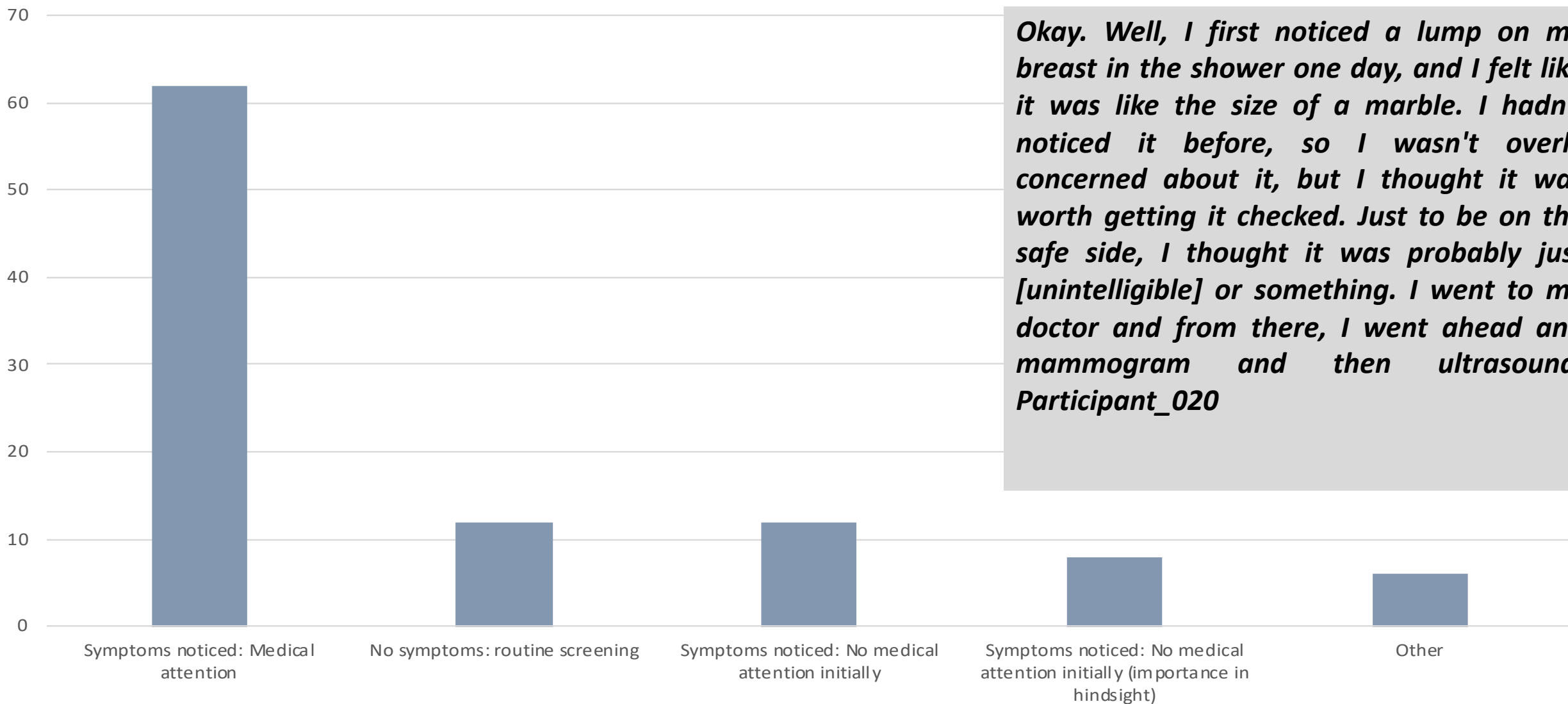


No. I don't really recall any signs or symptoms. I know one of my friends told me that it was getting harder to wake me up, so maybe I was a bit more tired than usual. Actually, I found the lump on my breast. I was in pain. My breast was sore, and I felt a lump there. Then when I looked at myself in the mirror, I don't know whether I was imagining or not, I swear I saw bruising, so I thought I'd injured myself at the time. That's pretty much what happened with me. Participant_028

Okay. It was actually on a Wednesday. I was getting ready for work. I noticed a large lump under my left arm, and I just thought that's a bit unusual. I went to work and mentioned it to a few people. What I actually did was I thought I'll ring up and make an appointment for the doctor on Friday. If the lump is still there on Friday, I'll go to the doctor. If it's not there, I'll cancel it. It was there on Friday, so I went to the doctor. Participant_046

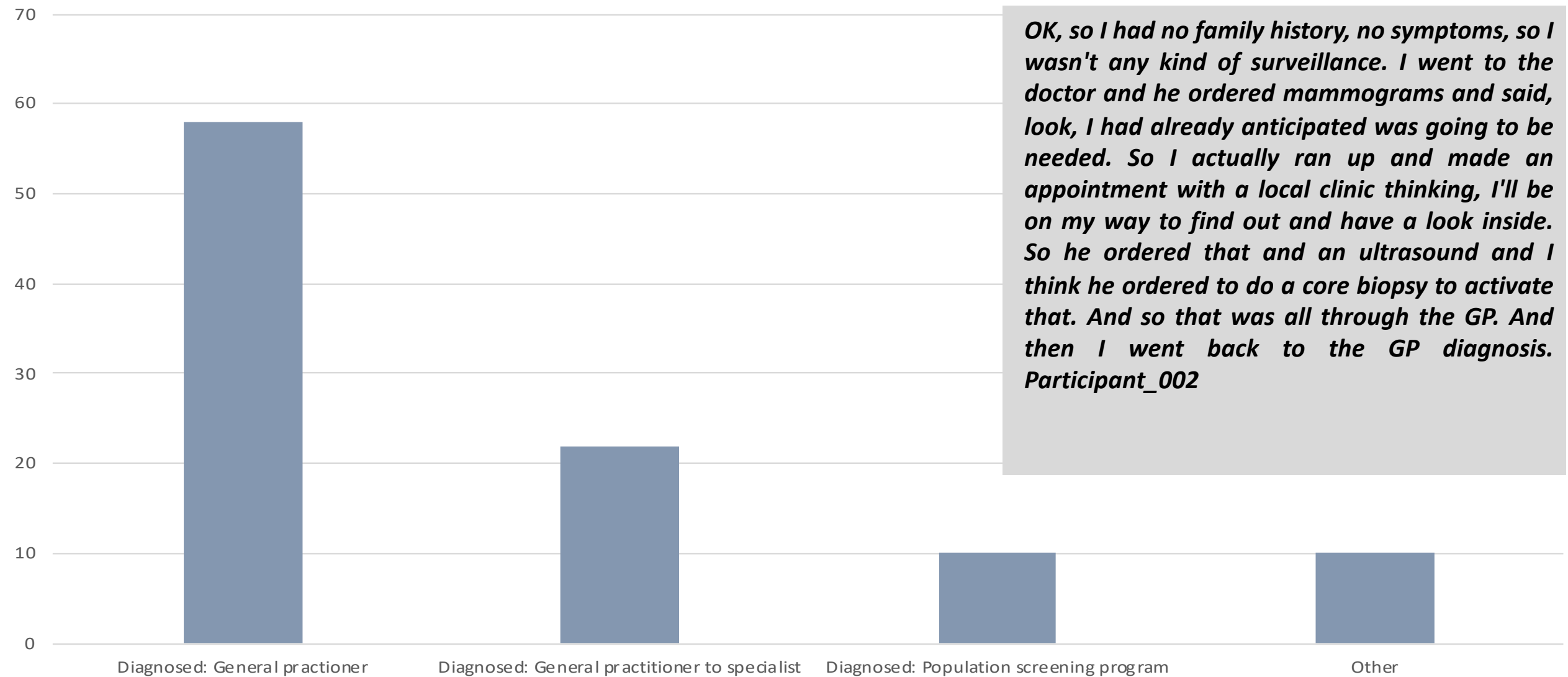
**Symptoms leading to diagnosis
(% of all participants)**





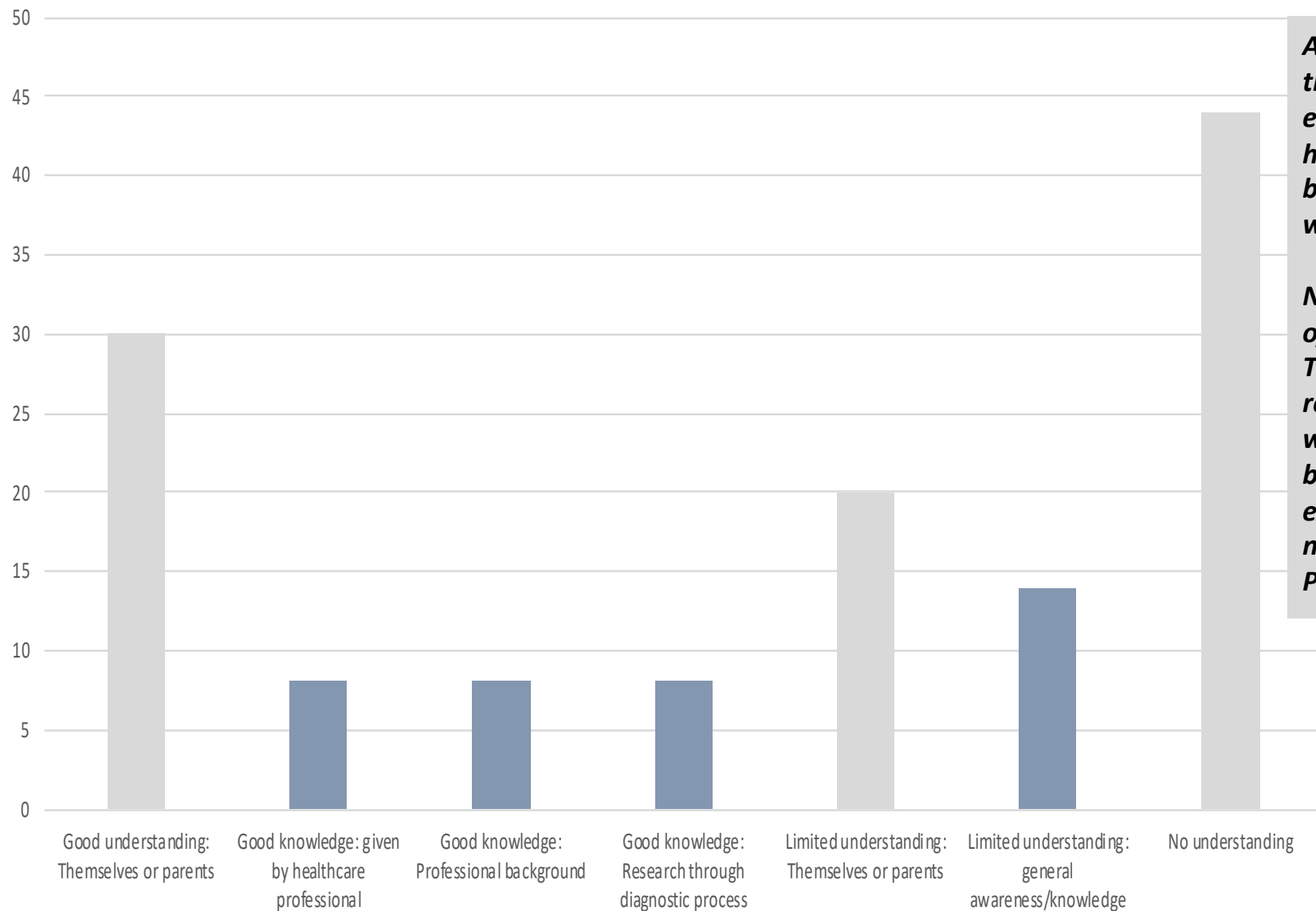
*Okay. Well, I first noticed a lump on my breast in the shower one day, and I felt like it was like the size of a marble. I hadn't noticed it before, so I wasn't overly concerned about it, but I thought it was worth getting it checked. Just to be on the safe side, I thought it was probably just [unintelligible] or something. I went to my doctor and from there, I went ahead and mammogram and then ultrasound.
Participant_020*





OK, so I had no family history, no symptoms, so I wasn't any kind of surveillance. I went to the doctor and he ordered mammograms and said, look, I had already anticipated was going to be needed. So I actually ran up and made an appointment with a local clinic thinking, I'll be on my way to find out and have a look inside. So he ordered that and an ultrasound and I think he ordered to do a core biopsy to activate that. And so that was all through the GP. And then I went back to the GP diagnosis. Participant_002

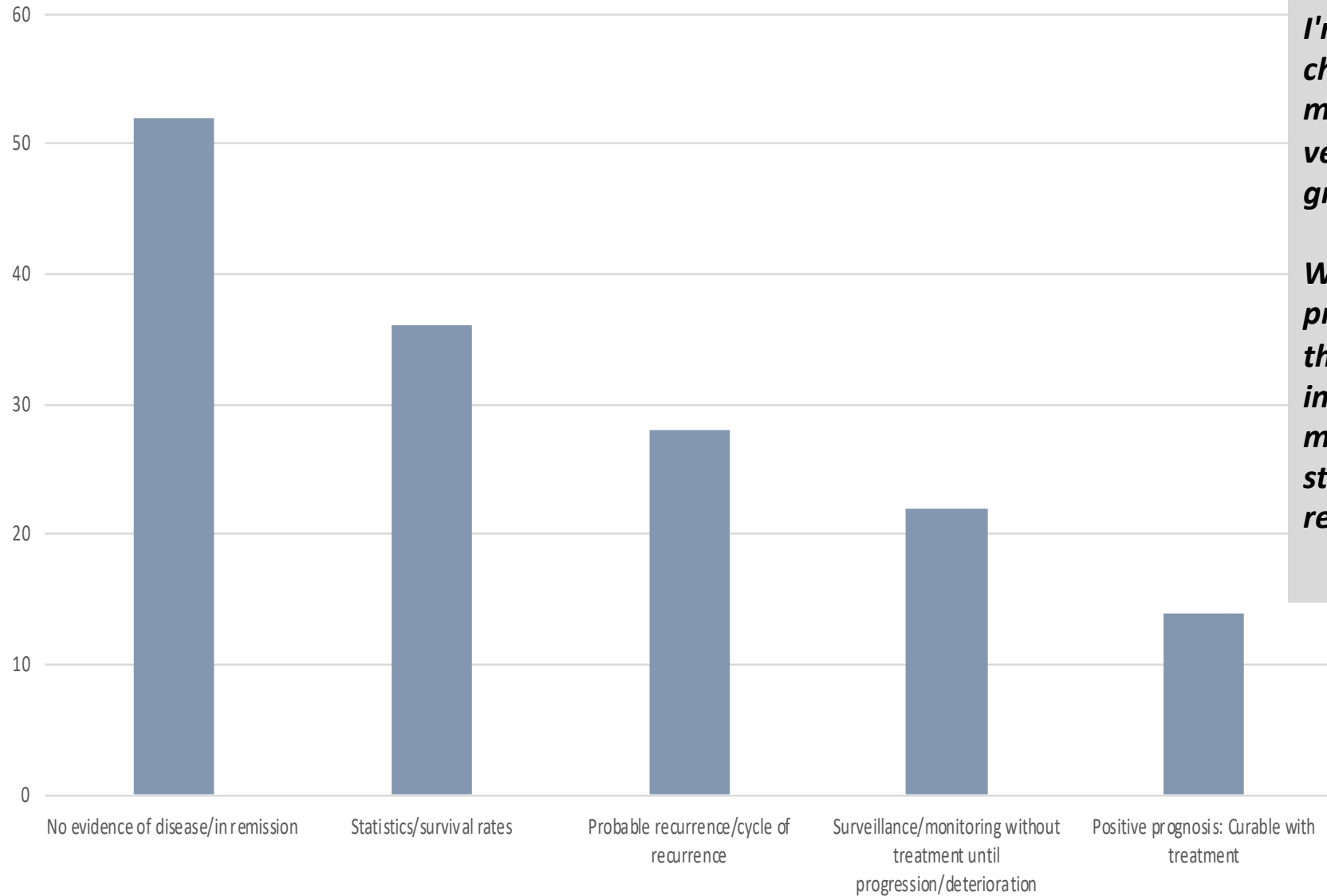




A lot. Due to our family history, I knew a lot. Obviously, there's all sorts of different types of breast cancer. Not everybody is the same and of course, mine was not hormone-based but I've had two sisters hormone-based, one sister who was triple-negative and my mum was triple-negative. Yes. Participant_022

Nothing, zero. Absolutely zero. We were in the middle of COVID here in LOCATION. There were no resources. There was no emotional health. I felt very isolated, really lonely. Someone who has no family history, I wasn't offered a help from a nurse or anyone who's been through it, you know any volunteers. What to expect from the chemo. What other questions that I needed to ask? In fact, I had to fight to get my- Participant_042





I'm NED at the moment and we're just doing the chemotherapy and the radiation to mop up, is my understanding, and make sure there's no very small particles in there that could be growing to reoccur. Participant_007

Well, currently, I've been told I have a good prognosis. My cancer is really aggressive, so there's still a high chance that it can come back in the next three years. I'm being closely monitored but other than that, I've been told it's still on the positive side because I got a good response to chemo. Participant_016



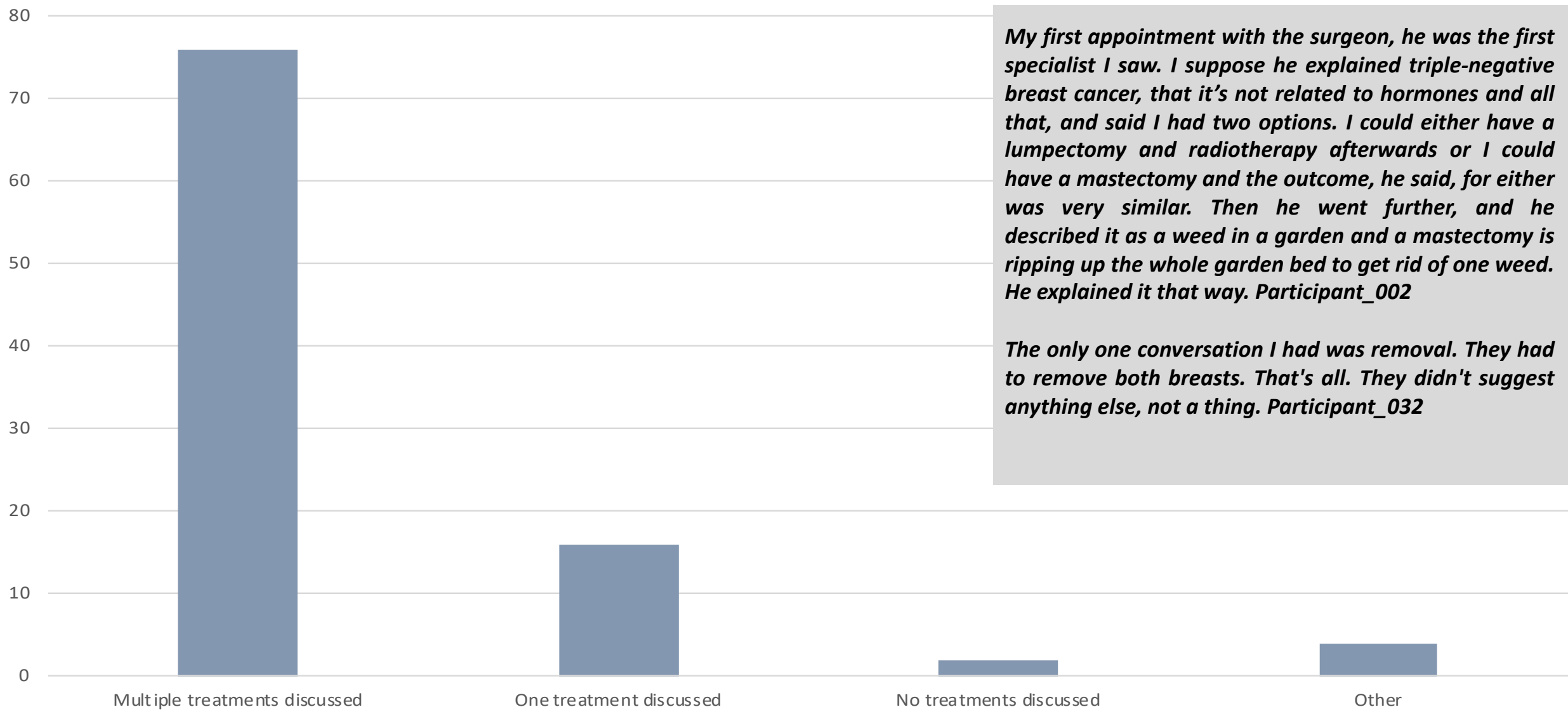
Section 4



Decision Making

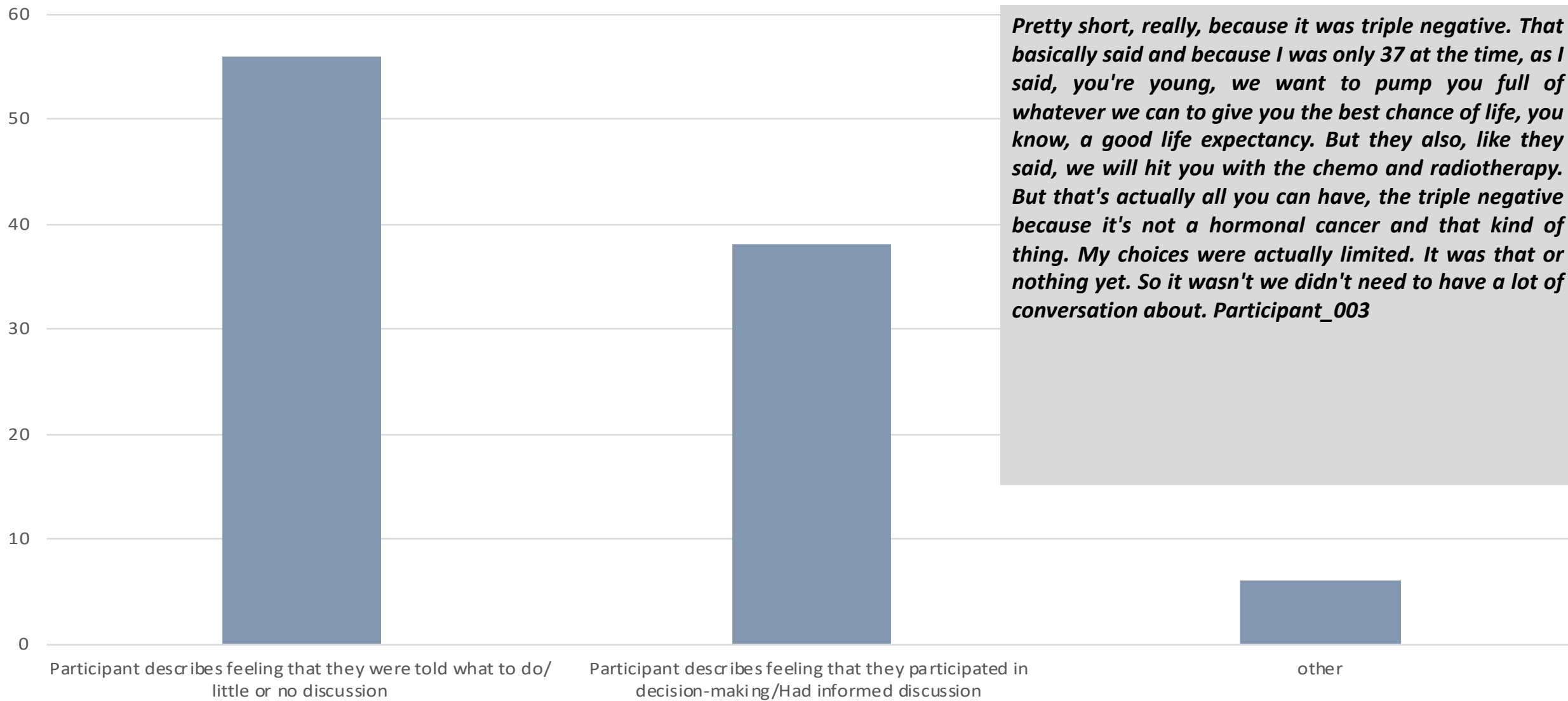
In the decision-making section, you can find information about the conversations that were had about treatment options at diagnosis, what is important to people when they make decisions about treatment, and whether decision-making changes over time.





My first appointment with the surgeon, he was the first specialist I saw. I suppose he explained triple-negative breast cancer, that it's not related to hormones and all that, and said I had two options. I could either have a lumpectomy and radiotherapy afterwards or I could have a mastectomy and the outcome, he said, for either was very similar. Then he went further, and he described it as a weed in a garden and a mastectomy is ripping up the whole garden bed to get rid of one weed. He explained it that way. Participant_002

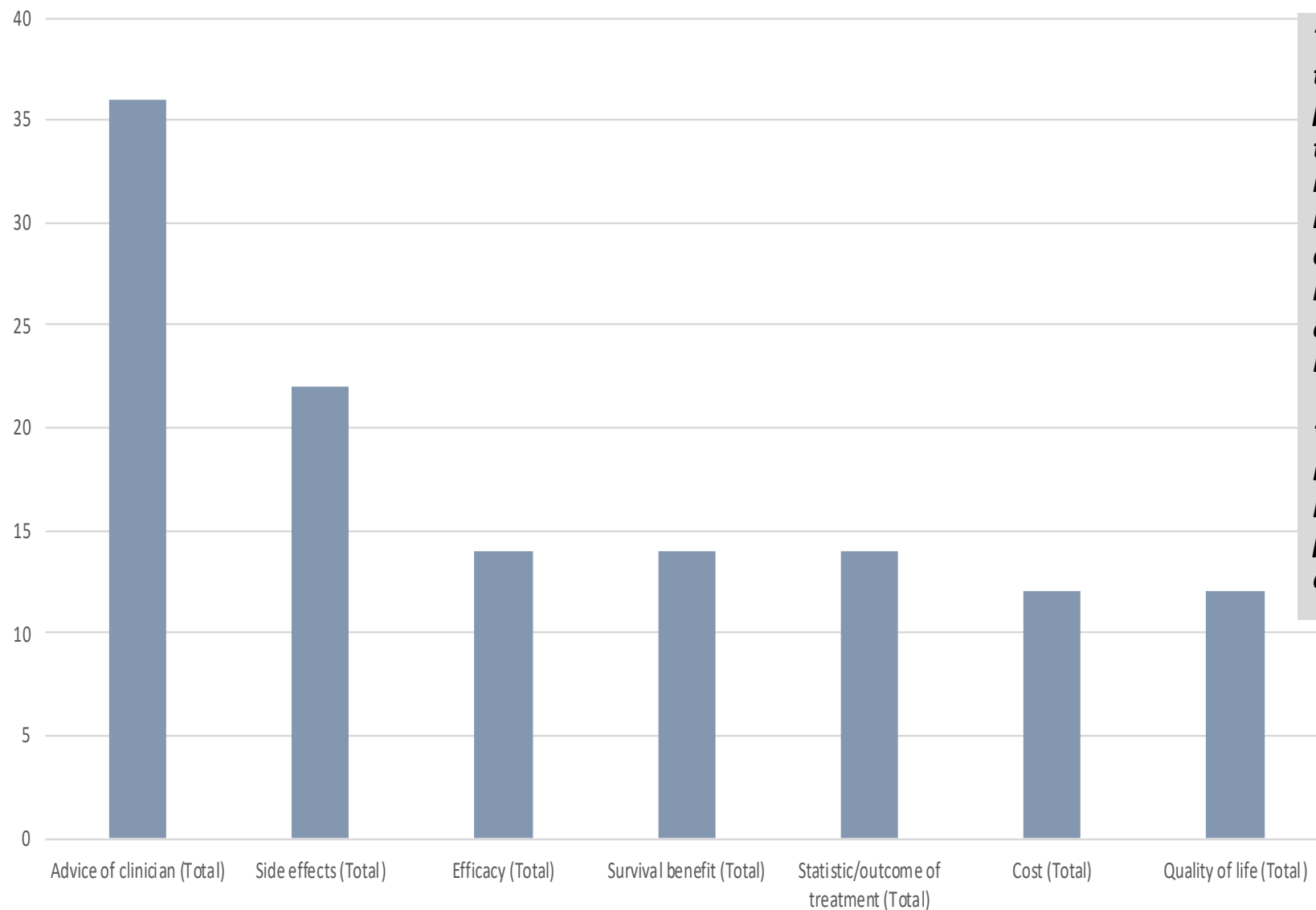
The only one conversation I had was removal. They had to remove both breasts. That's all. They didn't suggest anything else, not a thing. Participant_032



Pretty short, really, because it was triple negative. That basically said and because I was only 37 at the time, as I said, you're young, we want to pump you full of whatever we can to give you the best chance of life, you know, a good life expectancy. But they also, like they said, we will hit you with the chemo and radiotherapy. But that's actually all you can have, the triple negative because it's not a hormonal cancer and that kind of thing. My choices were actually limited. It was that or nothing yet. So it wasn't we didn't need to have a lot of conversation about. Participant_003

Discussions about treatment (Participation in discussions) (% of all participants)

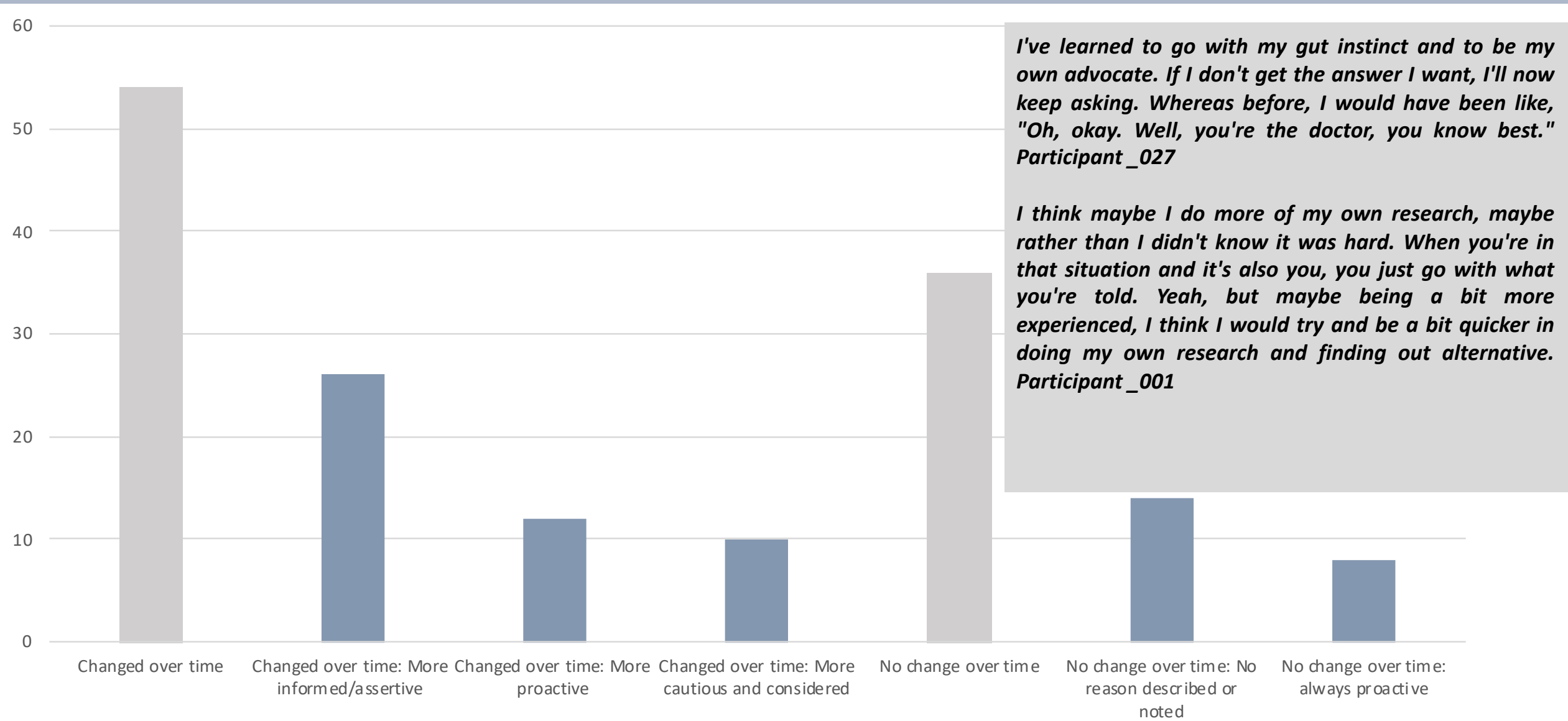




The biggest thing I take into consideration is obviously the specialist's advice. The other thing was my age, I personally wanted to go as aggressive as possible with this because I'm young and I wanted to give myself the best chance of surviving this and prevent a reoccurrence, so I think those things. Obviously, also the distance from my house to the hospital. For me, the biggest thing was I had a baby, so I just wanted to have enough provisions, that someone can look after him. Participant_016

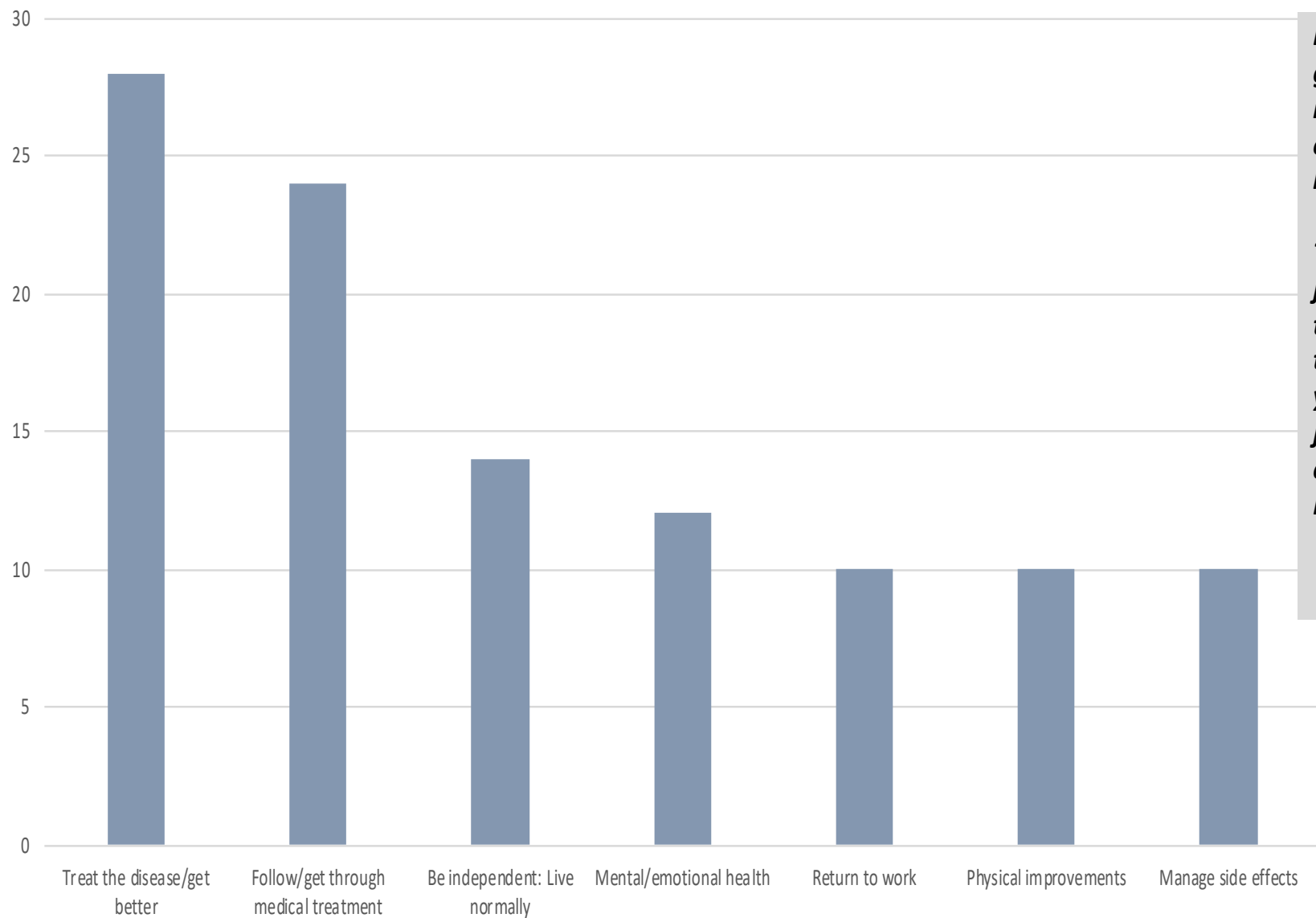
To be honest, I didn't know enough information to really make the decisions. I kind of just trusted them and listened to what they said. I was not a very good person. I didn't ask many questions. I kind of just went along with it. Participant_019





*I've learned to go with my gut instinct and to be my own advocate. If I don't get the answer I want, I'll now keep asking. Whereas before, I would have been like, "Oh, okay. Well, you're the doctor, you know best."
Participant_027*

*I think maybe I do more of my own research, maybe rather than I didn't know it was hard. When you're in that situation and it's also you, you just go with what you're told. Yeah, but maybe being a bit more experienced, I think I would try and be a bit quicker in doing my own research and finding out alternative.
Participant_001*

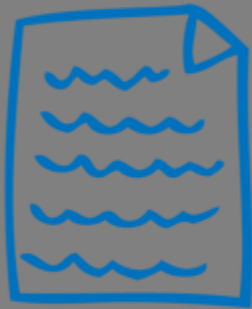


Pretty much the goal was to get rid of the cancer, and get through this part of my life, and get back to normal life. Pretty much the goal was to get rid of the cancer, and get through this part of my life, and get back to normal life. Participant_025

To be honest, at those first appointments, it was all just about how do we get rid of the cancer? I think all the other stuff kind of just seemed part and parcel that you would have side effects and it would affect your life negatively. But I think my main goals would just how the hell do we get rid of it and the rest will deal with as it comes, if that makes sense. Participant_010



Section 5



Treatment

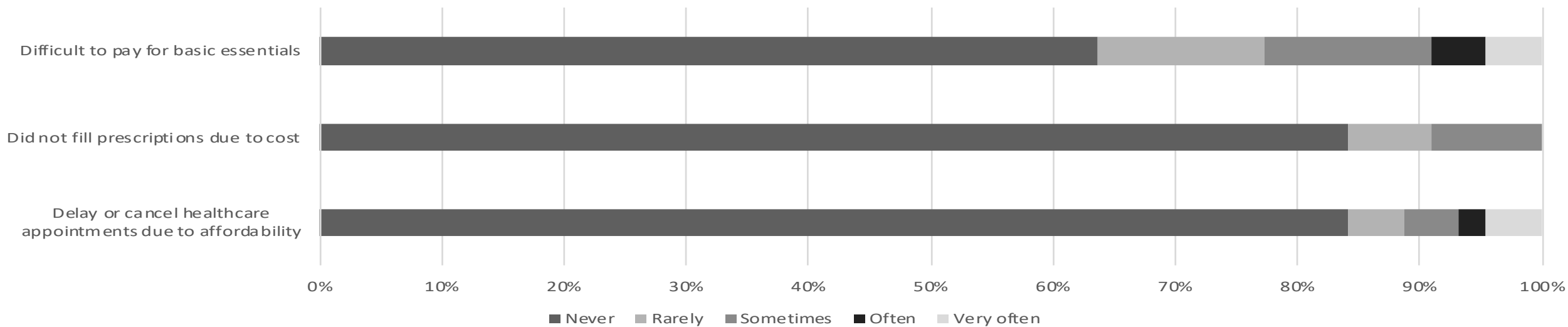
The treatment section is one of the largest sections in each study. Information is available in relation to the types of treatments people have experienced as well as rating quality of life and effectiveness for each treatment. There is information about the main providers of treatment, access to health professionals and information about which part of the health system participants were treated in. There is information about affordability of healthcare, any reduced income for the patient or their family, an additional costs or changes to employment. There is then also detailed information about the treatments that the participants have experienced, whether they had any side effects, their description of mild side effects and severe side effects, and any complementary therapies that they may have used. Information in relation to access to allied health is also available. Information about what needs to change to feel like treatment is effective, and adherence to treatment is also presented. In this section, there is also information on whether discussions about clinical trials were held with clinicians, and for those who have been on a trial, what their experience was like.

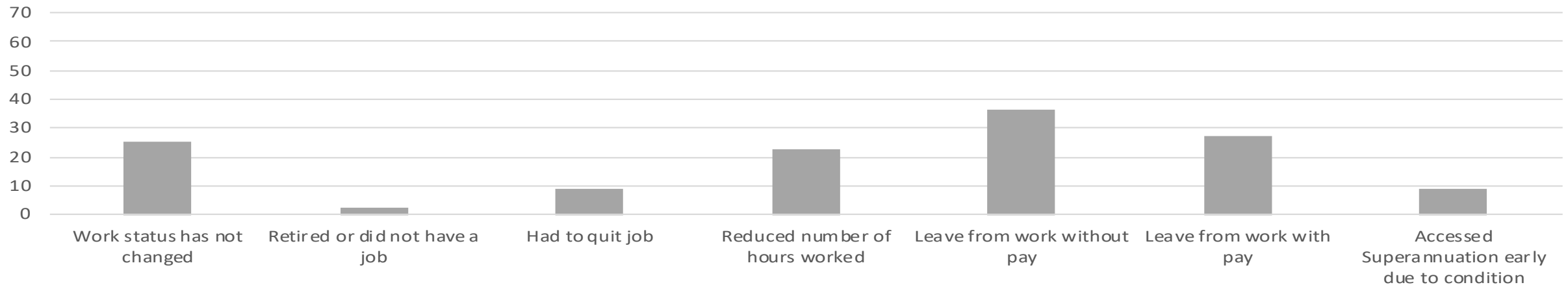


Healthcare professional	Number (n=44)	Percent
Medical oncologist	44	100.00
Radiation oncologist	31	70.45
Specialist surgeon	42	95.45
Palliative care specialist	2	4.55
Breast cancer care coordination discharge planner or key worker	14	31.82
Oncology/chemotherapy nurse	38	86.36
Breast care nurse	37	84.09
Lymphoedema practitioner	16	36.36
Speech therapist	0	0.00
Genetic counsellor	22	50.00
General practitioner	41	93.18
Physiotherapist	21	47.73
Weight loss specialist	0	0.00
Dietitian/nutritionist	11	25.00
Occupational therapist	4	9.09
Exercise physiologist	14	31.82
Pharmacist	18	40.91
Counsellor	9	20.45
Psychologist	20	45.45
Chiropractor	6	13.64
Osteopath	6	13.64
Social worker	2	4.55



Health care services	Response	Number (n=44)	Percent
Private health insurance	No	11.00	25.00
	Yes	33.00	75.00
Asked whether you want to be treated as a public or private patient	No	16.00	36.36
	Yes	28.00	63.64
Asked whether you had private health insurance	No	5.00	11.36
	Yes	39.00	88.64
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	4.00	9.09
	Private patient	20.00	45.45
	Public patient	20.00	45.45
Which hospital system have you primarily been treated in	Both public and private	4.00	9.09
	Private	20.00	45.45
	Public	20.00	45.45





Participant's employment



Main carer/partner's employment



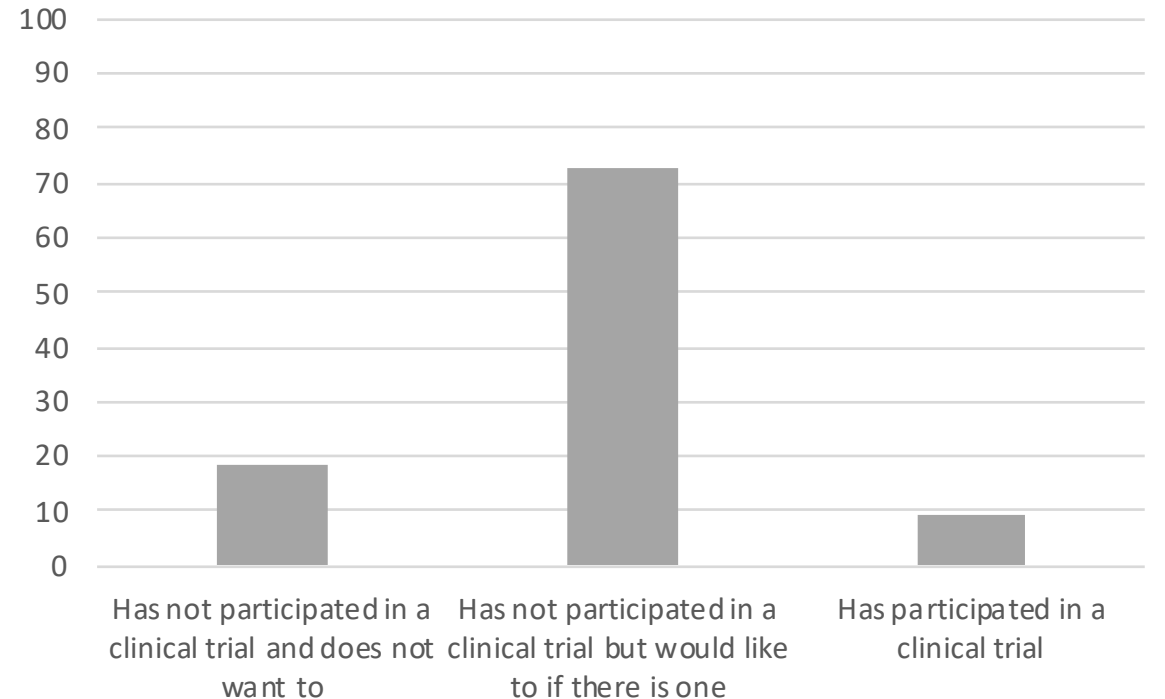
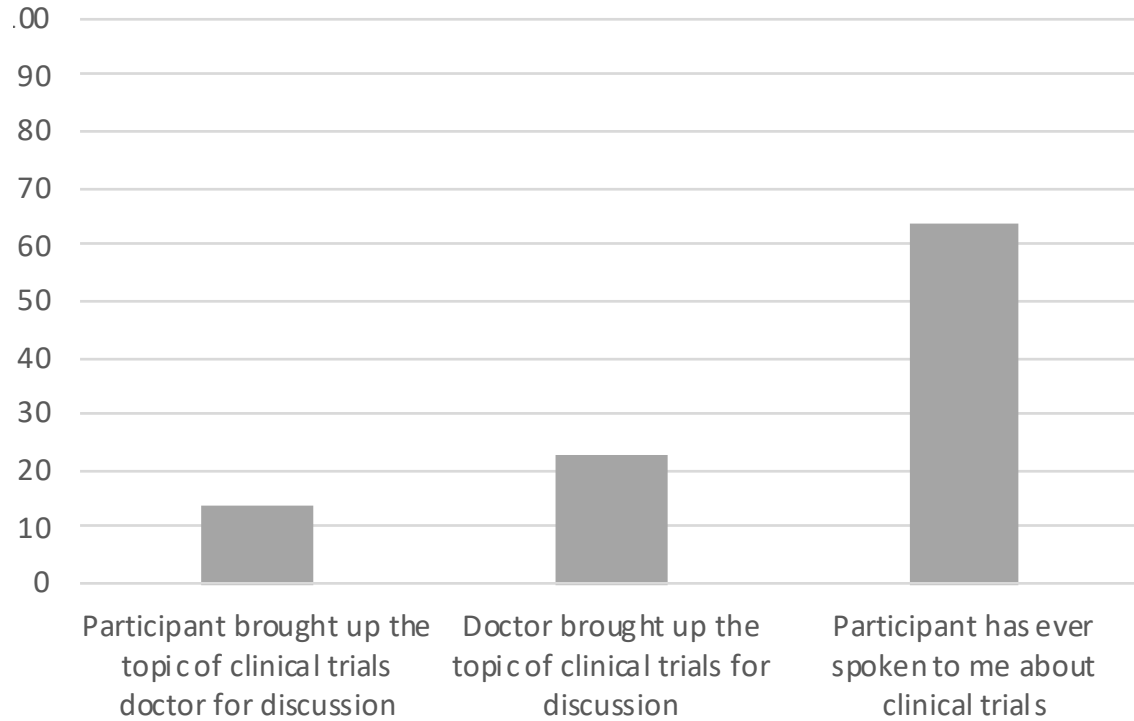
Surgery		Lumpectomy		Re-excision following lumpectomy		Mastectomy		Breast reconstruction		Surgery to remove ovaries		Surgery to relieve symptoms	
		n=19	%	n=2	%	n=19	%	n=13	%	n=7	%	n=1	%
Number		19	43.18	2	4.55	19	43.18	13	29.55	7	15.91	1	2.27
Year of surgery	2020 to 2021	9	47.37	0	0.00	9	47.37	6	46.15	2	28.57	0	0.00
	2017 to 2019	6	31.58	1	50.00	8	42.11	6	46.15	3	42.86	1	100.00
	2016 or before	4	21.05	1	50.00	2	10.53	1	7.69	2	28.57	0	0.00
Side effects	No side effects	8	42.11	1	50.00	1	5.26	1	7.69	1	14.29	0	0.00
	A high temperature	1	5.26	0	0.00	0	0.00	1	7.69		0.00	0	0.00
	Feeling generally unwell	3	15.79	1	50.00	4	21.05	2	15.38	2	28.57	0	0.00
	Feeling hot and cold	0	0.00	0	0.00	1	5.26	2	15.38		0.00	0	0.00
	Feeling sick	1	5.26	0	0.00	1	5.26	2	15.38	1	14.29	0	0.00
	Pain	0	0.00	1	50.00	17	89.47	11	84.62	3	42.86	1	100.00
	Shivering	10	52.63	0	0.00	1	5.26	2	15.38		0.00	0	0.00
	Swelling/redness around wound	3	15.79	0	0.00	5	26.32	6	46.15		0.00	0	0.00
Other	1	5.26	0	0.00	4	21.05	2	15.38	1	14.29	0	0.00	
		Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Quality of life		3	1.00	-	-	2	1.00	3	2.00	4	2.00	-	-
Effectiveness		5	1.00	-	-	5	1.00	4	1.00	5	1	-	-

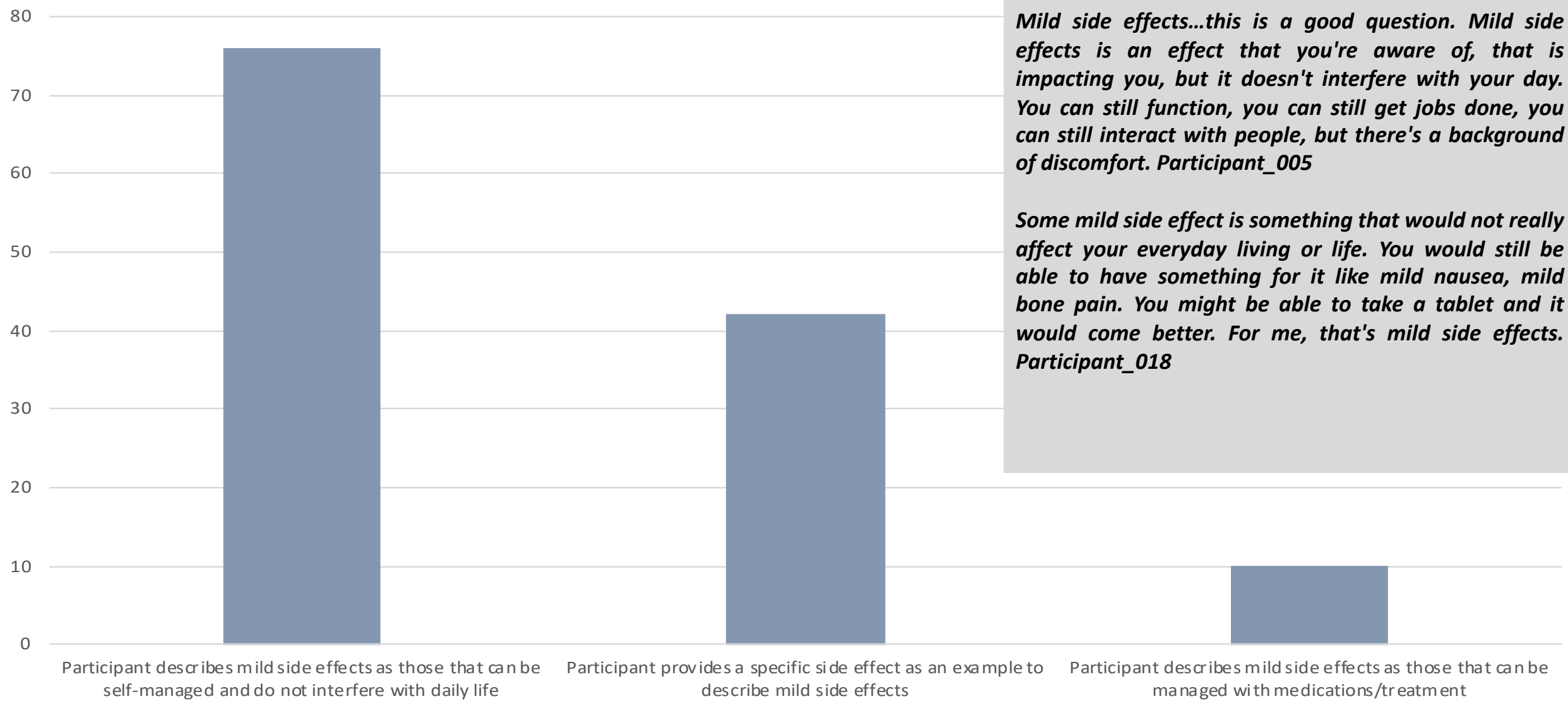
Drug treatments	Number (n=44)	Percent
Doxorubicin, cyclophosphamide, and paclitaxel	17	38.64
Paclitaxel	11	25.00
Capecitabine	10	22.73
Doxorubicin and cyclophosphamide	8	18.18
Carboplatin paclitaxel	6	13.64
Doxorubicin	5	11.36
Carboplatin	3	6.82
Docetaxel	3	6.82
Docetaxel and cyclophosphamide	3	6.82
Fluorouracil, epirubicin, and cyclophosphamide	3	6.82
Cyclophosphamide and methotrexate	2	4.55
Denosumab	1	2.27
Zoledronic acid	1	2.27



Radiotherapy		Primary site		Secondary site	
		n=25	%	n=3	%
Number		25	56.82	3	6.82
Year of treatment	2020 to 2021	12	27.27	1	33.33
	2017 to 2019	9	20.45	1	33.33
	2016 or before	4	9.09	1	33.33
Treatment status	Treatment completed	22	88.00	0	0.00
	Treatment ongoing	1	4.00	0	0.00
	No response	2	8.00	0	0.00
Side effects	No side effects	2	8.00	0	0.00
	Discomfort when swallowing	3	12.00	0	0.00
	Fatigue	18	72.00	3	100.00
	Loss of appetite and weight loss	2	8.00	1	33.33
	Nausea and vomiting	2	8.00	1	33.33
	Sexual issues	2	8.00	0	0.00
	Skin problems (red, irritated, swollen, blistered, sunburned, tanned)	19	76.00	3	100.00
	Sore mouth	2	8.00	0	0.00
	Stiff joints and muscles	5	20.00	1	33.33
	Swollen limbs	0	0.00	1	33.33
		Median	IQR	Median	IQR
Quality of life		4	2	-	-
Effectiveness		4.5	1	-	-

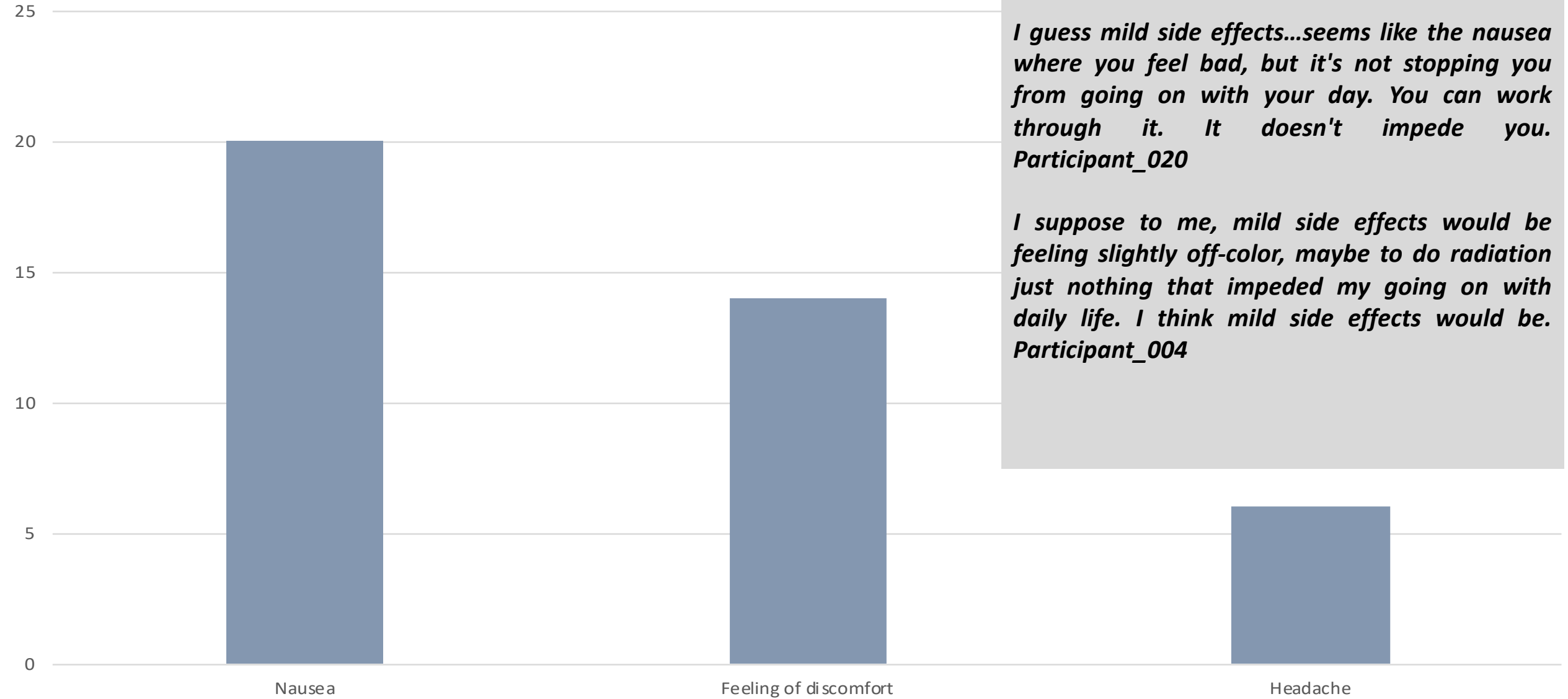






Mild side effects...this is a good question. Mild side effects is an effect that you're aware of, that is impacting you, but it doesn't interfere with your day. You can still function, you can still get jobs done, you can still interact with people, but there's a background of discomfort. Participant_005

Some mild side effect is something that would not really affect your everyday living or life. You would still be able to have something for it like mild nausea, mild bone pain. You might be able to take a tablet and it would come better. For me, that's mild side effects. Participant_018

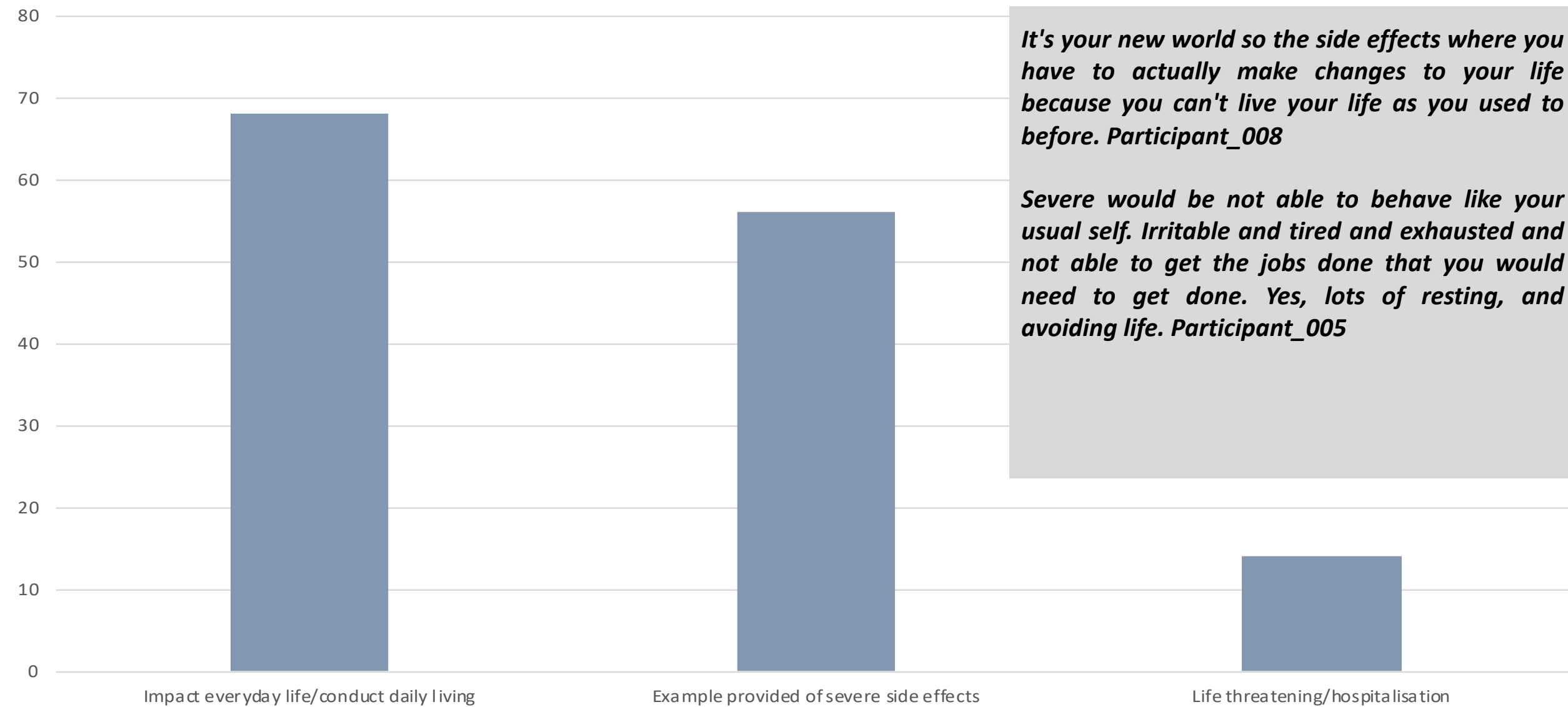


I guess mild side effects...seems like the nausea where you feel bad, but it's not stopping you from going on with your day. You can work through it. It doesn't impede you. Participant_020

I suppose to me, mild side effects would be feeling slightly off-color, maybe to do radiation just nothing that impeded my going on with daily life. I think mild side effects would be. Participant_004

Description of mild side effects: Specific example (% of all participants)

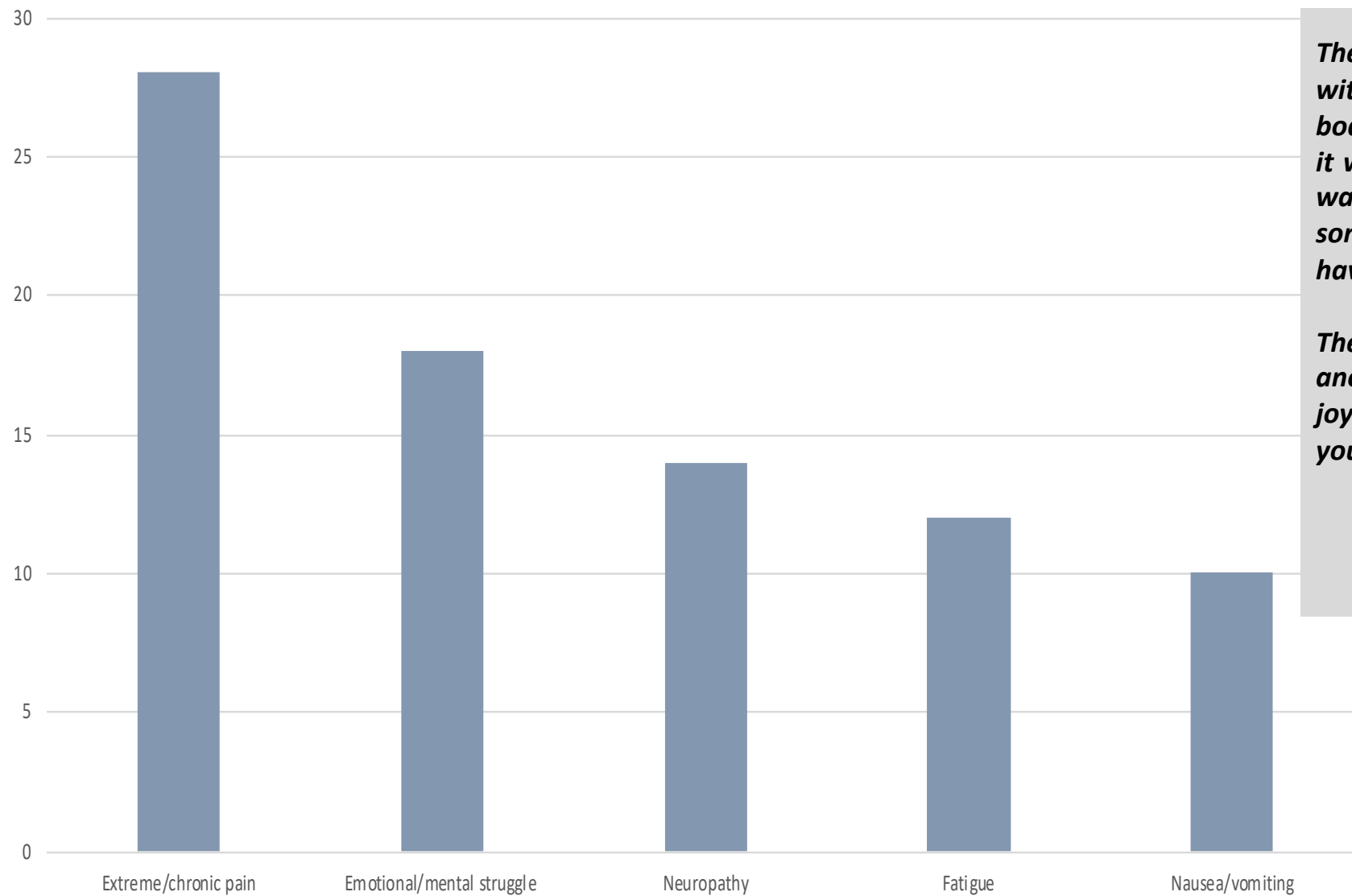




It's your new world so the side effects where you have to actually make changes to your life because you can't live your life as you used to before. Participant_008

Severe would be not able to behave like your usual self. Irritable and tired and exhausted and not able to get the jobs done that you would need to get done. Yes, lots of resting, and avoiding life. Participant_005



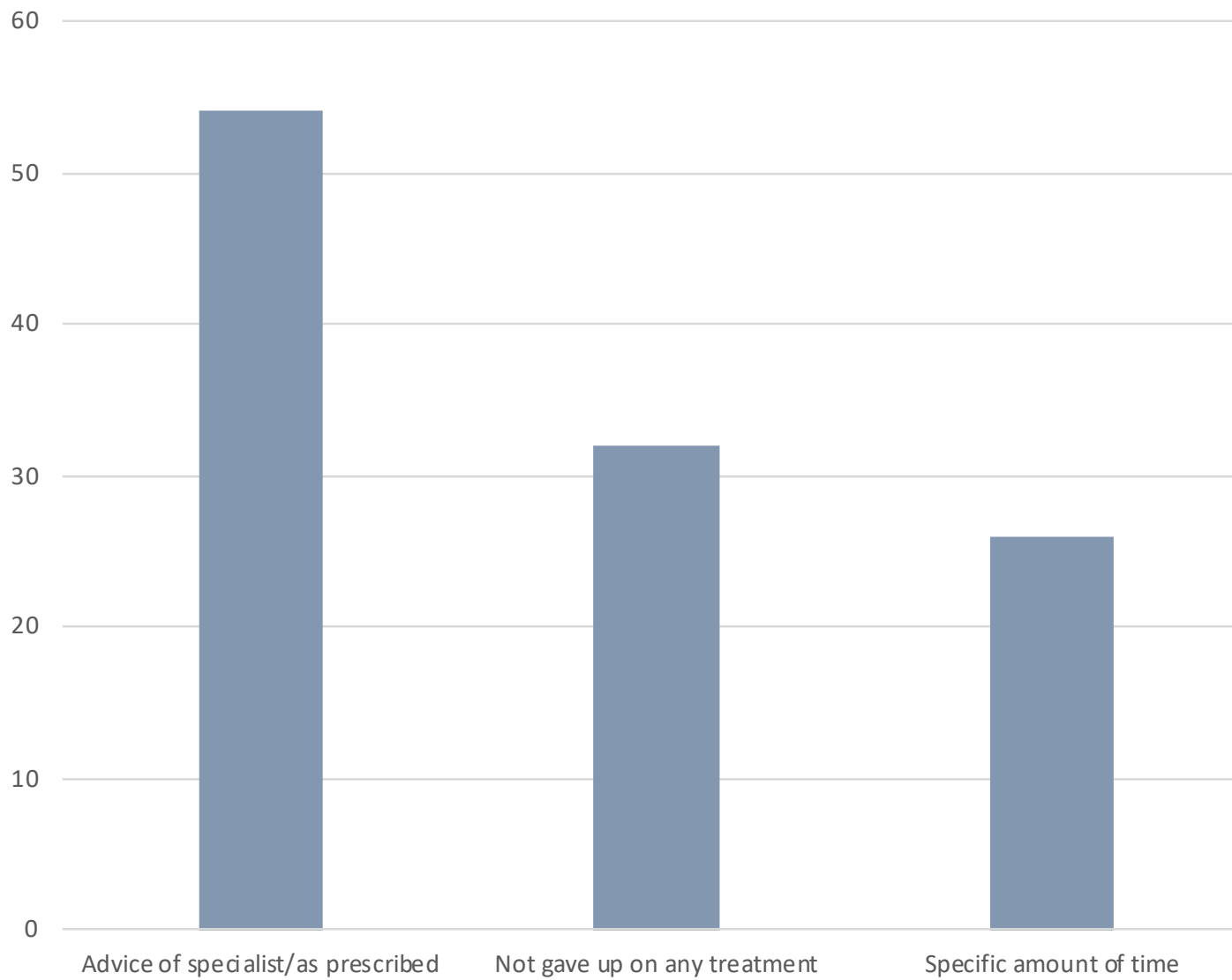


The severe side effects were crippling. They messed with your mind in the sense that every part of your body ached from your toes to the top of your head and it was a [inaudible] pain. It was an internal pain and it was unbearable and as I said to several people, it's something I wouldn't wish on my worst enemy was to have to go through that kind of pain. Participant_027

There are two words in English, it was debilitating and another was, it sucks life out of you, you have no joy...You can't do anything, you're sad, yes, dark, sad, you can't do anything. Participant_042

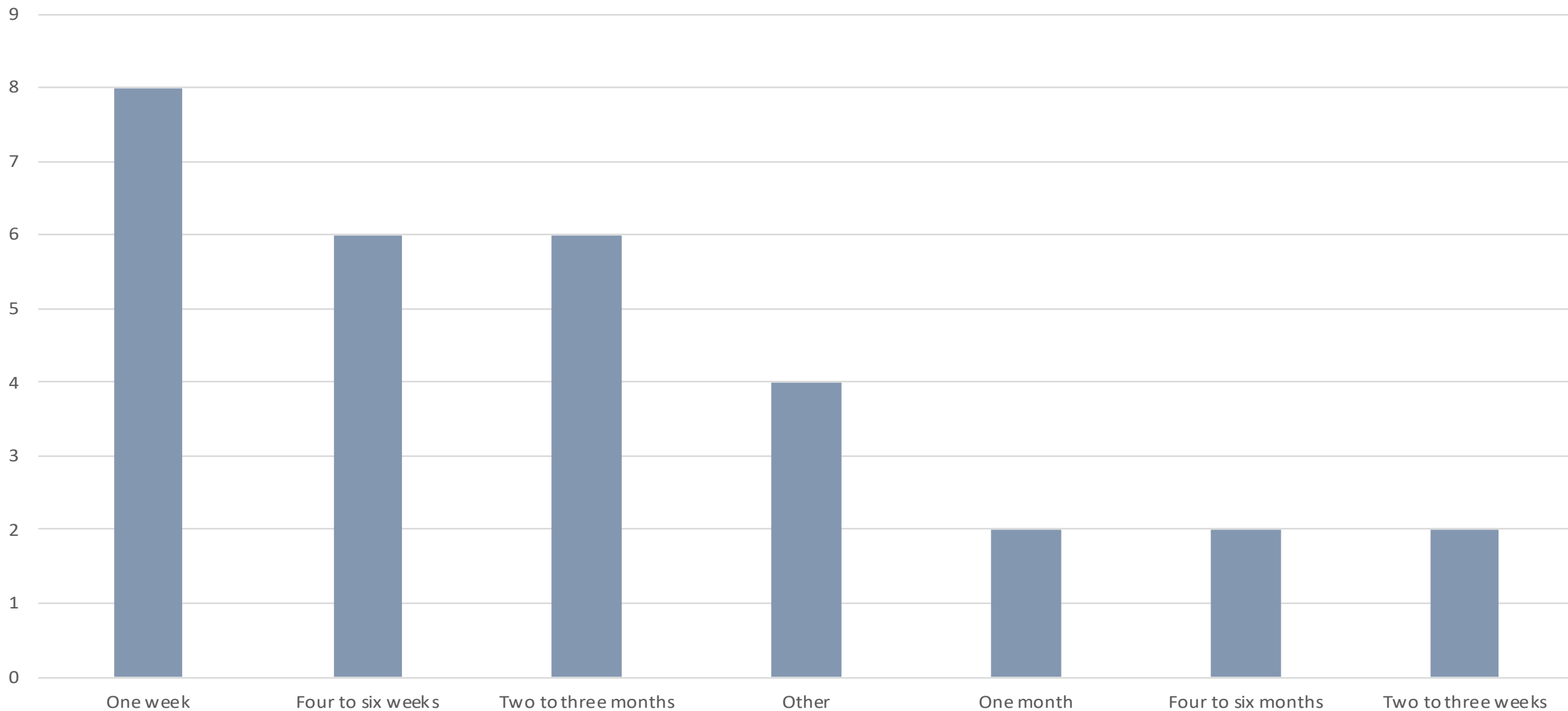
Description of severe side effects: Specific side effect examples (% of all participants)





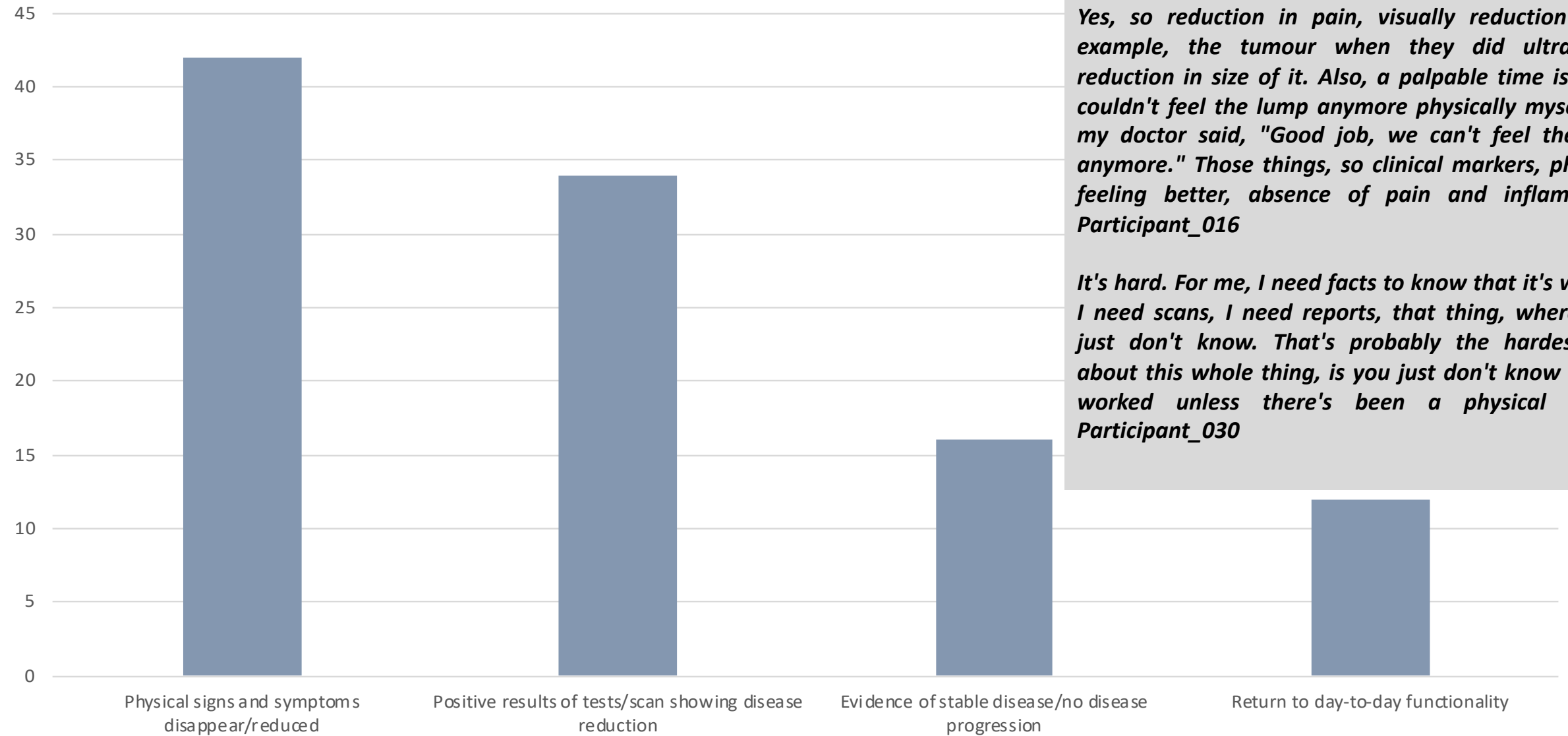
If I don't think it's working, I don't know. I would keep going with it because I wouldn't, I wouldn't assume that I knew if it was working or not. OK, so I think I would stick with it, although I did refuse some medication they would of after my surgery. So I was being offered drugs for pain relief, but I researched side effects and so I just didn't want to take it. So I refused drugs. But pain relief, I wouldn't. I would. I trusted my oncologist. Participant_001

Would depend on the medication and what they what the medical advice was about, how long it takes to work. For example, if I said it takes three months to work on what if it wasn't working the way it was, like if you were hoping that it came to spread after three months and that's not what we need. Participant_002



**Adherence to treatment: specific amount of time
(% of all participants)**



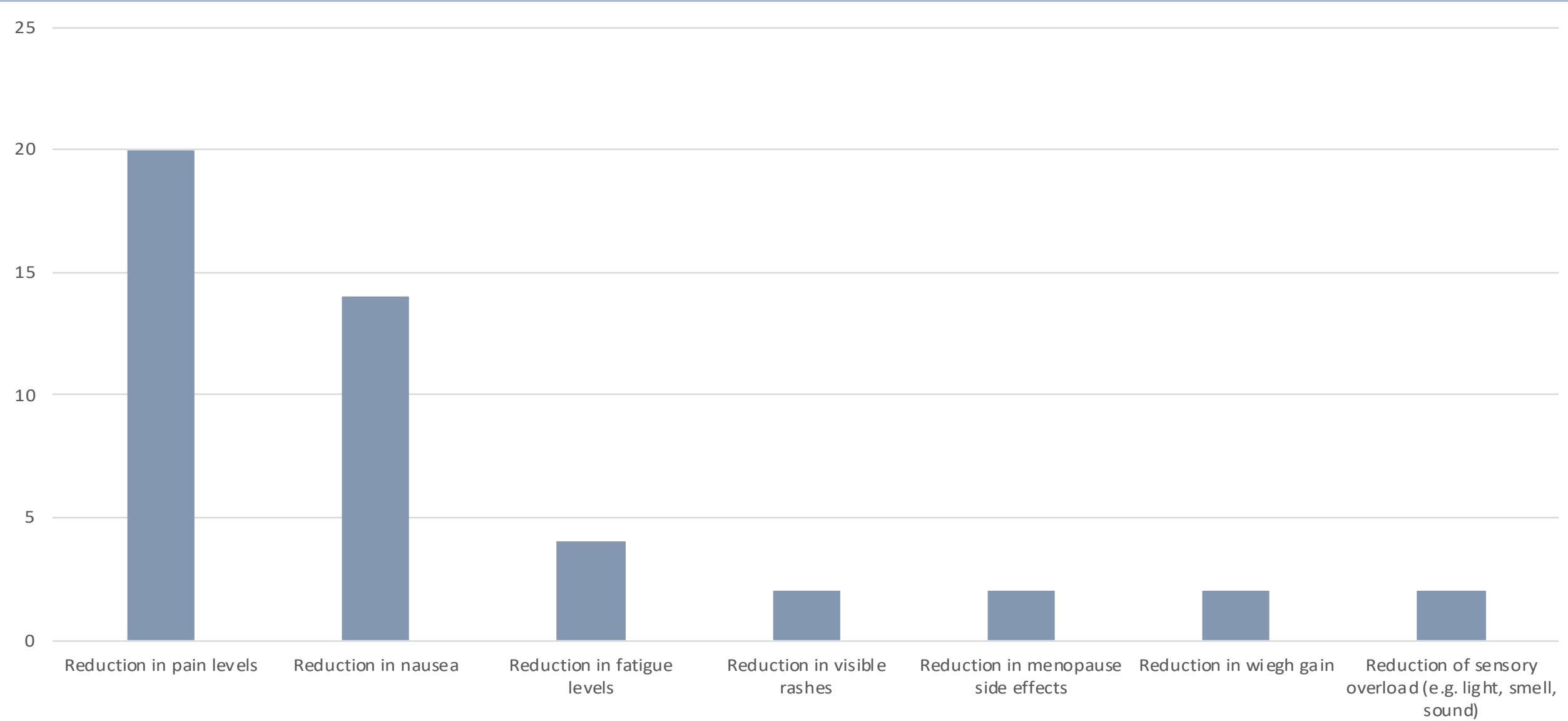


Yes, so reduction in pain, visually reduction in, for example, the tumour when they did ultrasounds, reduction in size of it. Also, a palpable time is when I couldn't feel the lump anymore physically myself, or if my doctor said, "Good job, we can't feel the lumps anymore." Those things, so clinical markers, physically feeling better, absence of pain and inflammation. Participant_016

It's hard. For me, I need facts to know that it's working. I need scans, I need reports, that thing, whereas you just don't know. That's probably the hardest thing about this whole thing, is you just don't know that it's worked unless there's been a physical change. Participant_030

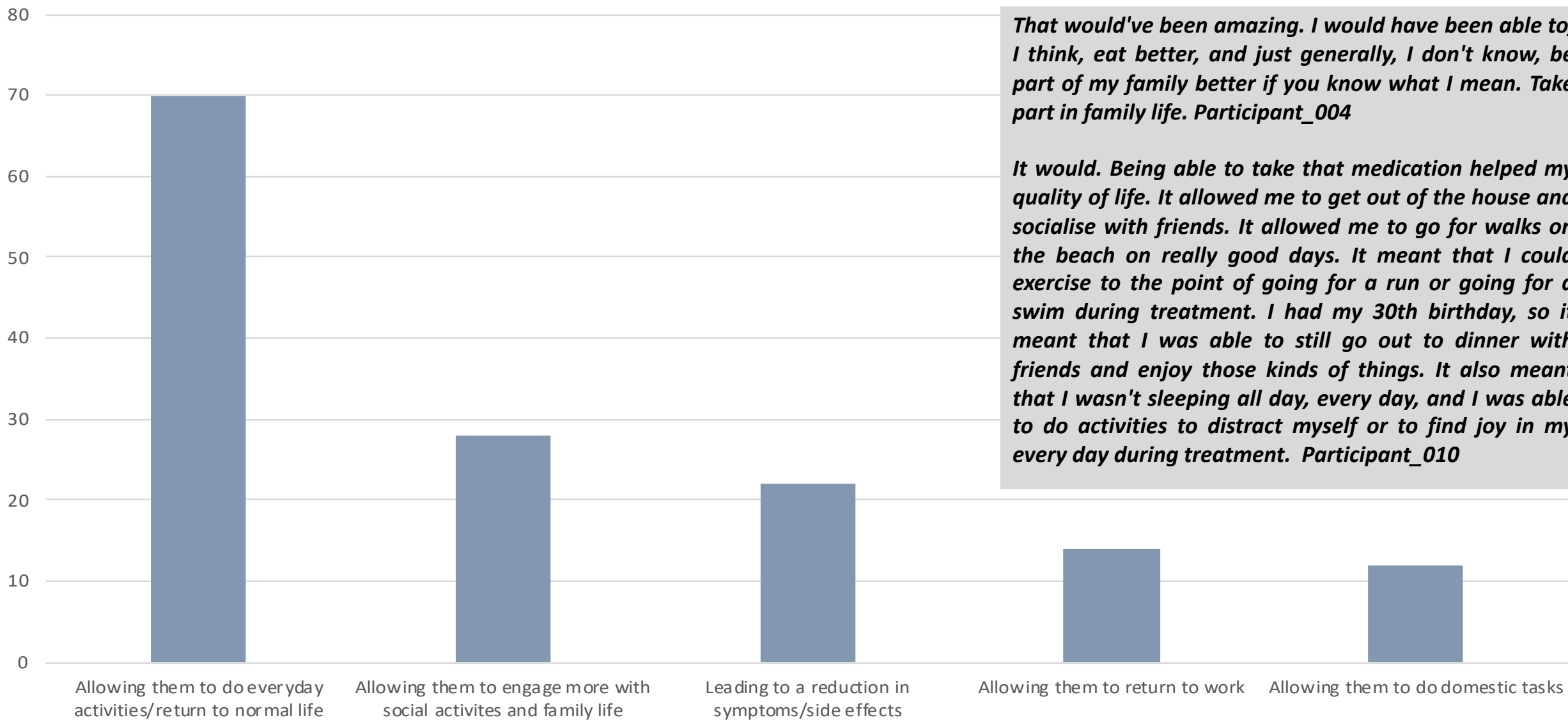
What needs to change to feel like treatment is working (% of all participants)





**What needs to change to feel like treatment is working:
specific symptoms (% of all participants)**





That would've been amazing. I would have been able to, I think, eat better, and just generally, I don't know, be part of my family better if you know what I mean. Take part in family life. Participant_004

It would. Being able to take that medication helped my quality of life. It allowed me to get out of the house and socialise with friends. It allowed me to go for walks on the beach on really good days. It meant that I could exercise to the point of going for a run or going for a swim during treatment. I had my 30th birthday, so it meant that I was able to still go out to dinner with friends and enjoy those kinds of things. It also meant that I wasn't sleeping all day, every day, and I was able to do activities to distract myself or to find joy in my every day during treatment. Participant_010

What would it mean if treatment worked (% of all participants)

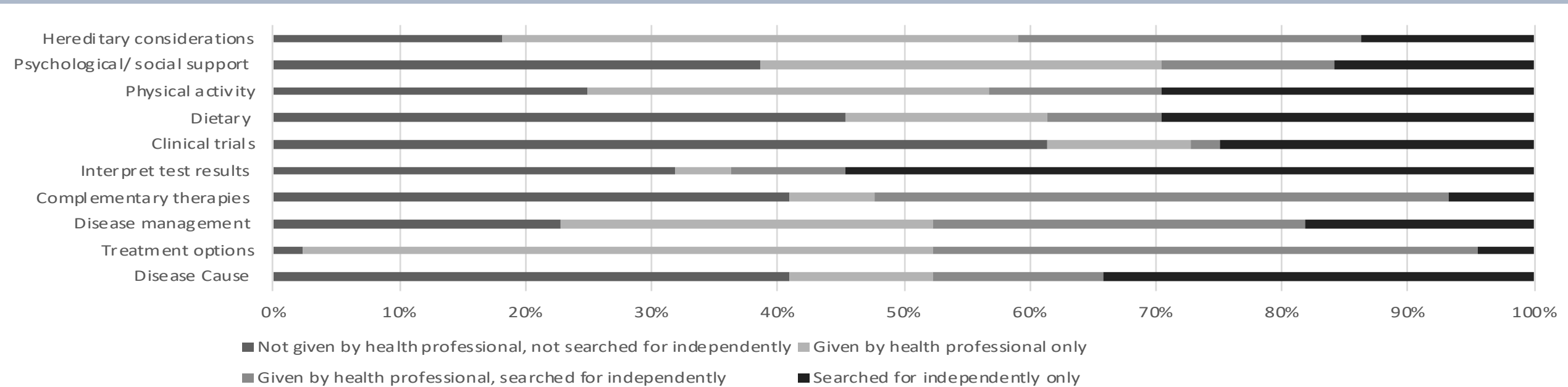
Section 6



Communication
&
Information

This section report access to information, information that was helpful and information that was not helpful, when participants feel they were most receptive to receiving information, information preferences, information topics for which information was received or searched for, as well as when it was received and additional information was required. This is also where there is information about healthcare professional communication and participant's knowledge and confidence in managing their own health using the Partners in Health tool.





The largest gaps in information, where information was neither given to patients nor searched for independently were Clinical trials (n = 27, 61.36%) and Dietary (n = 20, 45.45%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were Treatment options (n = 22, 50.00%) and Hereditary considerations (n = 18, 40.91%).

The topics that participants were given most information from both healthcare professionals and searching independently for were Sum of Complementary therapies (n = 20, 45.45%) and Treatment options (n = 19, 43.18%).

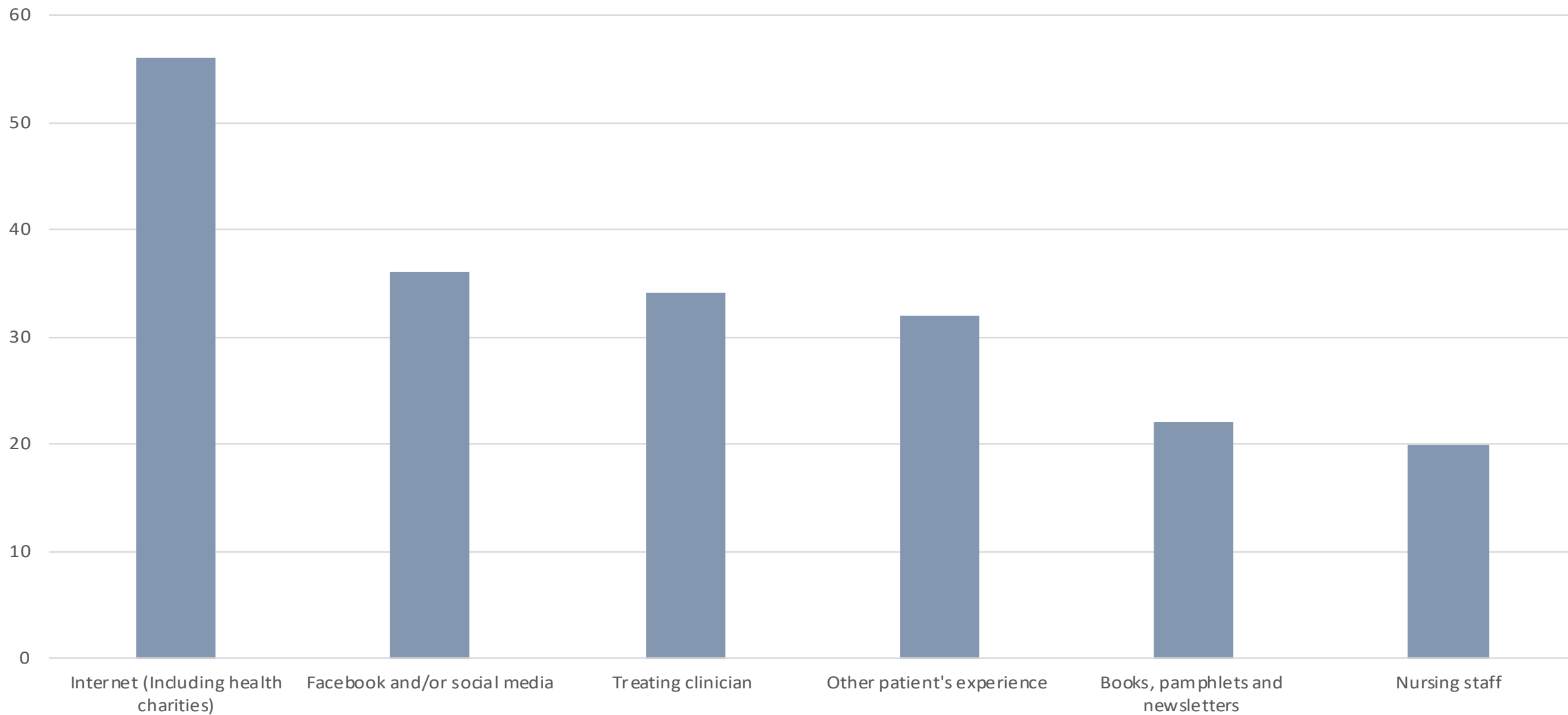
The topics that participants searched for independently after not receiving information from healthcare professionals were Disease management (n = 24, 54.55%) and Sum of Complementary therapies (n = 15, 34.09%) (Table 6.35, Figure 6.48).

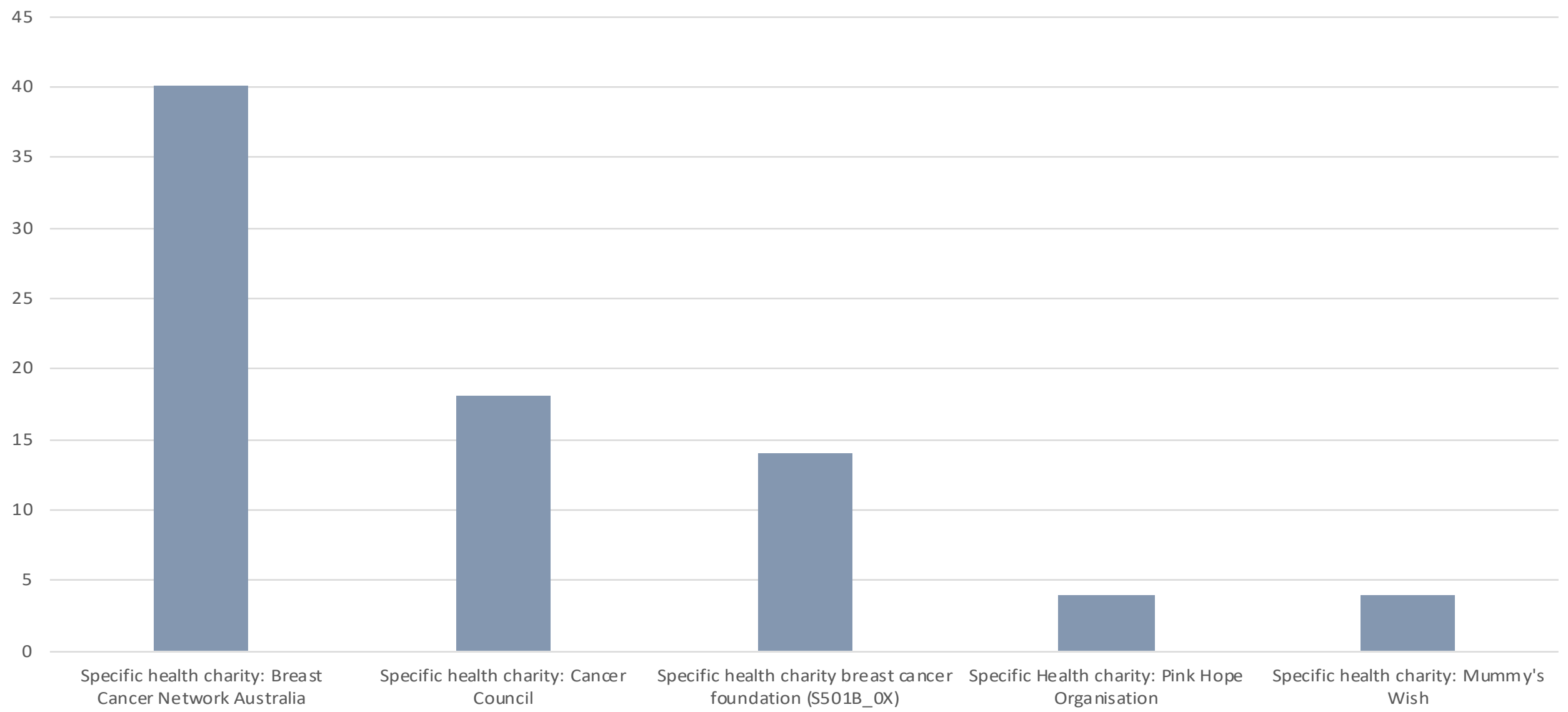


Partners in health scale (n=44)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge*	25.98	3.51	26.50	5.00	0 to 32	5
Coping*	16.18	4.26	16.00	8.00	0 to 24	4
Recognition and management of symptoms	19.61	2.66	20.00	2.50	0 to 24	5
Adherence to treatment	14.45	1.65	15.00	2.00	0 to 16	5
Total score*	76.23	8.93	76.00	12.50	0 to 96	4

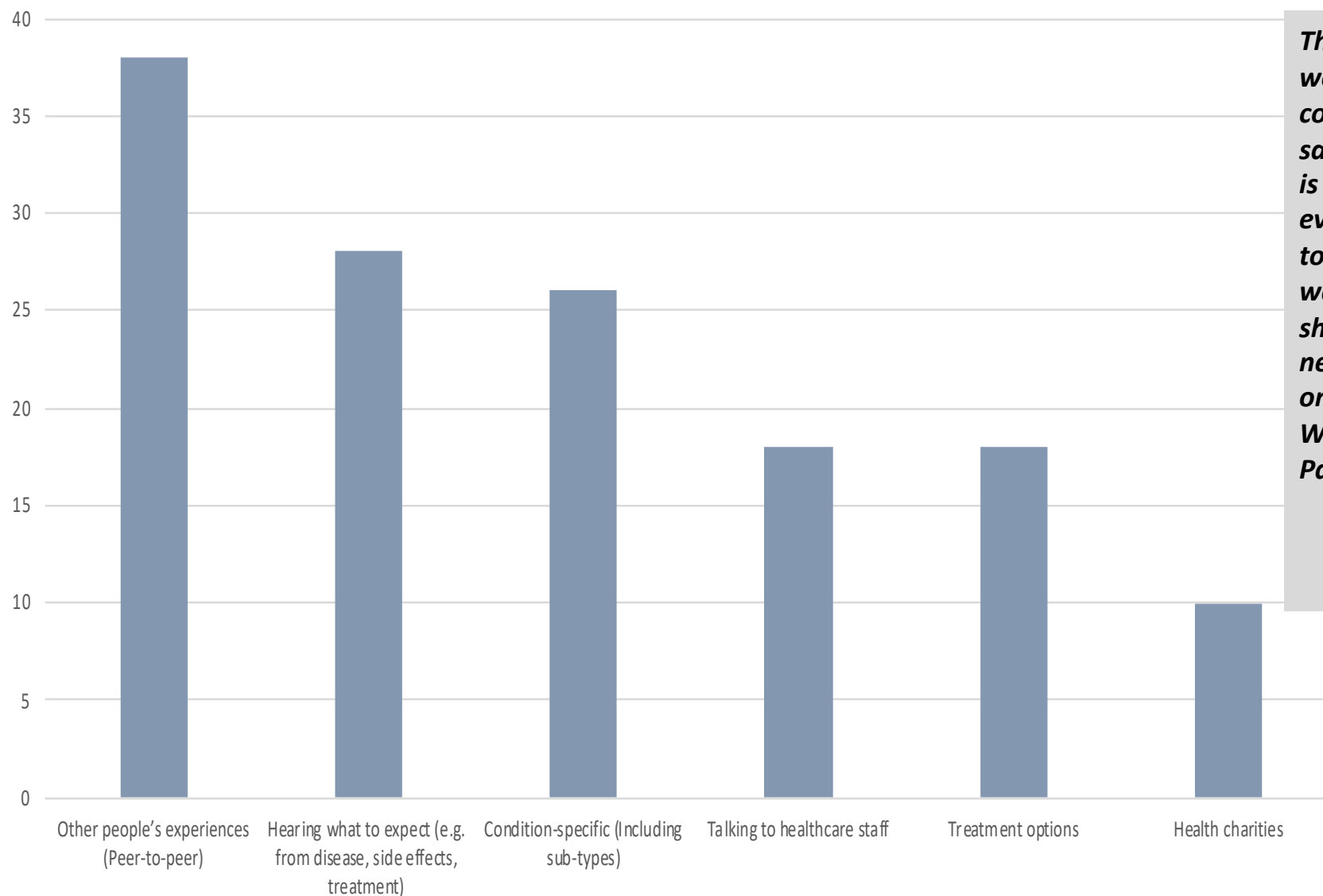
*Normal distribution use mean and SD as measure of central tendency





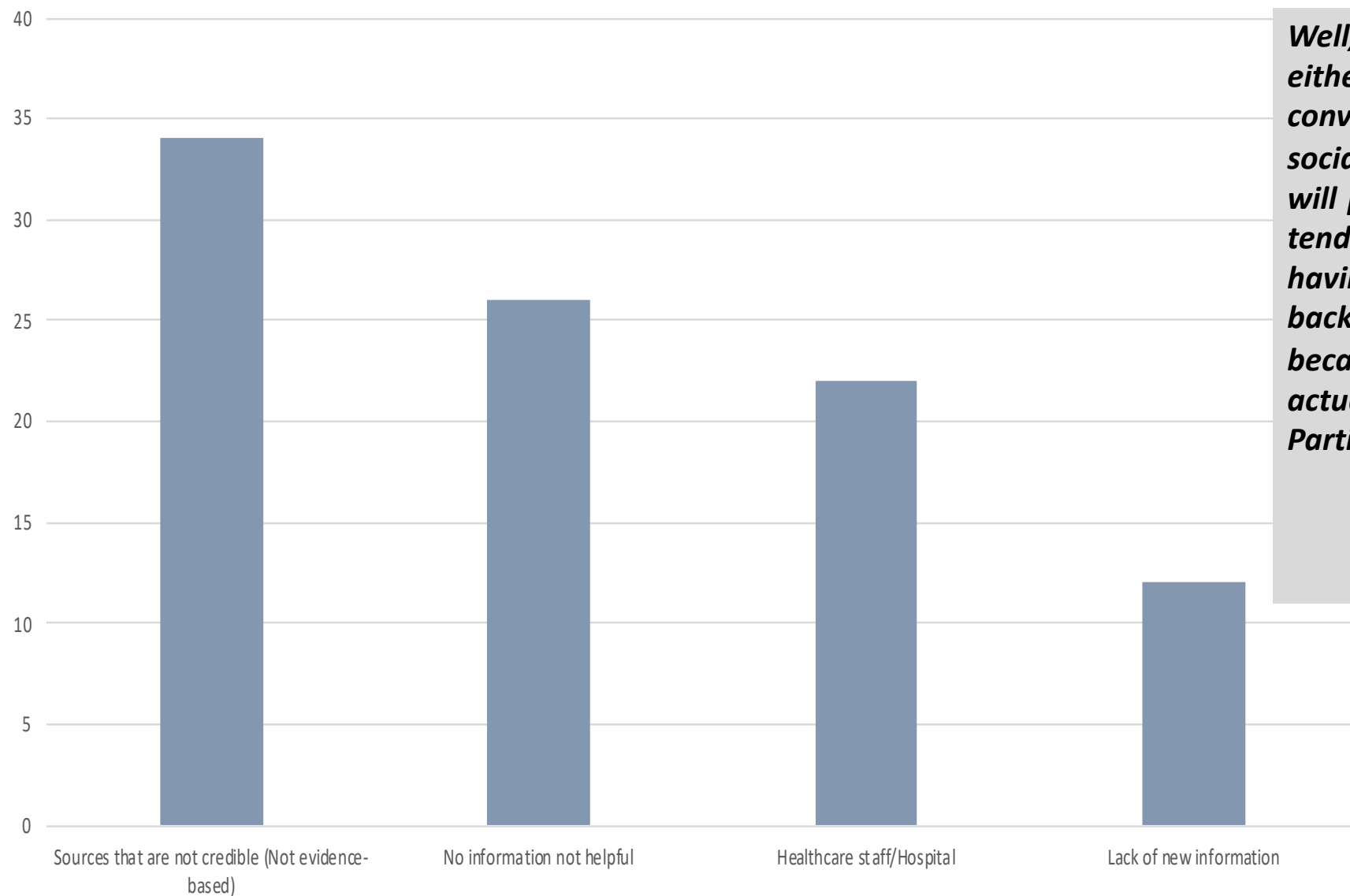


**Information accessed – specific charity
(% of all participants)**



The most helpful was the sort of direct support from women who are also going through it. So the connexions I made with other women who were able to say, this is how I coped with this, this is what I find. This is this is what it looks like to have a mastectomy. And even that was one lovely woman who said, do you want to feel like you should see and feel the reconstruction was like. So that was the most useful was real people sharing their experiences. That was the information I needed. The actual reality, rather than just a paragraph on, you know, triple negative means this and that. Whatever it was, the real experiences themselves. Participant_001

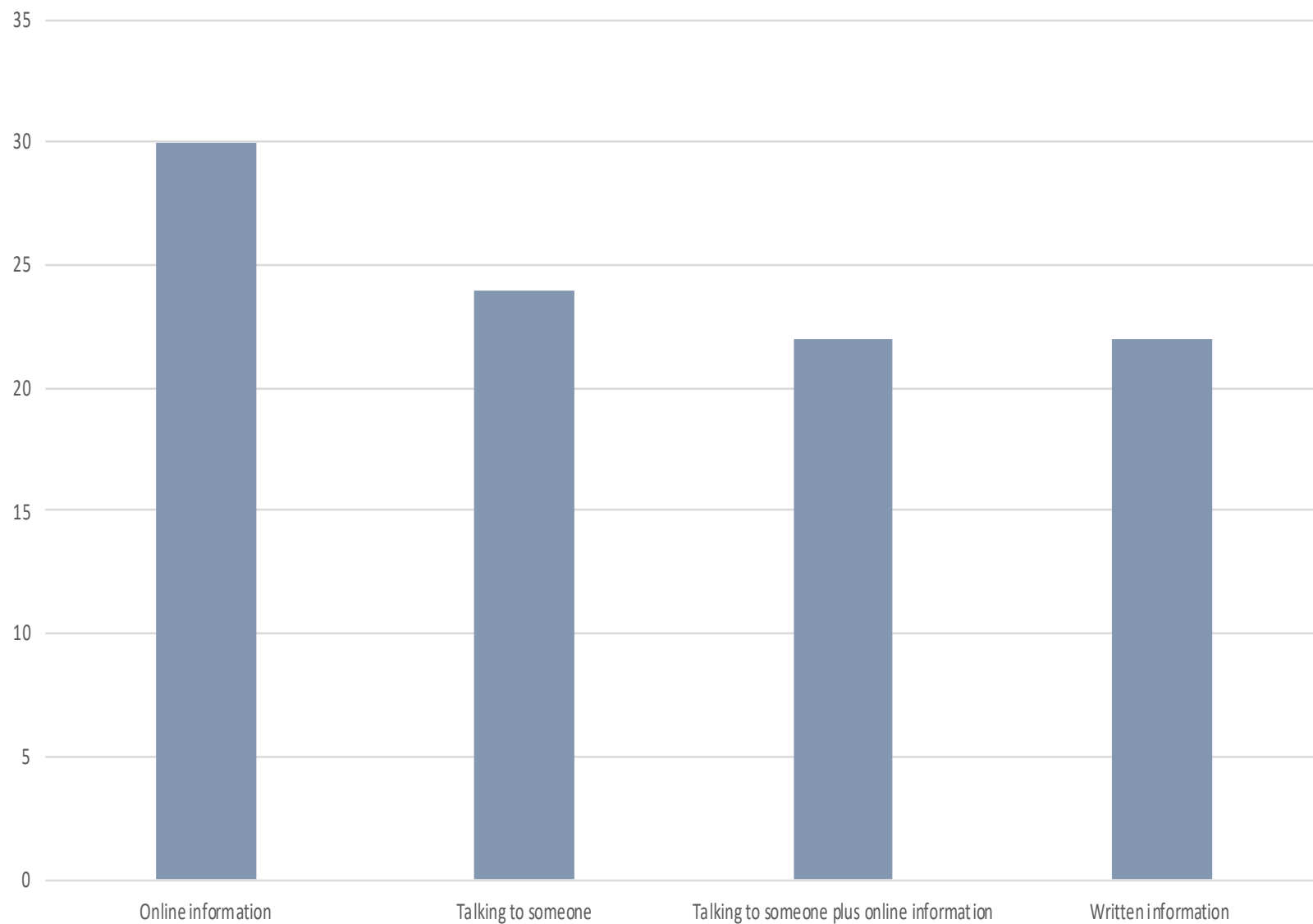




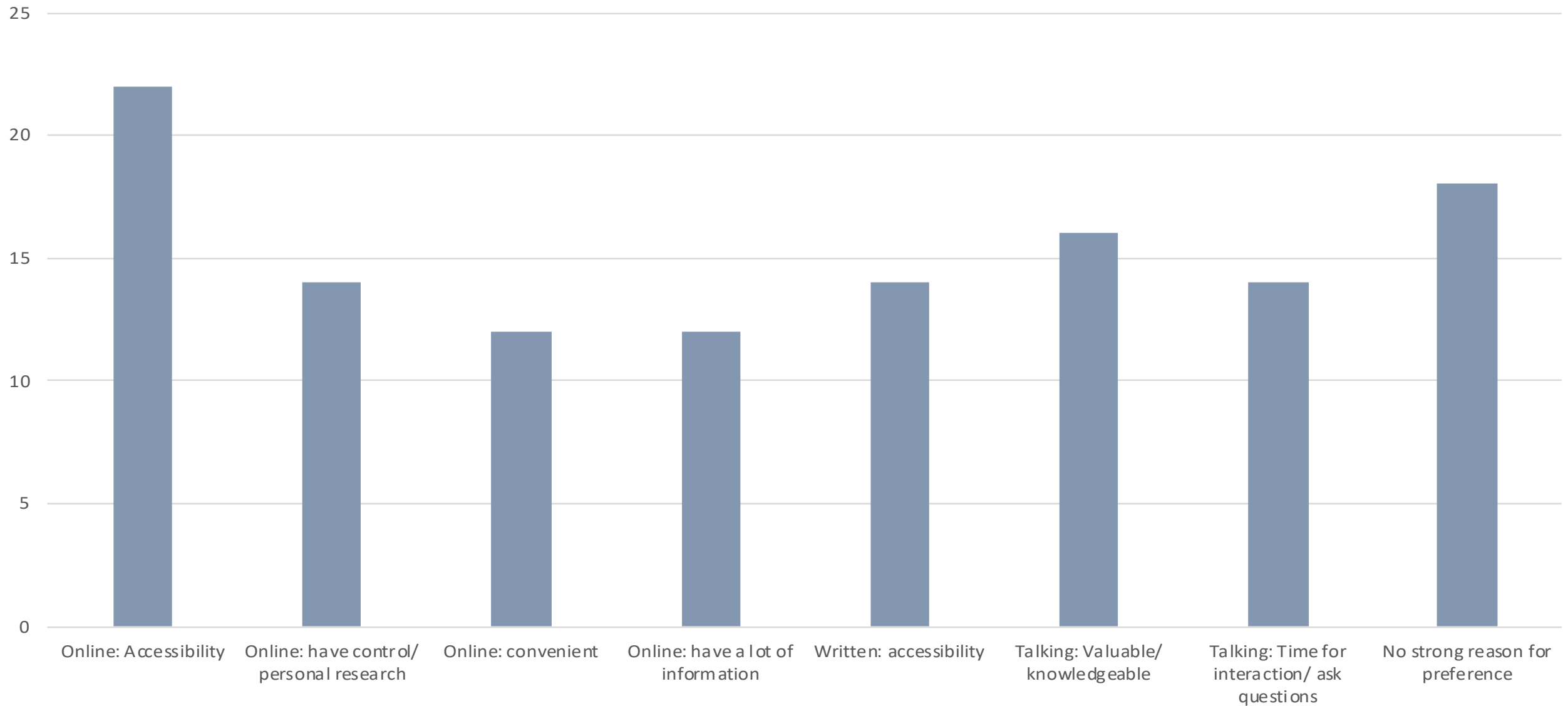
*Well, once again, just probably gossip that's either come third hand through different conversations that you've had or also it might be social media things like Facebook. Often, things will pop up on there that are not very helpful, I tend to stay clear of stuff like that. Probably, having that medical background or health background that does help avoid a lot of that because you're aware of whether things are actual information or whether it's just garbage
Participant_013*

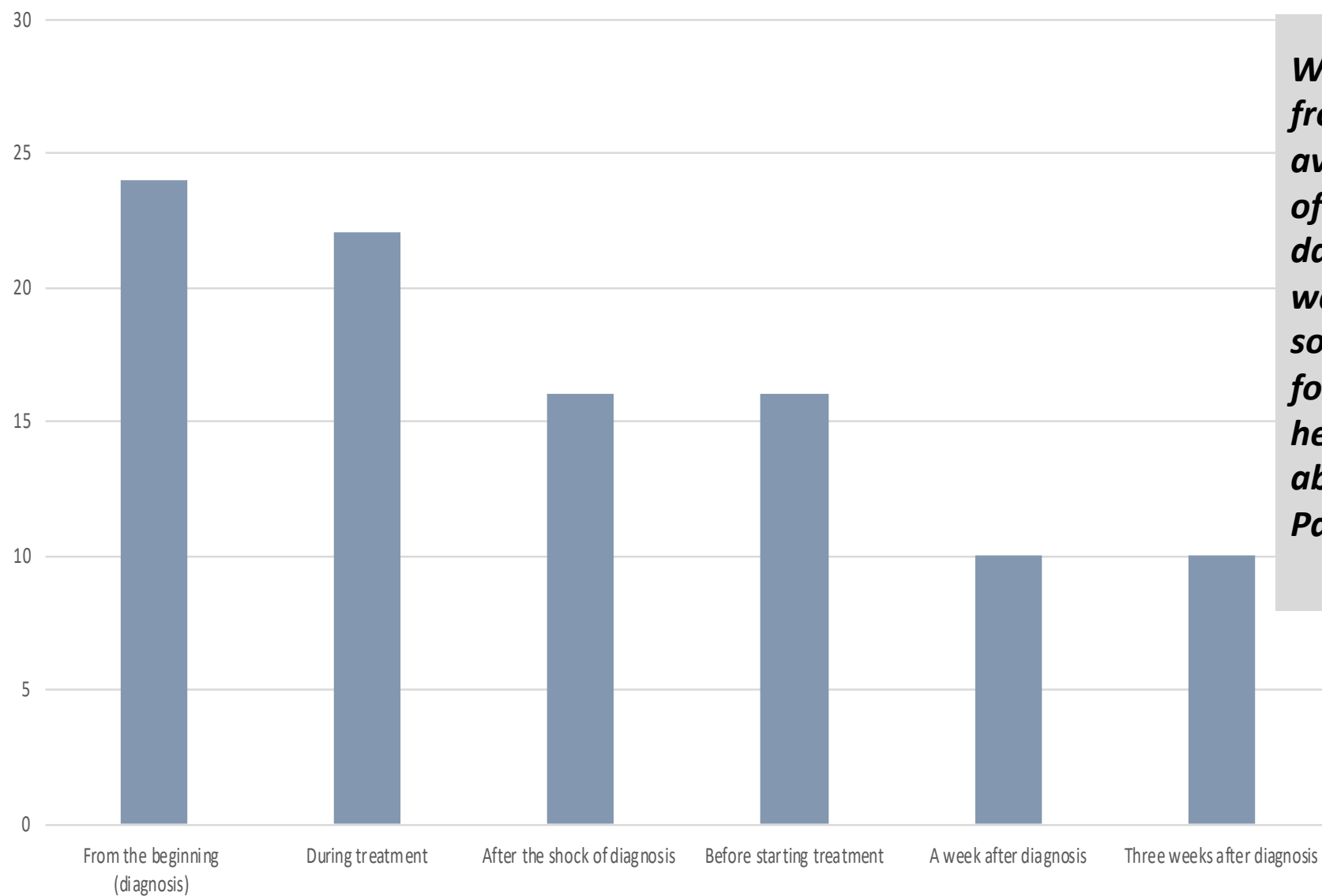


Information that has not been helpful (% of all participants)



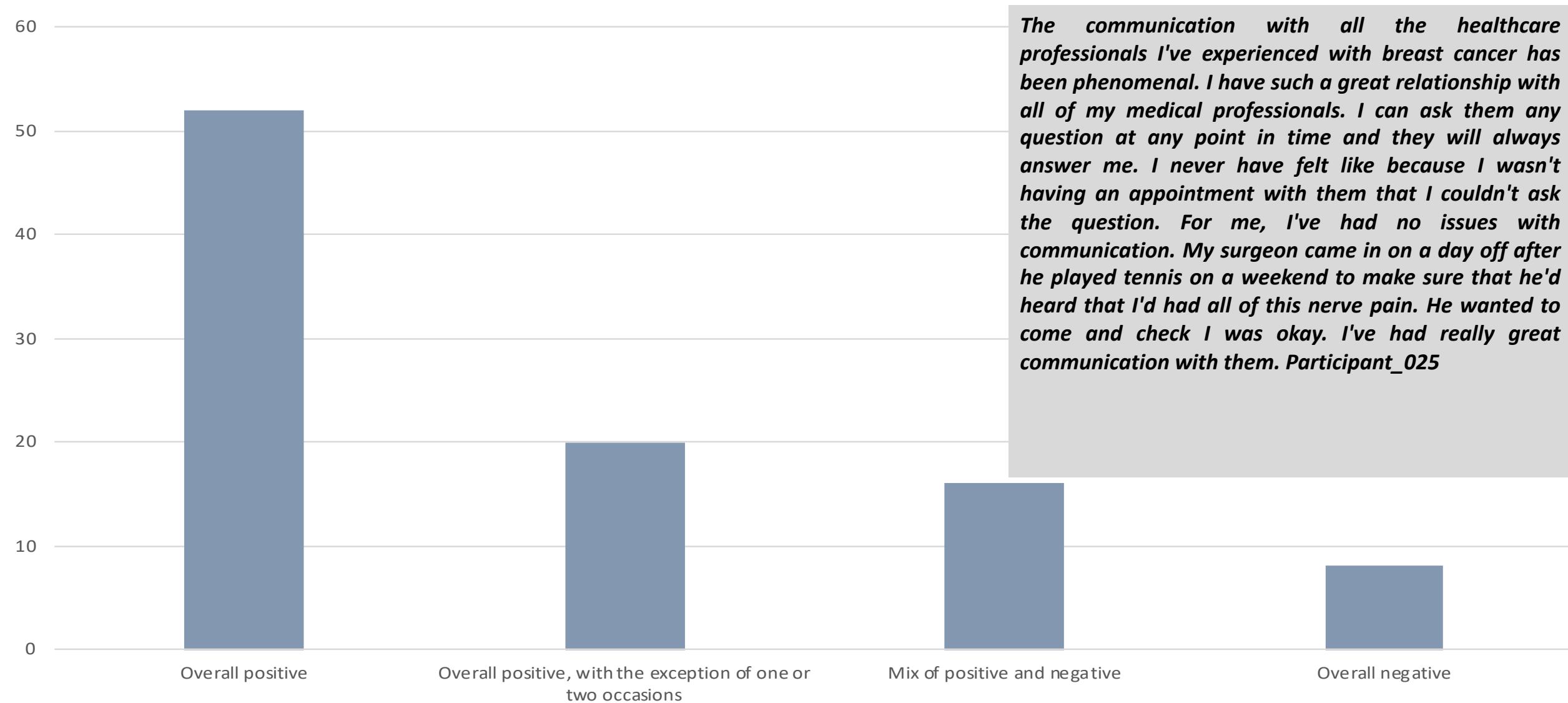
Probably I would probably start with a reliable online source with it. You know, my dad said he had jumped onto this website. This is what I recommend. Have a rate of that. I would do that and then either speak to a GP or briskness. If I'd been had questions that online, didn't you know that I didn't comprehend the information, not then speak to someone so it could be explained one on one. Participant_003





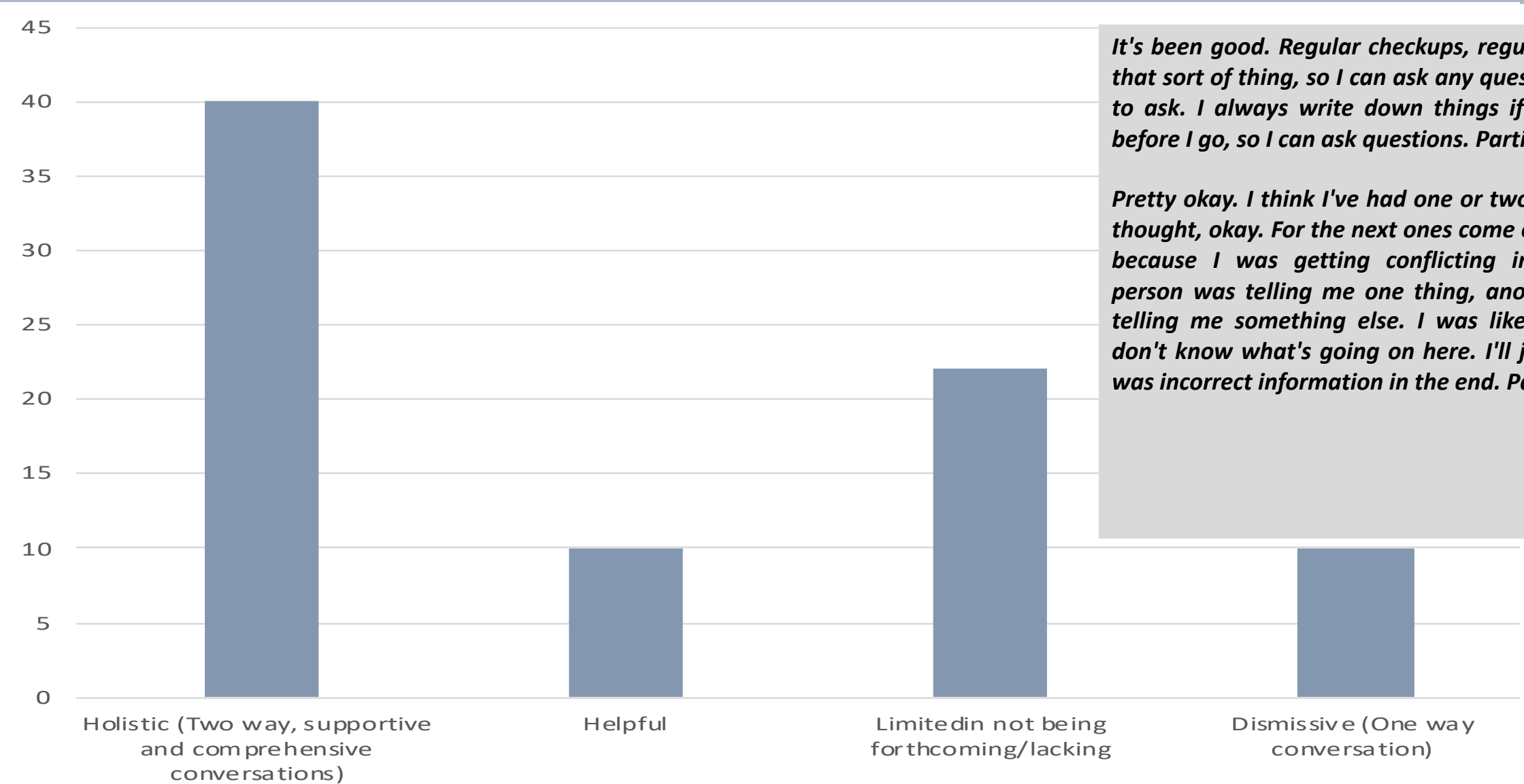
Well, I wanted every scrap of information from that. Right now I'm different to average, but I know it something that point of diagnosis is it's too much to take all the data within clinicians, which, like I said, I want to know what is available right to someone in my situation. So I was asking for more detail and being provided. It helps. I say that point of diagnosis being absolutely overloaded could be.
Participant_002





The communication with all the healthcare professionals I've experienced with breast cancer has been phenomenal. I have such a great relationship with all of my medical professionals. I can ask them any question at any point in time and they will always answer me. I never have felt like because I wasn't having an appointment with them that I couldn't ask the question. For me, I've had no issues with communication. My surgeon came in on a day off after he played tennis on a weekend to make sure that he'd heard that I'd had all of this nerve pain. He wanted to come and check I was okay. I've had really great communication with them. Participant_025





It's been good. Regular checkups, regular catch-ups, all that sort of thing, so I can ask any questions that I need to ask. I always write down things if I think of them before I go, so I can ask questions. Participant_046

Pretty okay. I think I've had one or two doctors where I thought, okay. For the next ones come on...I think it was because I was getting conflicting information. One person was telling me one thing, another person was telling me something else. I was like, "Well, Hmm. I don't know what's going on here. I'll just wait," and it was incorrect information in the end. Participant_012

Section 7



Care
&
Support

A Care Coordination questionnaire tool is used and reported in this section to demonstrate how people have been able to navigate the health system. There is also information about the care and support people have received, including from the charity sector.

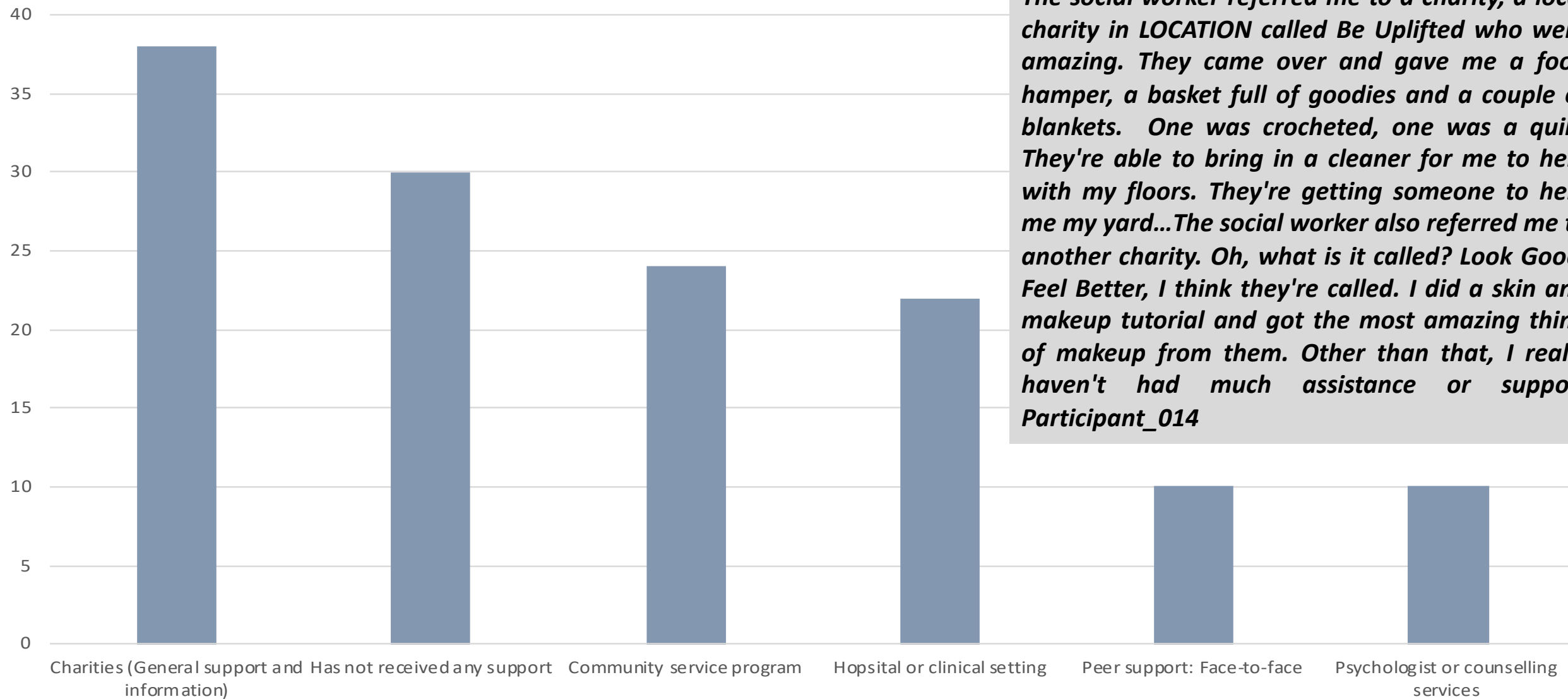


Care coordination scale (n=44)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	44.64	7.85	45.00	10.25	13 to 65	4
Navigation*	26.55	3.87	27.00	5.00	7 to 35	4
Total score*	71.18	10.28	72.00	12.50	20 to 100	4
Care coordination global measure	7.66	1.72	8.00	2.25	1 to 10	4
Quality of care global measure	8.45	1.21	9.00	1.00	1 to 10	5

*Normal distribution use mean and SD as measure of central tendency



Section 7



The social worker referred me to a charity, a local charity in LOCATION called Be Uplifted who were amazing. They came over and gave me a food hamper, a basket full of goodies and a couple of blankets. One was crocheted, one was a quilt. They're able to bring in a cleaner for me to help with my floors. They're getting someone to help me my yard...The social worker also referred me to another charity. Oh, what is it called? Look Good, Feel Better, I think they're called. I did a skin and makeup tutorial and got the most amazing thing of makeup from them. Other than that, I really haven't had much assistance or support
Participant_014



Section 8



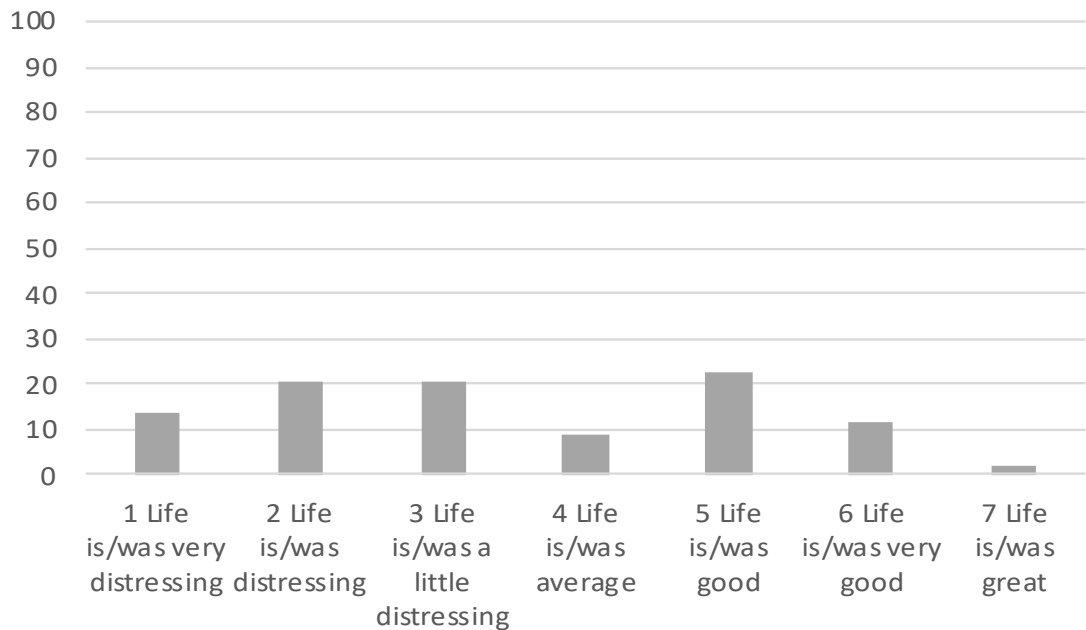
Quality of Life

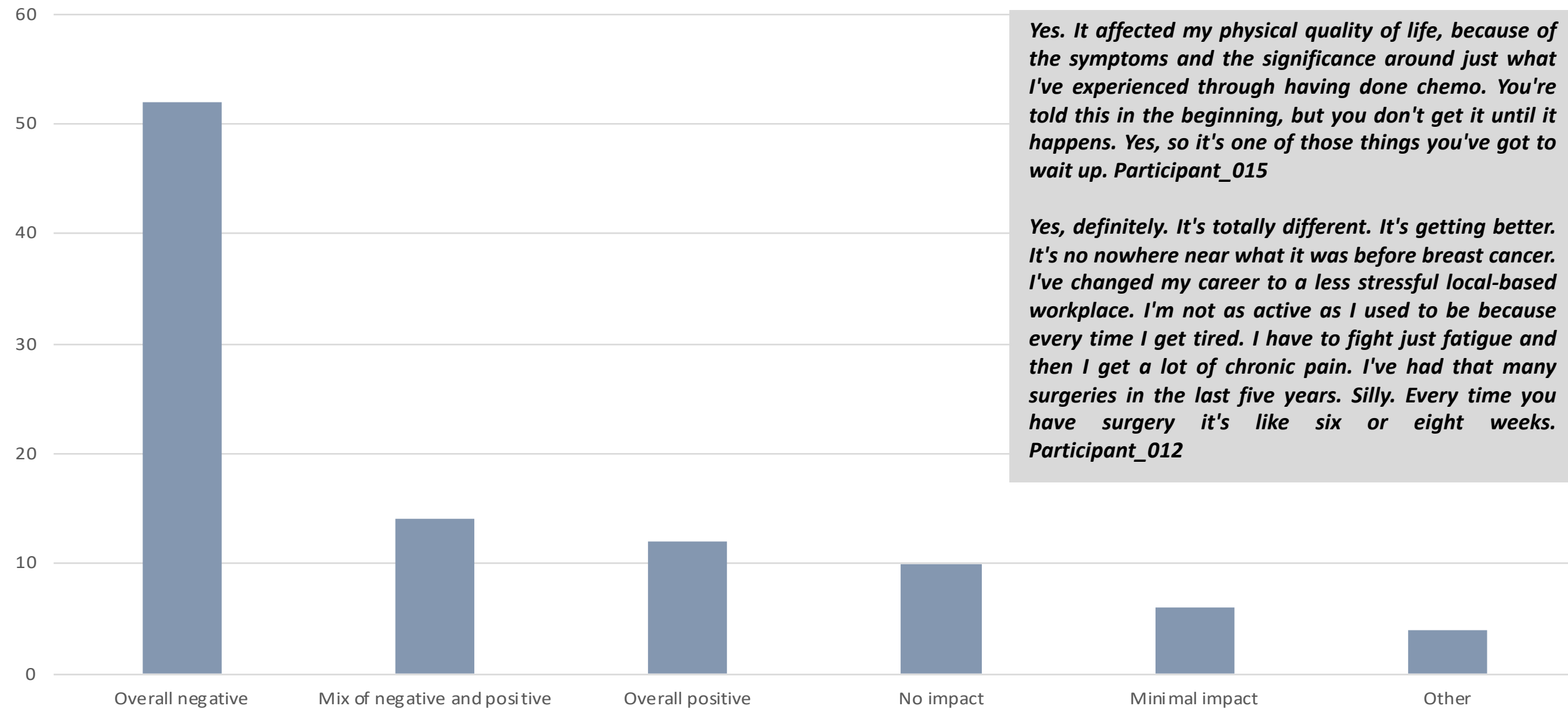
In this section, information is available in relation to the impact that the condition or disease has on quality of life, regular activities to maintain mental health, regular activities to maintain physical health, impact on relationships, impact on family and relationships, cost considerations. The Fear of Progression tool is used and reported here to describe the level of anxiety that participants may have in relation to their condition.



Fear of progression (n=50)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	35.89	7.50	36.00	9.25	12 to 60	3

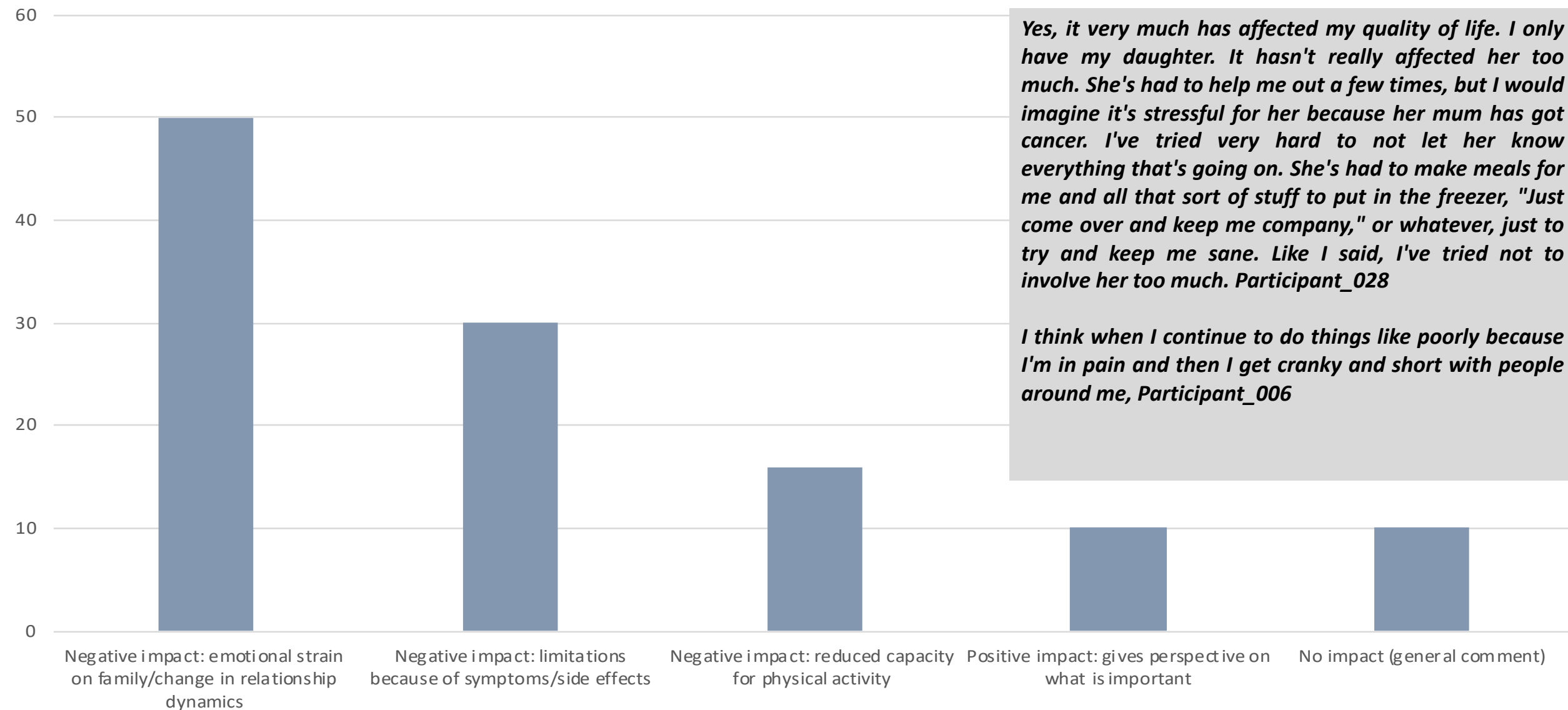
*Normal distribution use mean and SD as measure of central tendency





Yes. It affected my physical quality of life, because of the symptoms and the significance around just what I've experienced through having done chemo. You're told this in the beginning, but you don't get it until it happens. Yes, so it's one of those things you've got to wait up. Participant_015

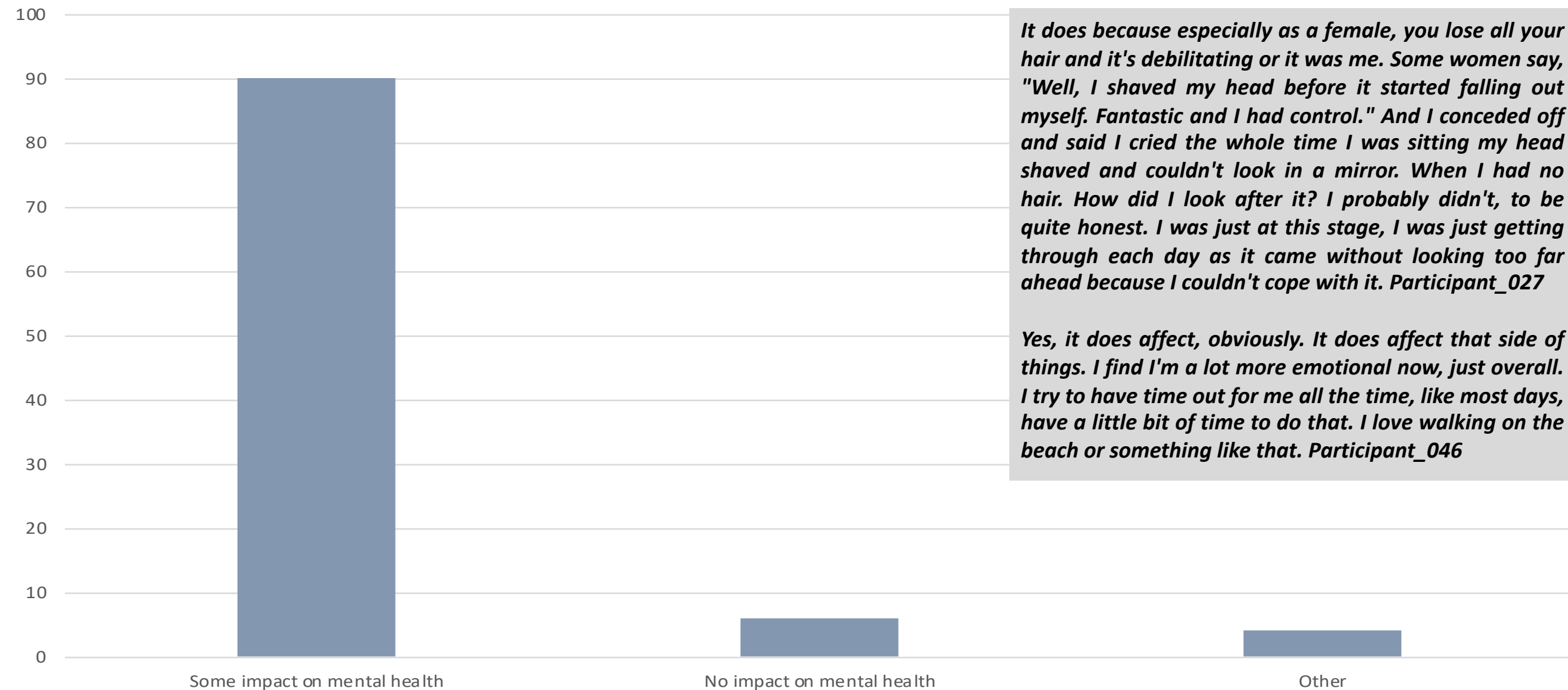
Yes, definitely. It's totally different. It's getting better. It's no nowhere near what it was before breast cancer. I've changed my career to a less stressful local-based workplace. I'm not as active as I used to be because every time I get tired. I have to fight just fatigue and then I get a lot of chronic pain. I've had that many surgeries in the last five years. Silly. Every time you have surgery it's like six or eight weeks. Participant_012



Yes, it very much has affected my quality of life. I only have my daughter. It hasn't really affected her too much. She's had to help me out a few times, but I would imagine it's stressful for her because her mum has got cancer. I've tried very hard to not let her know everything that's going on. She's had to make meals for me and all that sort of stuff to put in the freezer, "Just come over and keep me company," or whatever, just to try and keep me sane. Like I said, I've tried not to involve her too much. Participant_028

I think when I continue to do things like poorly because I'm in pain and then I get cranky and short with people around me, Participant_006

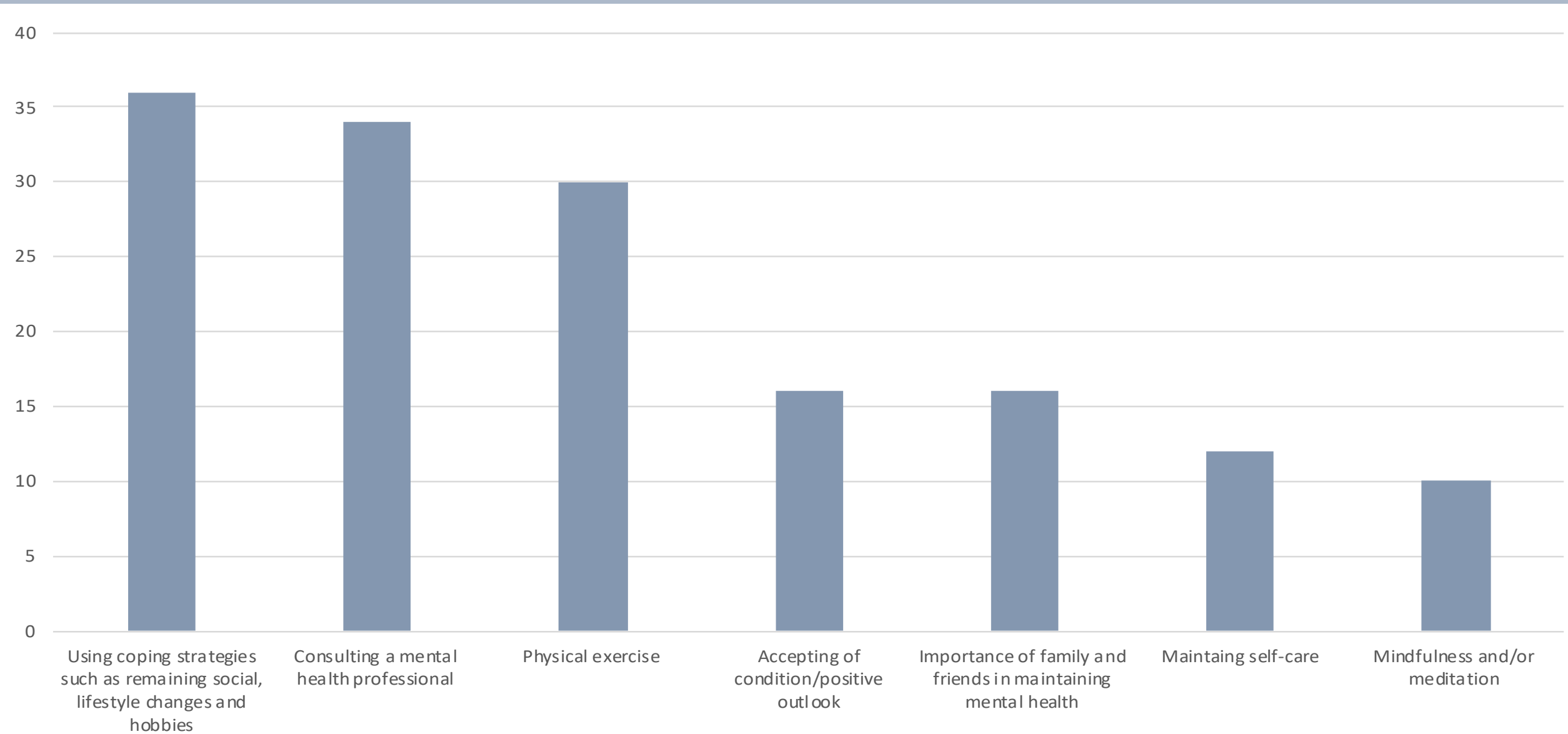




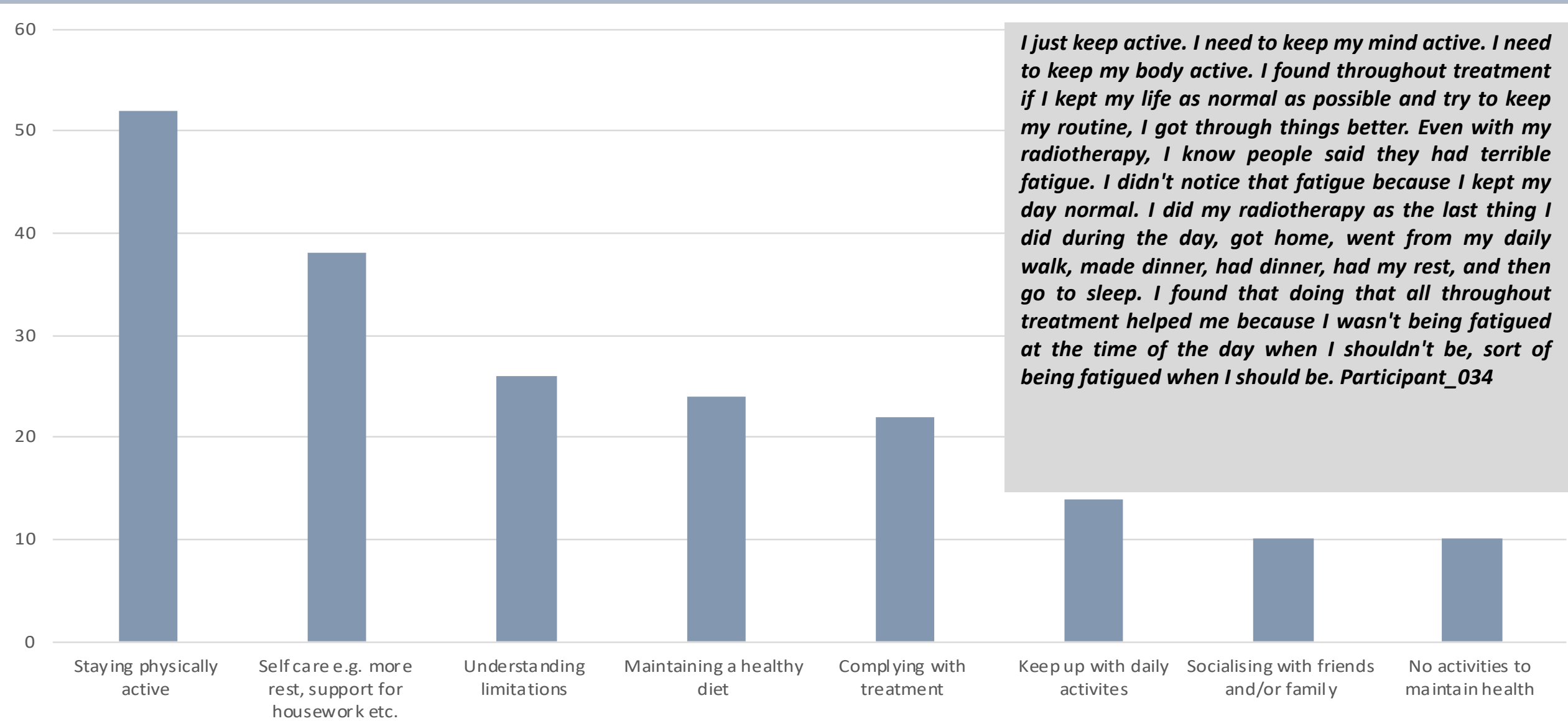
It does because especially as a female, you lose all your hair and it's debilitating or it was me. Some women say, "Well, I shaved my head before it started falling out myself. Fantastic and I had control." And I conceded off and said I cried the whole time I was sitting my head shaved and couldn't look in a mirror. When I had no hair. How did I look after it? I probably didn't, to be quite honest. I was just at this stage, I was just getting through each day as it came without looking too far ahead because I couldn't cope with it. Participant_027

Yes, it does affect, obviously. It does affect that side of things. I find I'm a lot more emotional now, just overall. I try to have time out for me all the time, like most days, have a little bit of time to do that. I love walking on the beach or something like that. Participant_046



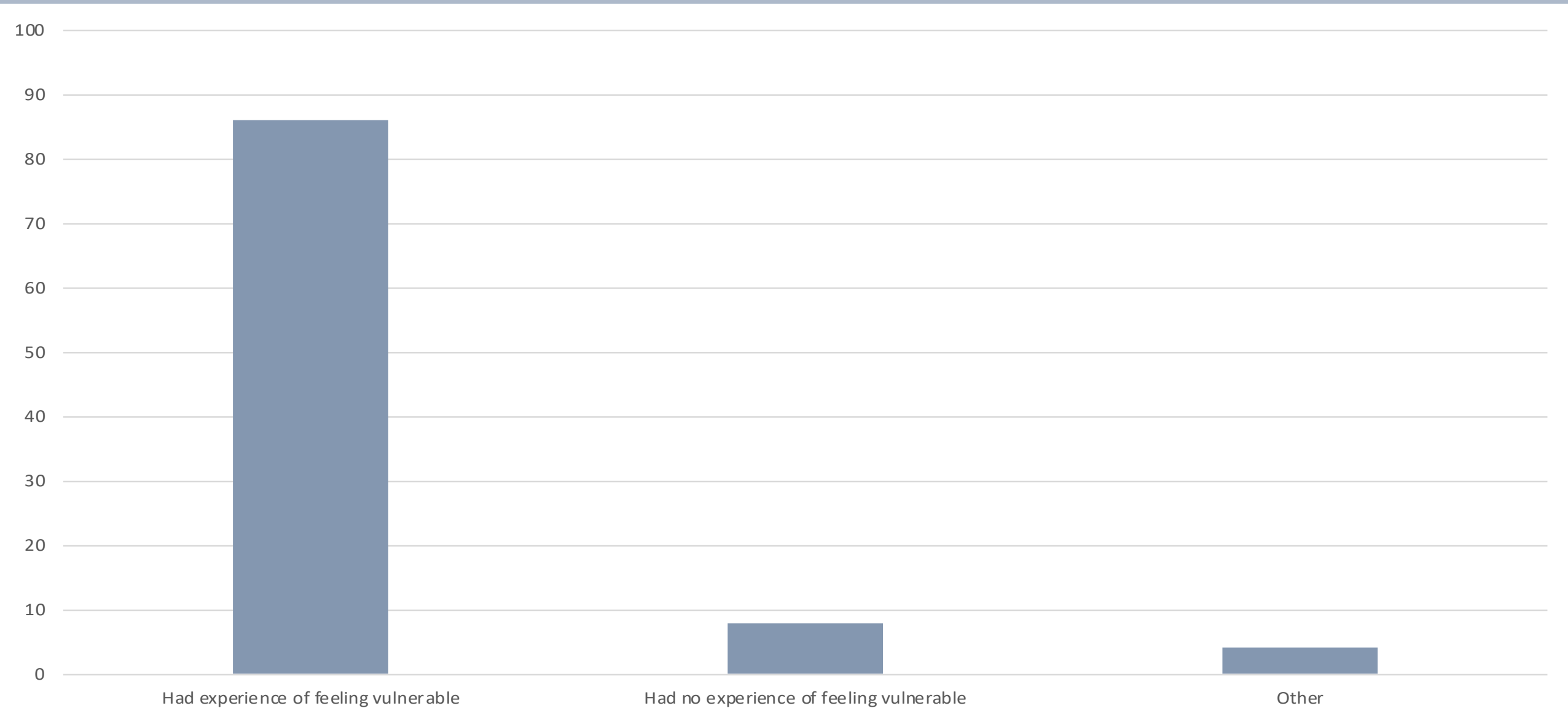


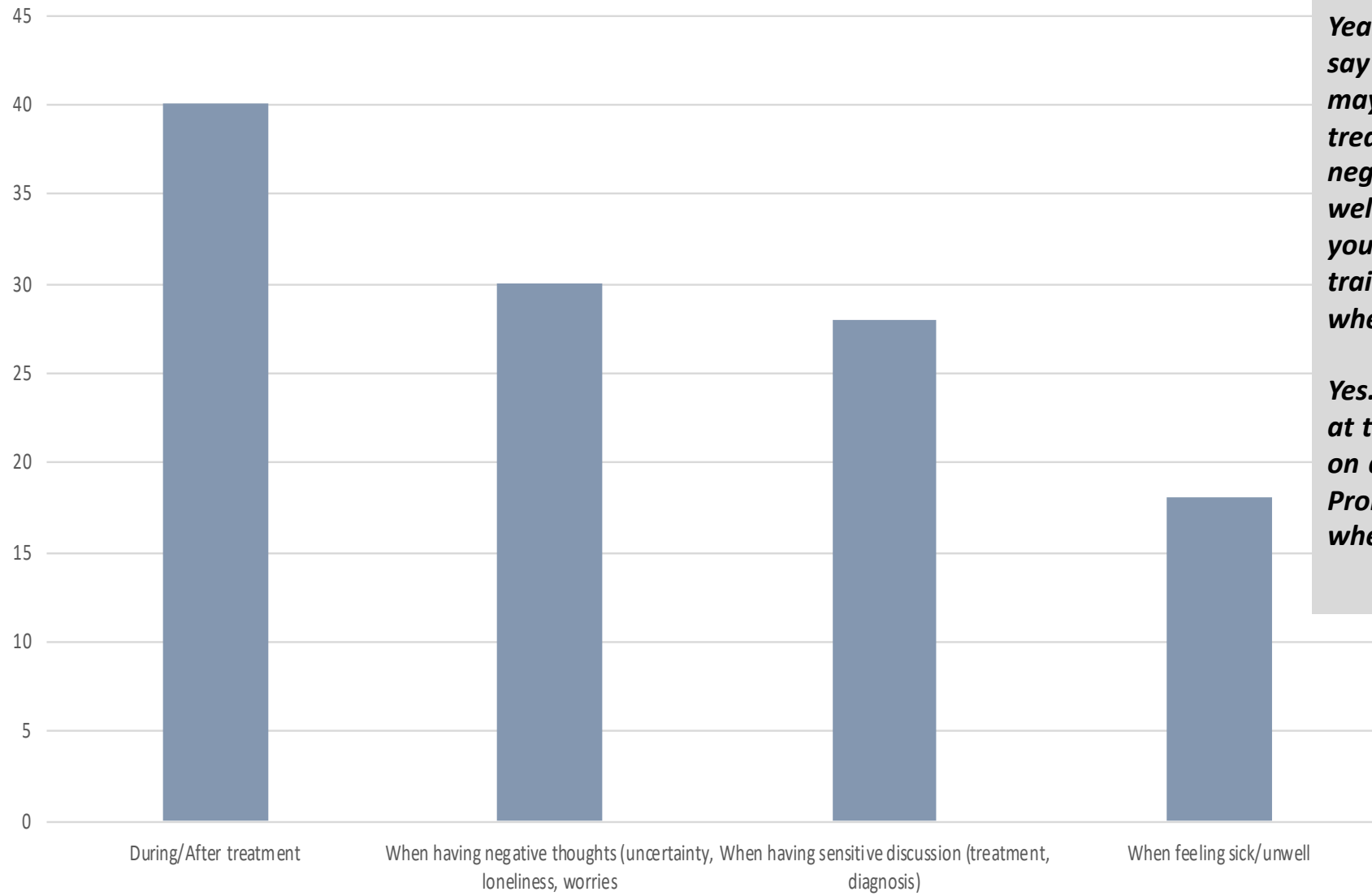
Regular activities to maintain mental health (% of all participants)



I just keep active. I need to keep my mind active. I need to keep my body active. I found throughout treatment if I kept my life as normal as possible and try to keep my routine, I got through things better. Even with my radiotherapy, I know people said they had terrible fatigue. I didn't notice that fatigue because I kept my day normal. I did my radiotherapy as the last thing I did during the day, got home, went from my daily walk, made dinner, had dinner, had my rest, and then go to sleep. I found that doing that all throughout treatment helped me because I wasn't being fatigued at the time of the day when I shouldn't be, sort of being fatigued when I should be. Participant_034

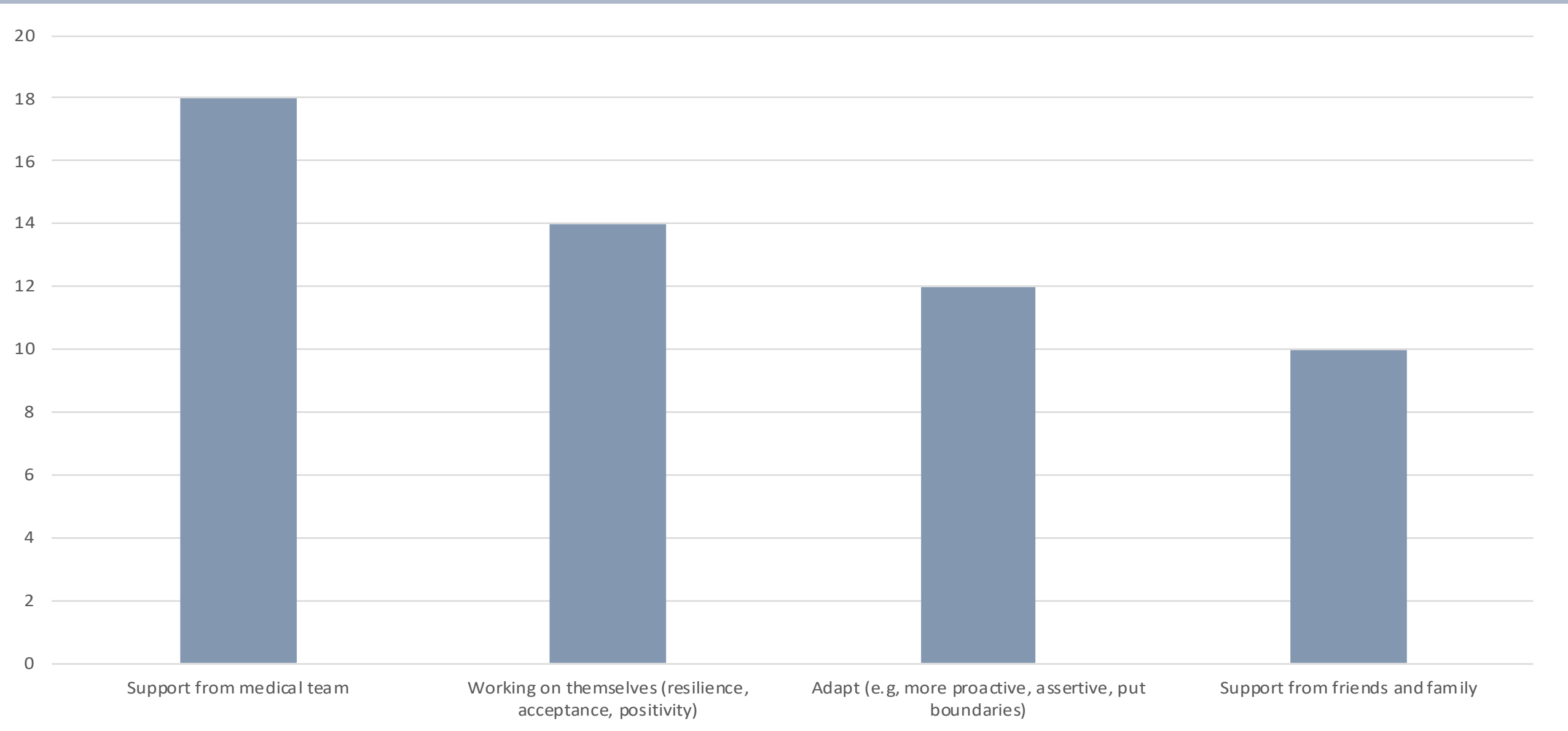
Regular activities to maintain general health (% of all participants)

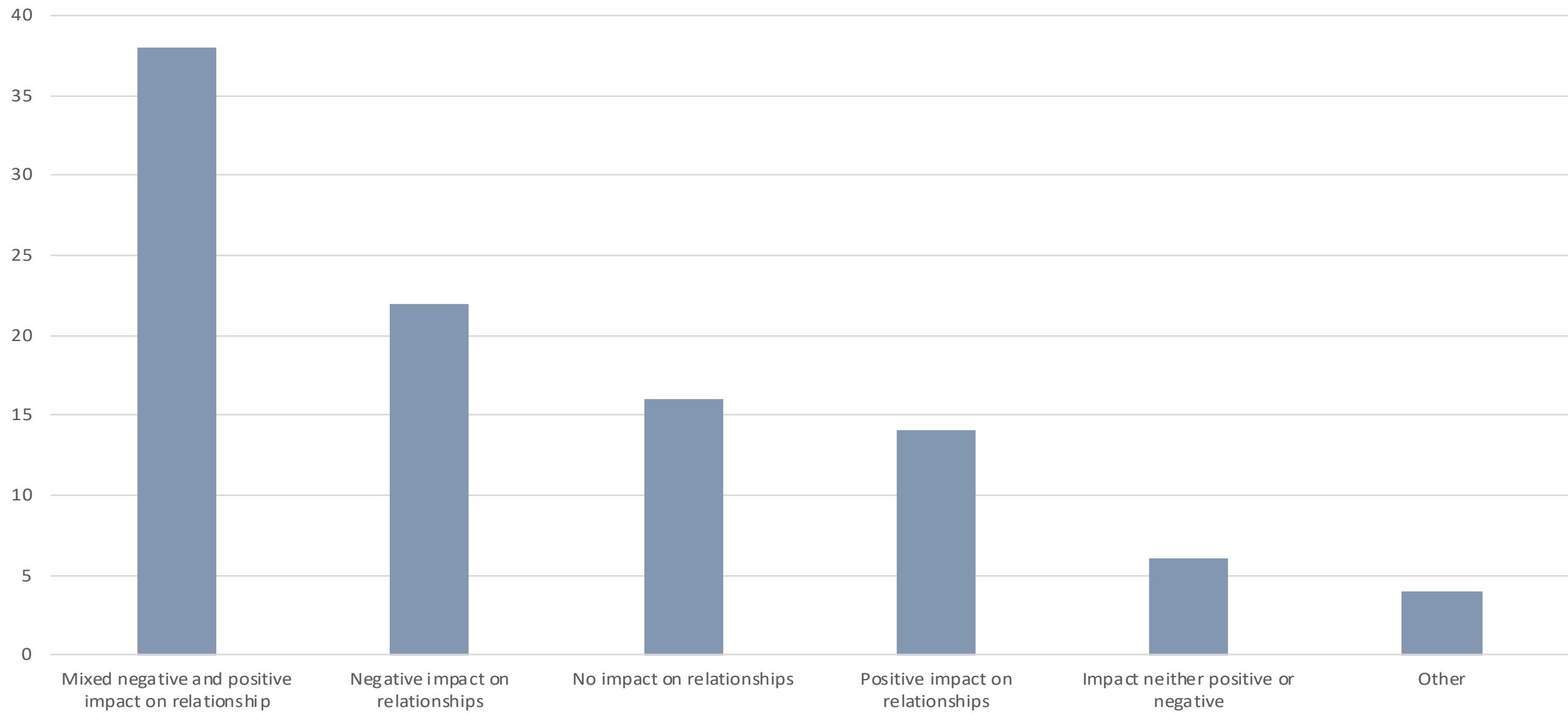


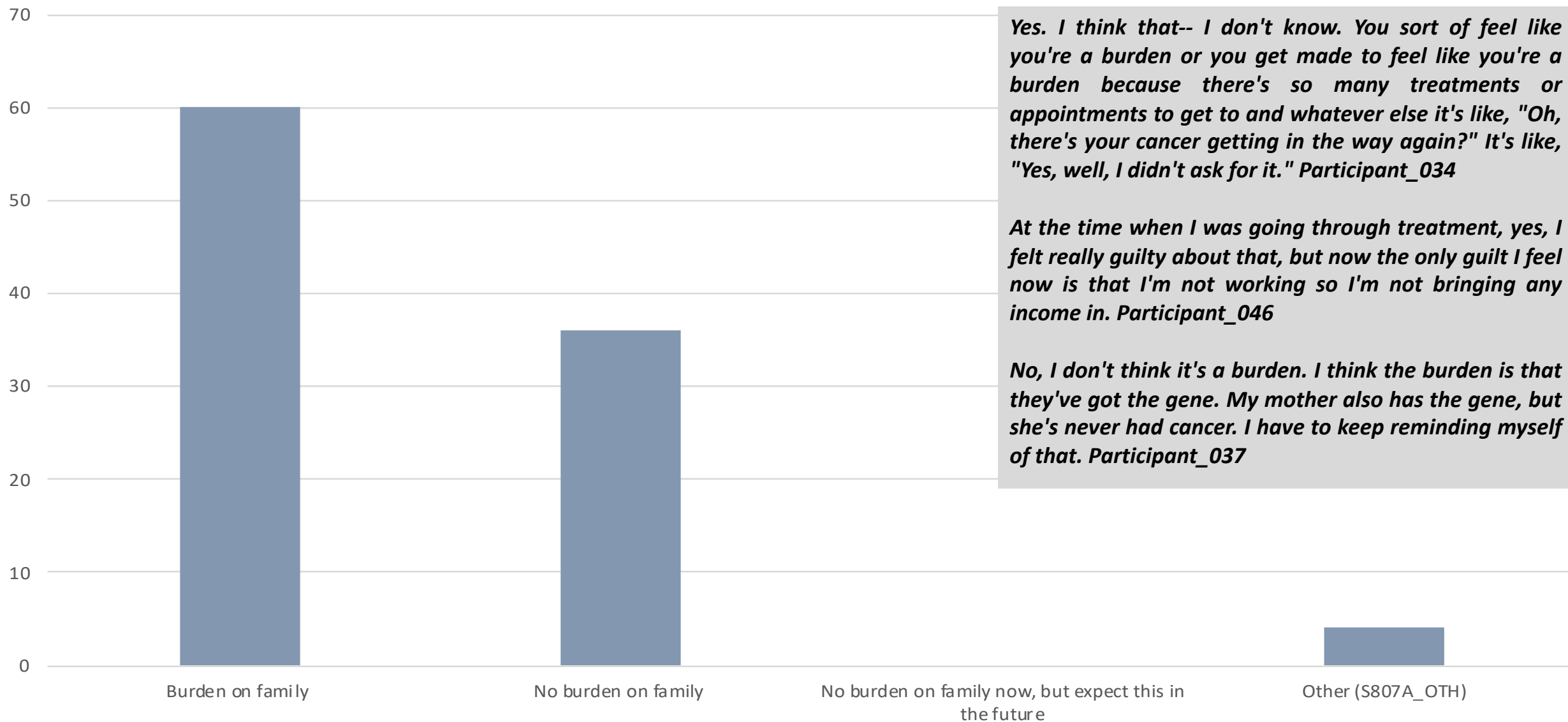


Yeah, I guess really the point of diagnosis, I'm going to say right through treatment, but then again, probably maybe the two in points where around diagnosis and treatment and then into treatment because the triple negative they did or anything to go on it. So it's like, well, the parachute, we don't home, but it's time for you to jump off the cliff. So it's a diagnosis made of training. And in that situation that you've mentioned, where you felt vulnerable. Participant_002

Yes. Pretty much from the start at times. Probably right at the start when I didn't know what the hell was going on and I was trying to get my head around everything. Probably in the day to stock is middle of the chemo when I was trying everything in one Participant_012





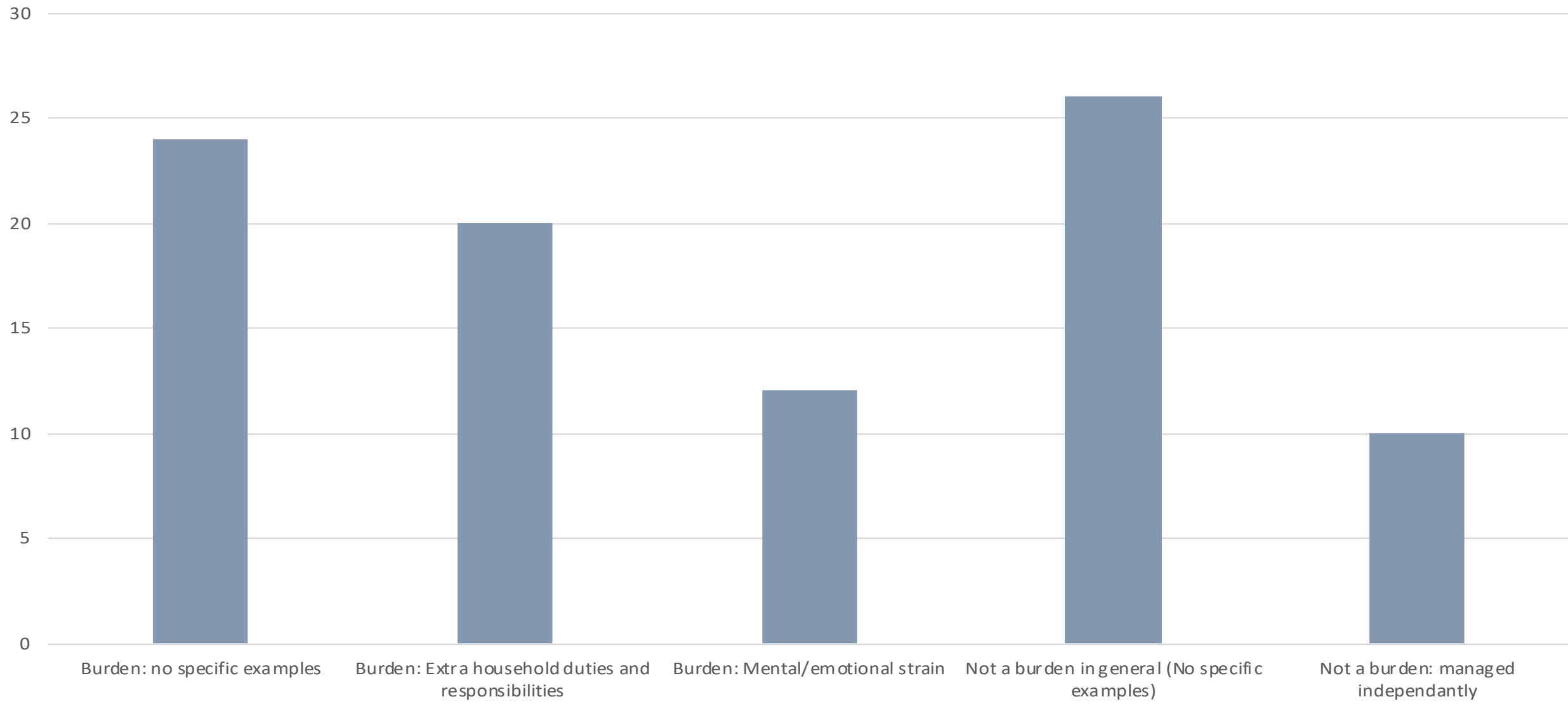


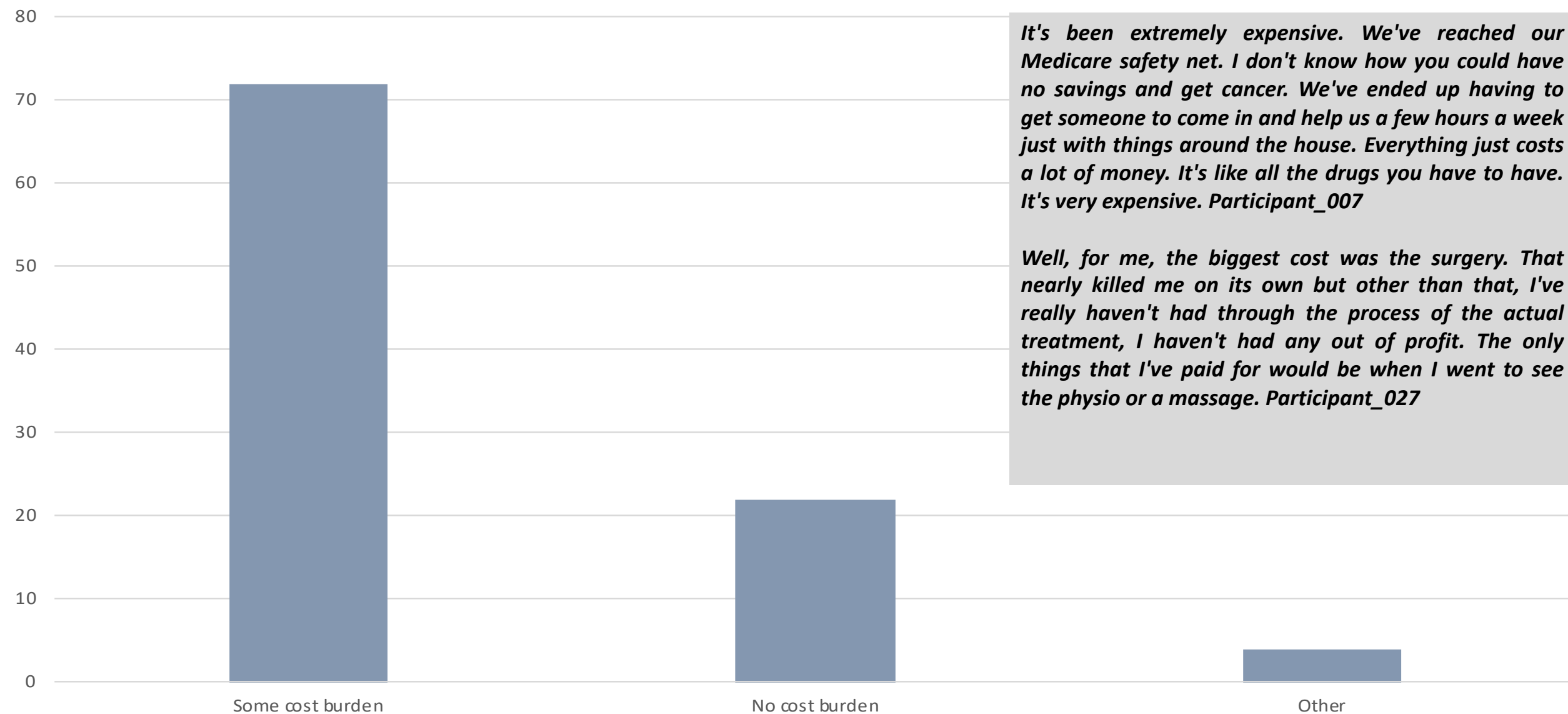
Yes. I think that-- I don't know. You sort of feel like you're a burden or you get made to feel like you're a burden because there's so many treatments or appointments to get to and whatever else it's like, "Oh, there's your cancer getting in the way again?" It's like, "Yes, well, I didn't ask for it." Participant_034

At the time when I was going through treatment, yes, I felt really guilty about that, but now the only guilt I feel now is that I'm not working so I'm not bringing any income in. Participant_046

No, I don't think it's a burden. I think the burden is that they've got the gene. My mother also has the gene, but she's never had cancer. I have to keep reminding myself of that. Participant_037



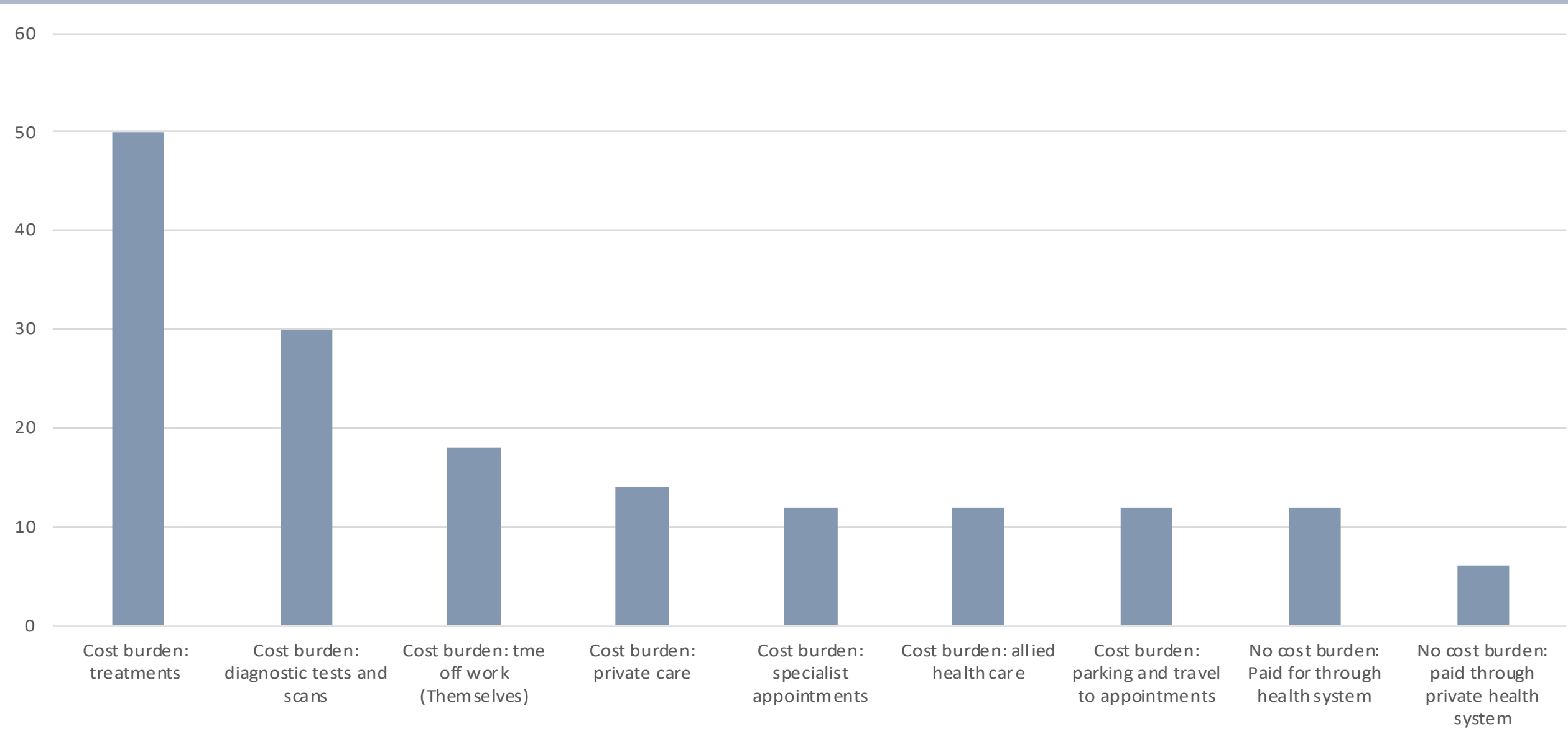




It's been extremely expensive. We've reached our Medicare safety net. I don't know how you could have no savings and get cancer. We've ended up having to get someone to come in and help us a few hours a week just with things around the house. Everything just costs a lot of money. It's like all the drugs you have to have. It's very expensive. Participant_007

Well, for me, the biggest cost was the surgery. That nearly killed me on its own but other than that, I've really haven't had through the process of the actual treatment, I haven't had any out of profit. The only things that I've paid for would be when I went to see the physio or a massage. Participant_027





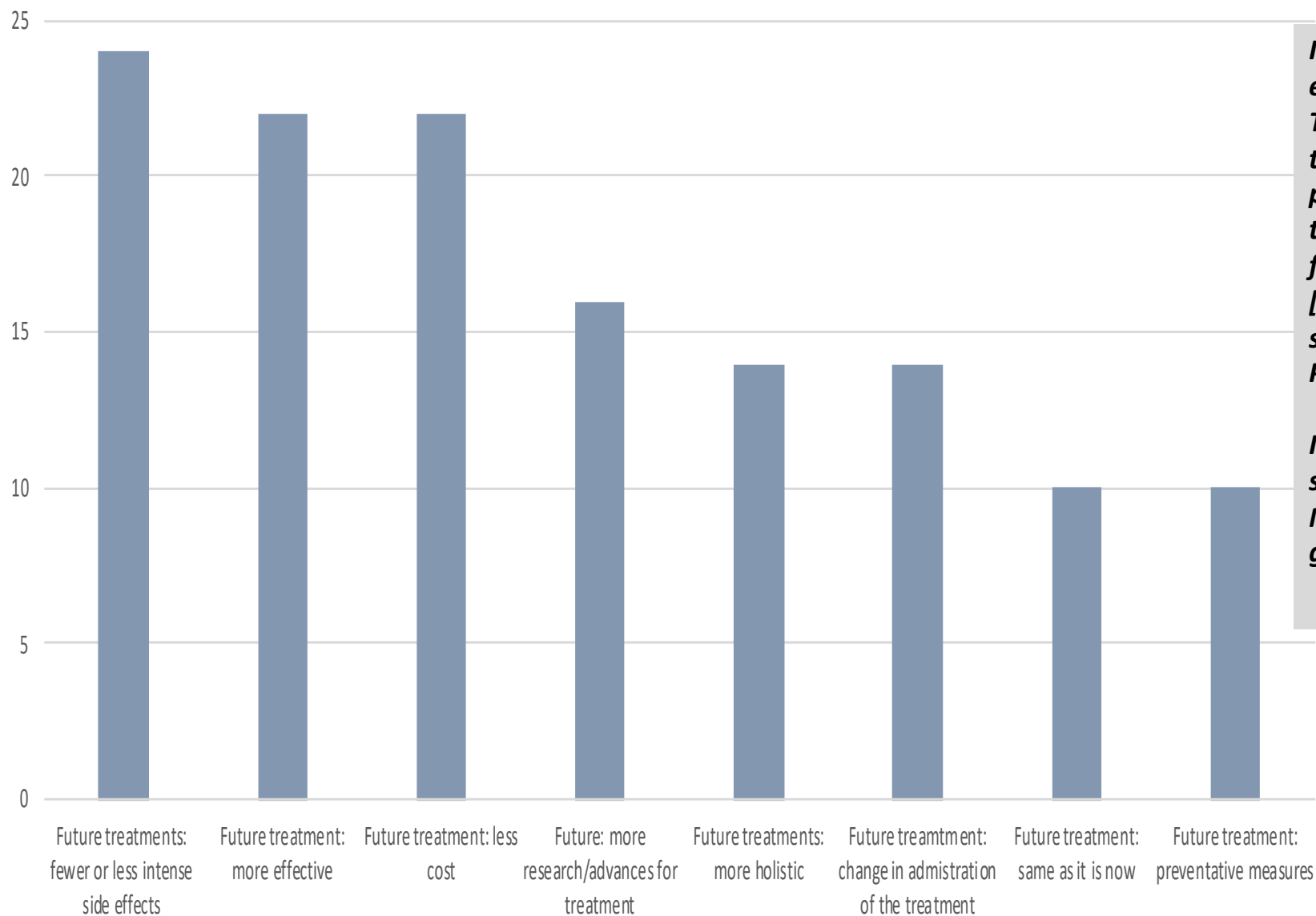
Section 9



Expectations
&
Messages to Decision-Makers

By the time participants are asked questions about their expectations of the future, they have had the chance to talk about everything that they have been through. It means that they have been able to reflect on what worked for them and what was potentially not so great. In this section there is information about what participants would like to see from future treatments, information, care and communication. We present the cohorts message to decision-makers about their condition and the values that are important to them when they make decisions about treatment and care. In this section there is also information about what people have been grateful for.

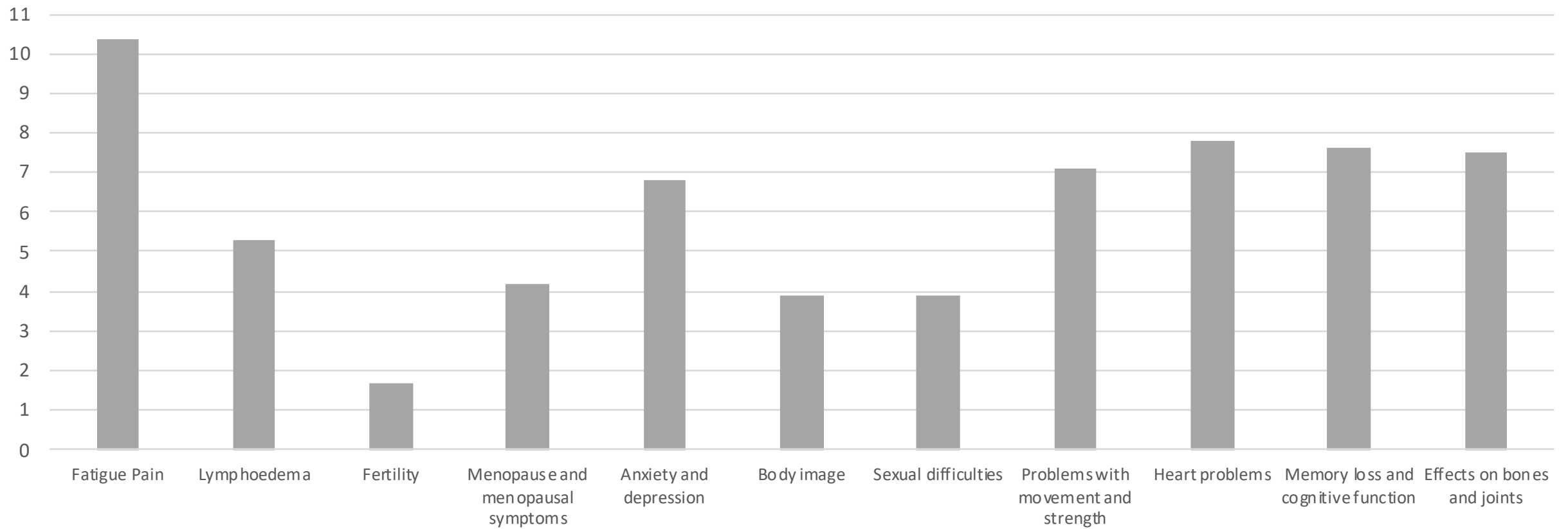


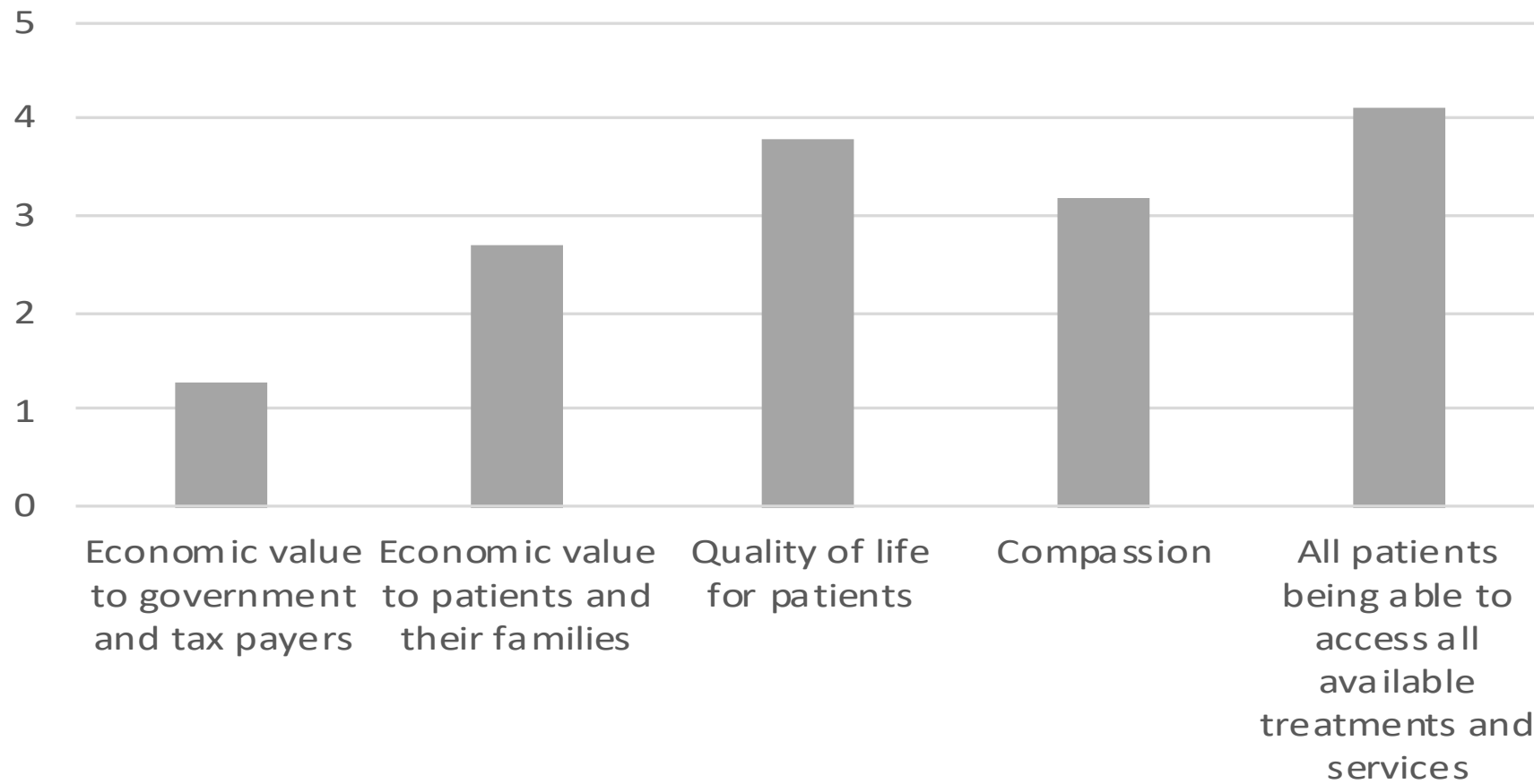


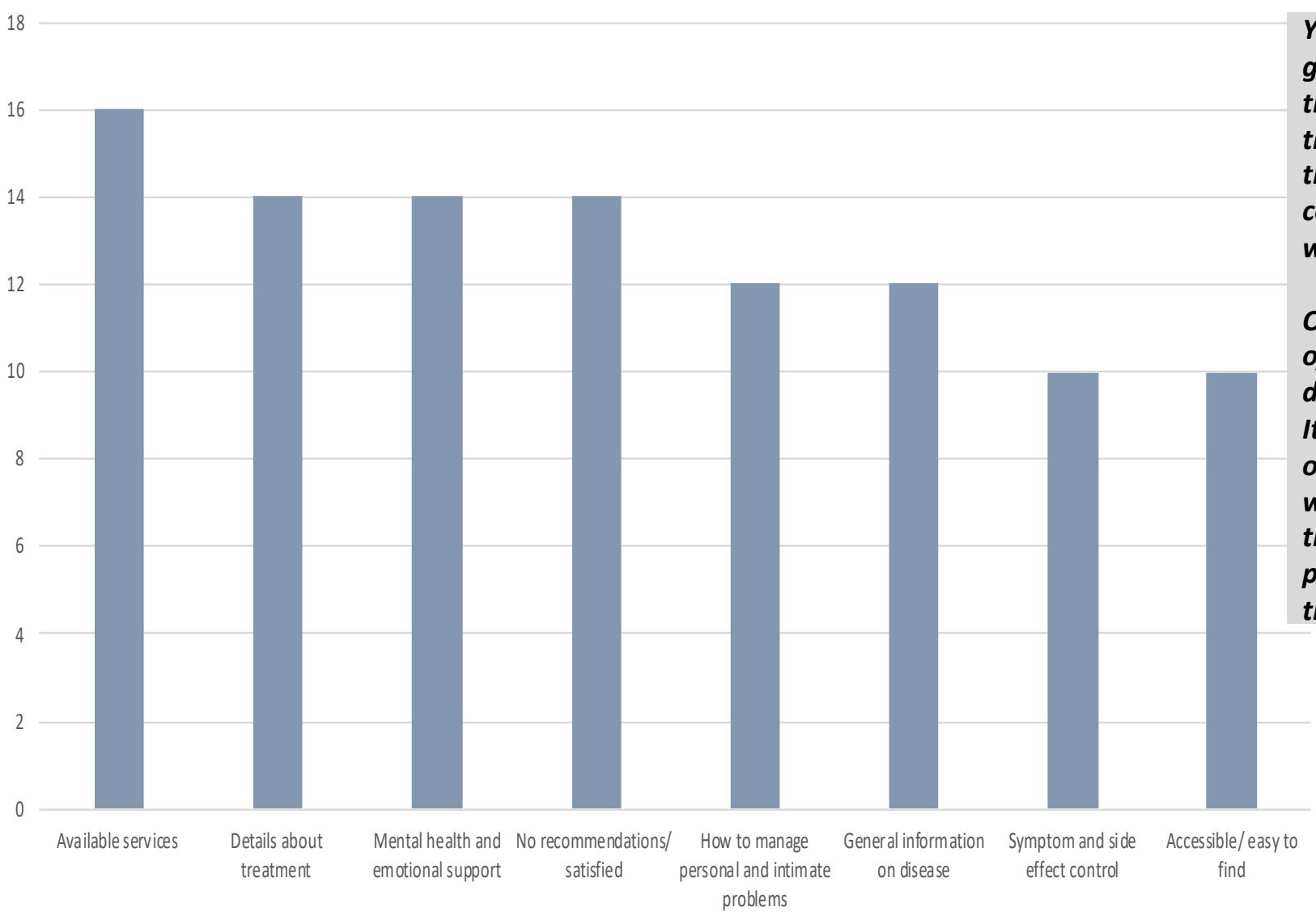
I don't feel like I was properly prepared for the side effects afterwards. They give you a sheet with them. They go, "You might get tired." When I said, I didn't take much time off work, my oncologist said, "Oh, people who don't take much time off work generally get tired later." She just said it like that not like, "Yes, you'll feel like you've been hit by a truck for like two years." [chuckles] There's not enough even information about side effects. They don't focus that much on side effects. Participant_008

I'd just like to see new treatments that are more successful with less side effects, more targeted, I guess. More targeted treatments, rather than your whole body getting sick. Participant_037







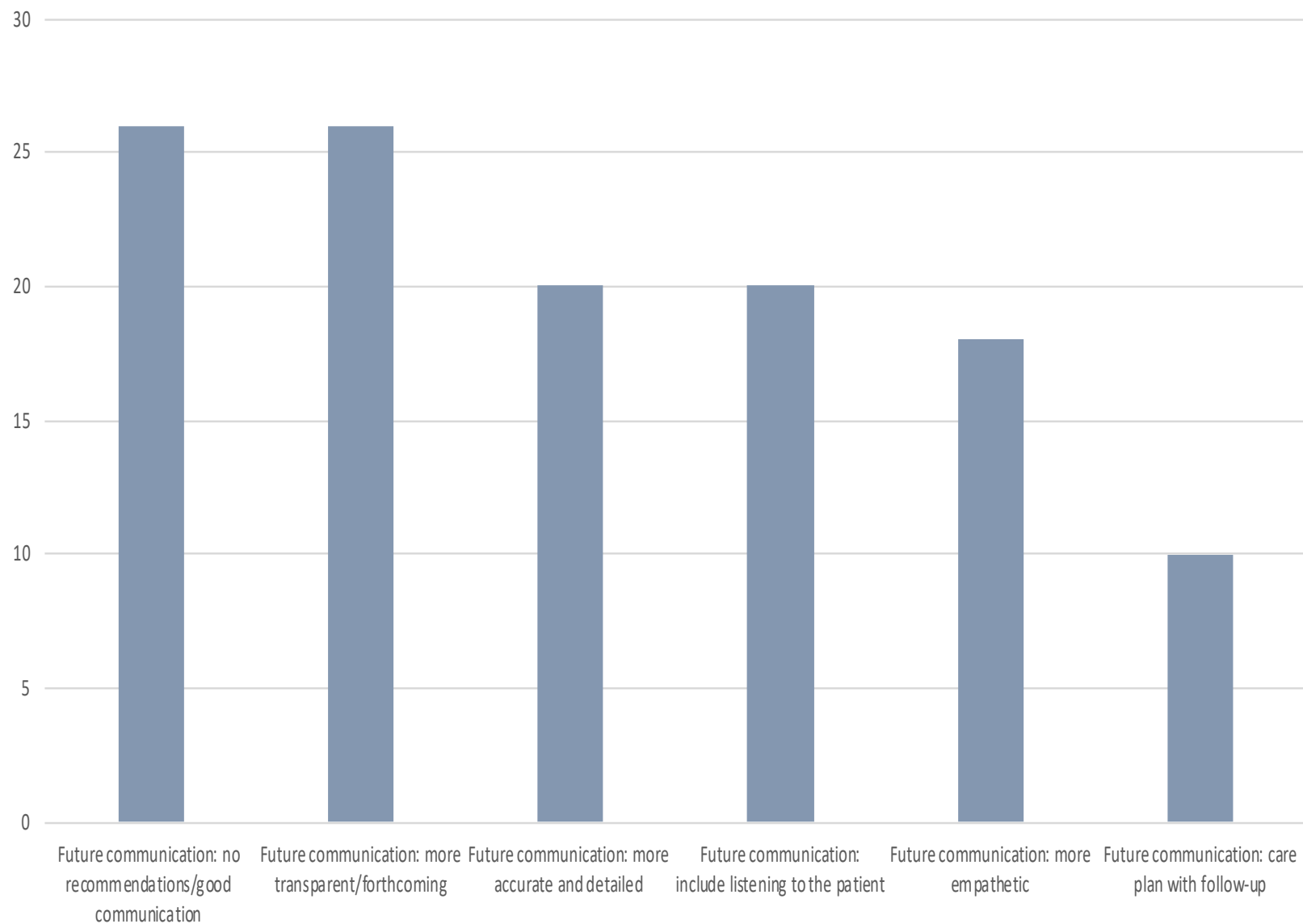


Yes. Even if it was, I don't know, a little pack that you've got towards, I don't know, at some stage in your treatment going, "Hey, these are some of the services that are going to be available to you" whether it's through the health system, whether it's through local community groups." A little information pack, I guess, would be good. Participant_020

Oh, maybe with choices with treatment. I really wasn't offered any different options and there was no discussion given when they put me on a treatment plan. It was just this is what we're doing. The only other option is not to do it and then that's your choice. There wasn't really that much and I've sort of learned since then that there are other options and there are other paths I could have gone down potentially. Maybe that. I think that's pretty big. Participant_012

Expectations of future information (% of all participants)

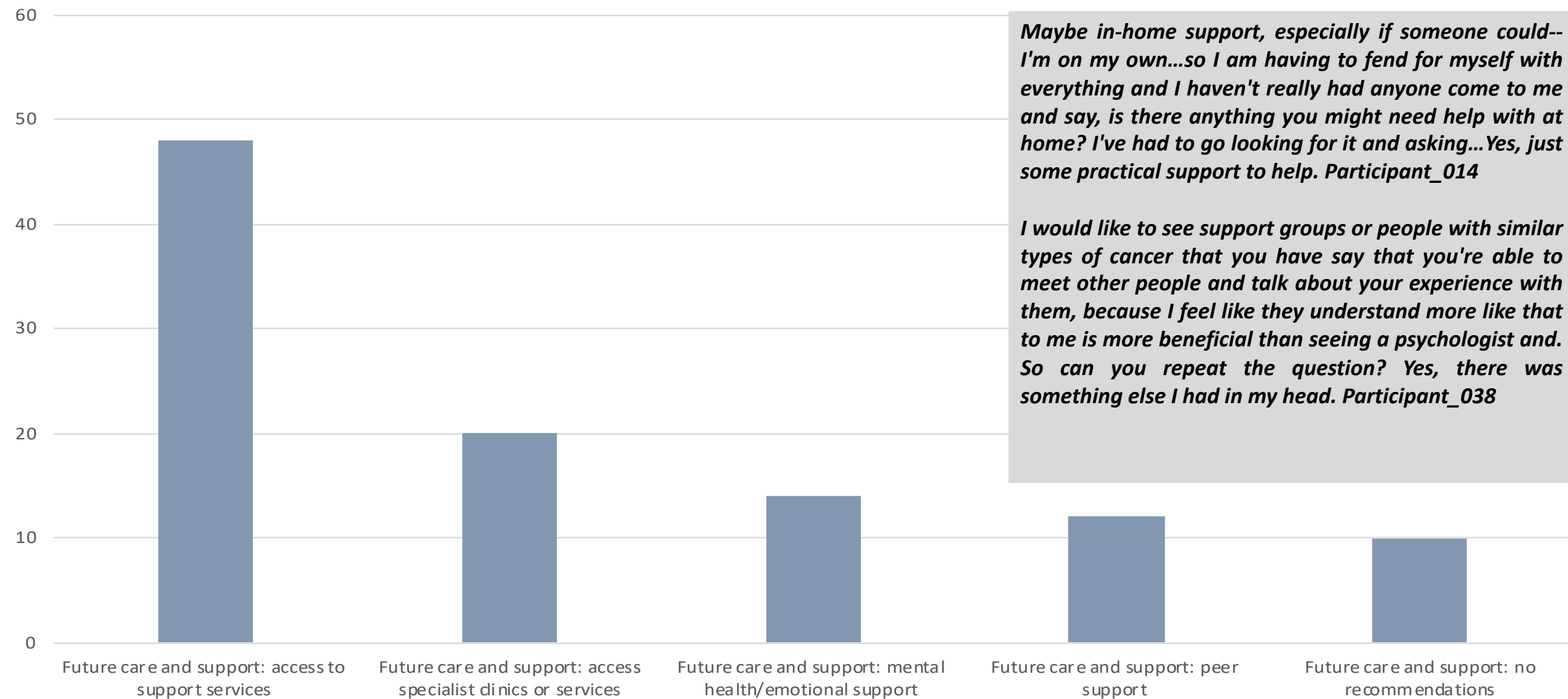


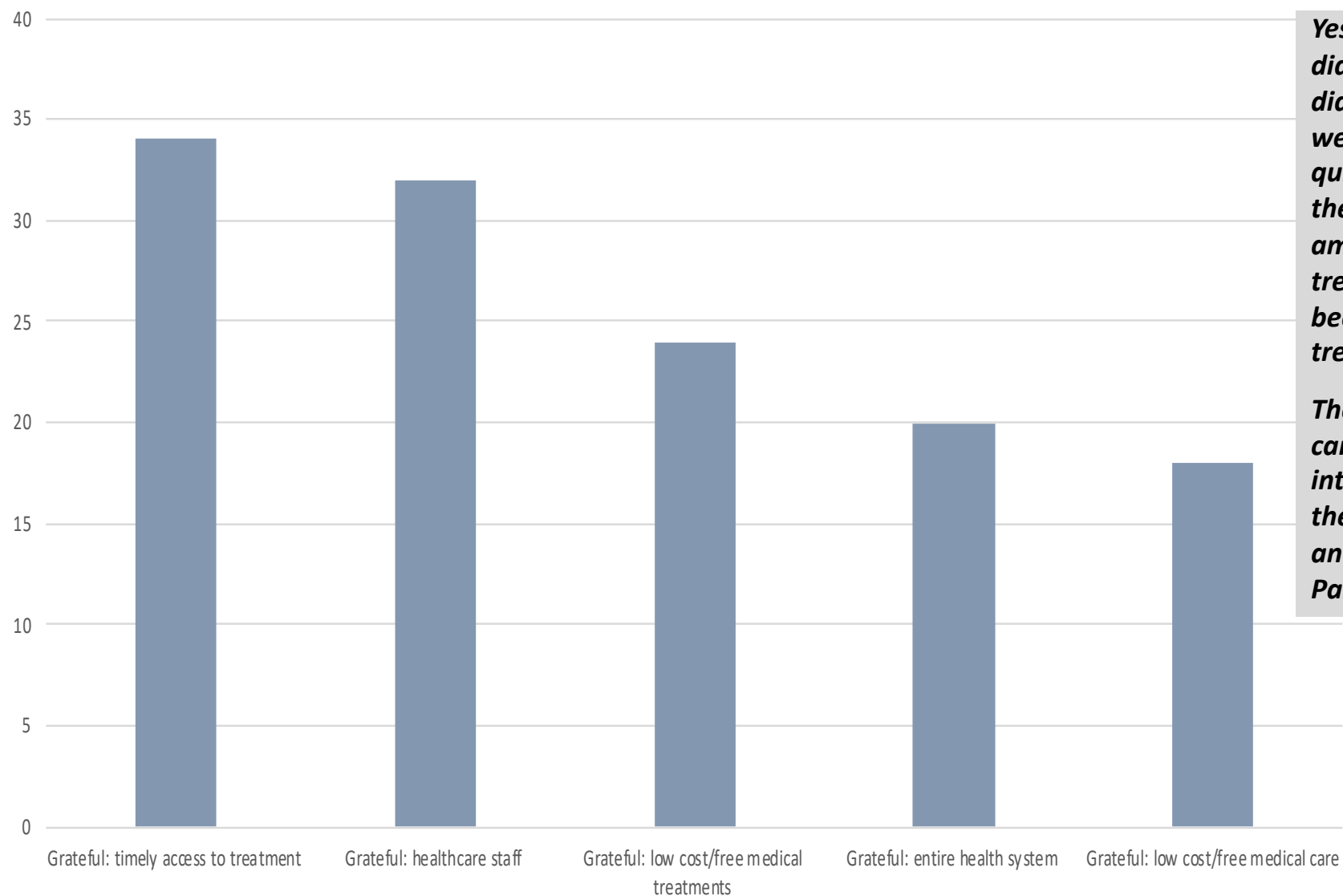


Honestly, I can't complain. It'd be nice if you turned up for a 1:30 PM appointment and you didn't go in at two o'clock, but I'm not going to hold that against anyone. If that's my only complaint, that's not a complaint. That's thinking up something there. I can't fault these cancer nurses. There is no one that's terrible. Participant_007

I guess it's hard for the medical teams to deal with because they're dealing with it all day every day, but sometimes you just feel like a number. For example, at one stage I was doing my radiation, into treatment, and said, "We need you to go and have CT scan." Okay it's as good as you said. No one ever explained to me why I needed to have CT scan. I think that to explain, have someone explain to you why this has happened or what is happening it's really the only thing that I can think of. Participant_020





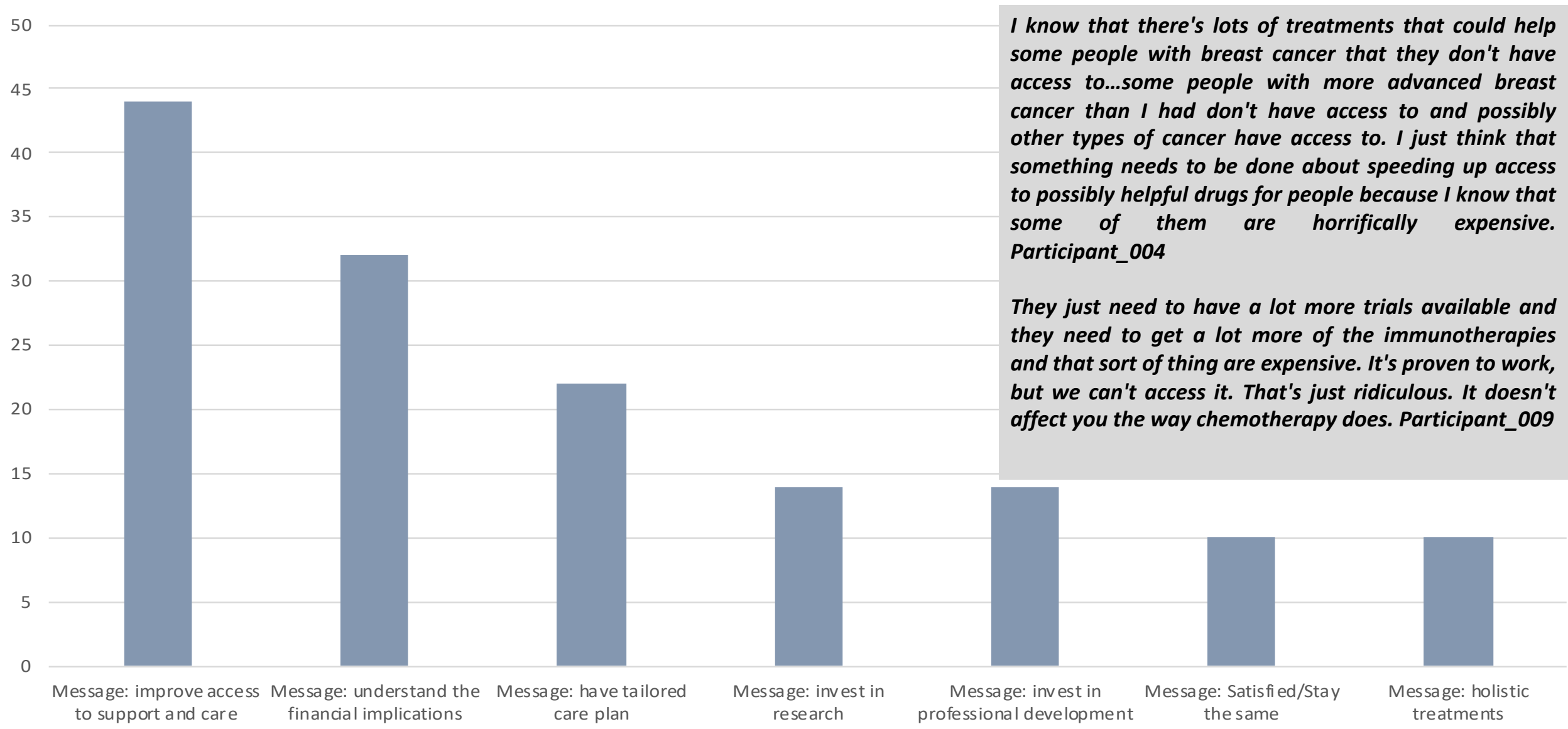


Yes, all of it has been really good. The speed from diagnosis to getting treatment was really quick. It didn't feel it at the time, but I think it was only five weeks from diagnosis to starting chemo. It was quite a quick turnaround. I was able to get appointments with the people I needed to see. The oncologist has been amazing, the breast care nurse has been amazing, the treatment team of the hospital are fantastic. It's all been excellent. There's been no issues at all with the treatment that I've been given. No. Participant_033

The fantastic doctors. We've got some of the best breast care nurses in the world, and very lucky to have gotten into here and had an exceptional result. I feel as though the team of nurses and everything are all very caring and very loving. The staff, they do amazing things. Participant_036

What participants are grateful for in the health system (% of all participants)





I know that there's lots of treatments that could help some people with breast cancer that they don't have access to...some people with more advanced breast cancer than I had don't have access to and possibly other types of cancer have access to. I just think that something needs to be done about speeding up access to possibly helpful drugs for people because I know that some of them are horribly expensive. Participant_004

They just need to have a lot more trials available and they need to get a lot more of the immunotherapies and that sort of thing are expensive. It's proven to work, but we can't access it. That's just ridiculous. It doesn't affect you the way chemotherapy does. Participant_009

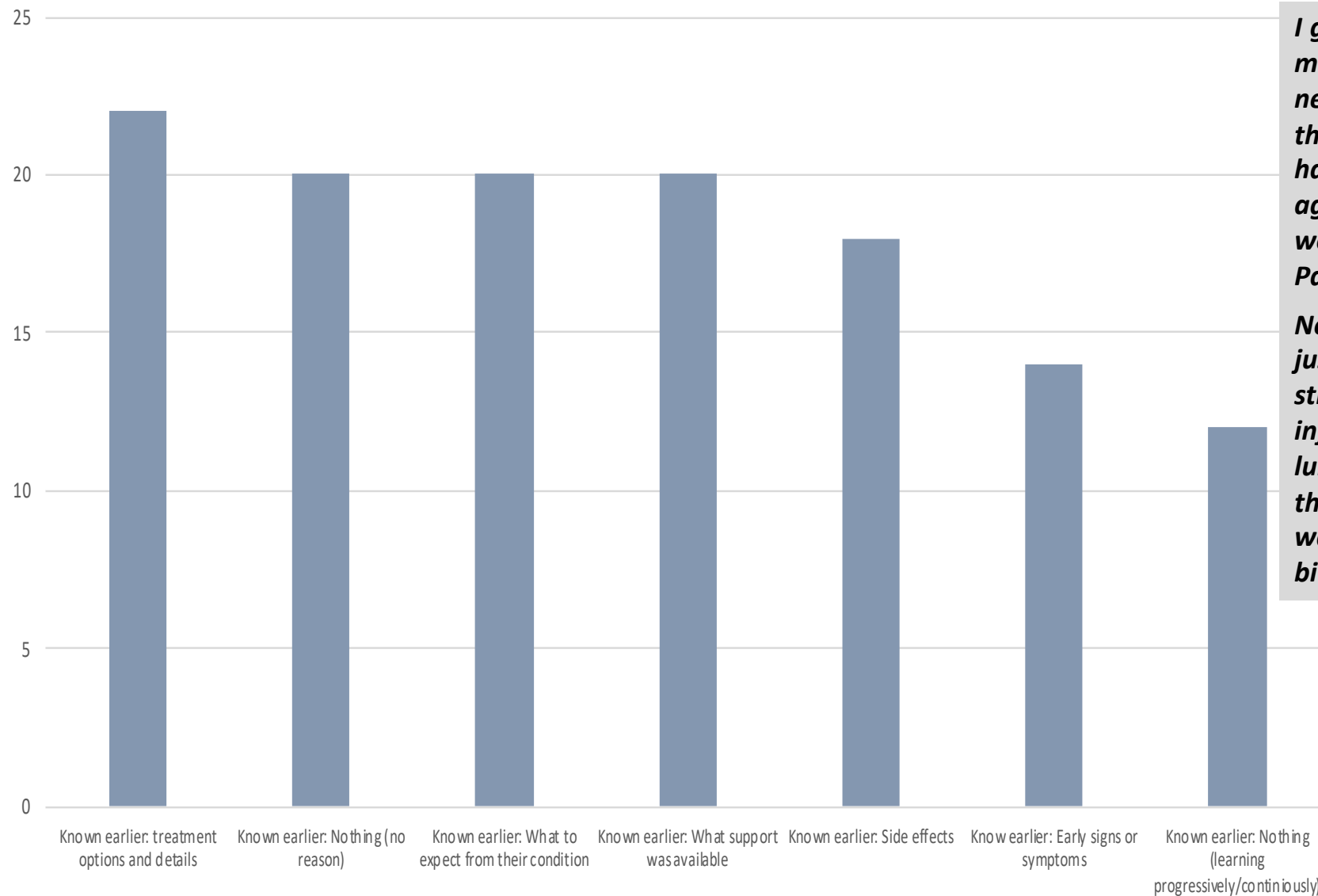
Section 10



Advice from current patients
to
patients in the future

In this section we present the response to the question 'what is your advice to other people who are diagnosed in the future?' This gives participants the chance to impart knowledge and for patients to feel connected with others in the community.



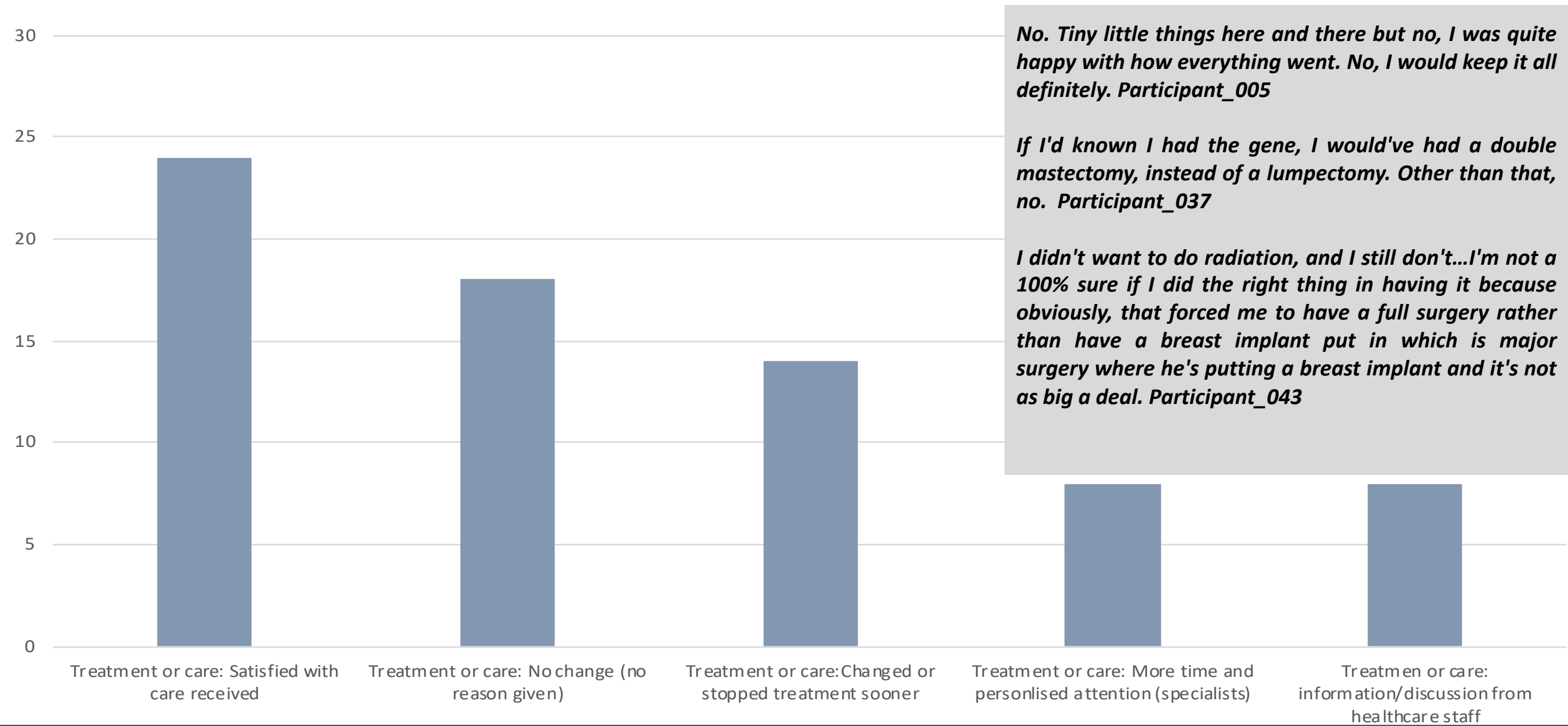


I guess the main thing for me would have been to know more about the long-term side effects and that if you need to stop treatment, it's okay to stop treatment. I think more knowledge and discussion about if you're having bad side effects, what your options are, and again what the pros and cons of stopping or continuing would make. For me, yes that would be the biggest one. Participant_020

Not really actually. I think I know most of the things, it's just a few questions and answers, but I don't get a straight answer for that anyway. I wish there was more information on the differences between mastectomy, lumpectomy, and then to choose which. I was put in that situation on making my own decision, what I wanted, and it's a huge decision. I just wish there was a bit more guidance in relation to that. Participant_016



Wish they had known earlier (% of all participants)



No. Tiny little things here and there but no, I was quite happy with how everything went. No, I would keep it all definitely. Participant_005

If I'd known I had the gene, I would've had a double mastectomy, instead of a lumpectomy. Other than that, no. Participant_037

I didn't want to do radiation, and I still don't...I'm not a 100% sure if I did the right thing in having it because obviously, that forced me to have a full surgery rather than have a breast implant put in which is major surgery where he's putting a breast implant and it's not as big a deal. Participant_043