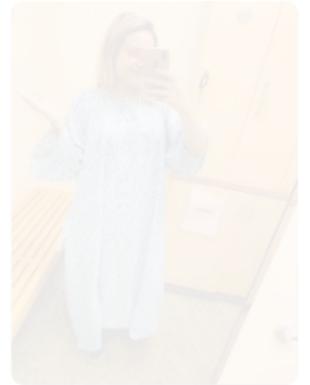
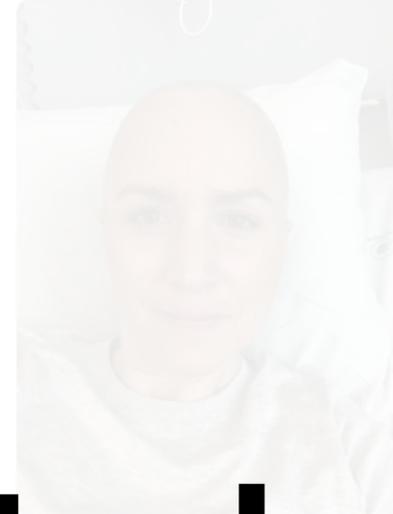


**WAR
ON
CANCER**



Mental Health Study

Is Cancer Care Addressing Your Mental Health?



About the study

-  Aim to better understand if/how cancer care addresses the mental health of persons with cancer during and after treatment
-  Survey released on 4 February 2021 — World Cancer Day
-  12 questions — multiple-choice and open-ended
-  All participants received information about the study and provided written informed consent to participate

957 participants



91%

women

44

years

average age - range: 17-78

49%

Sweden

n = 470

6%

USA

n = 59

36%

UK

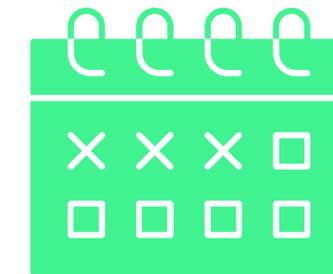
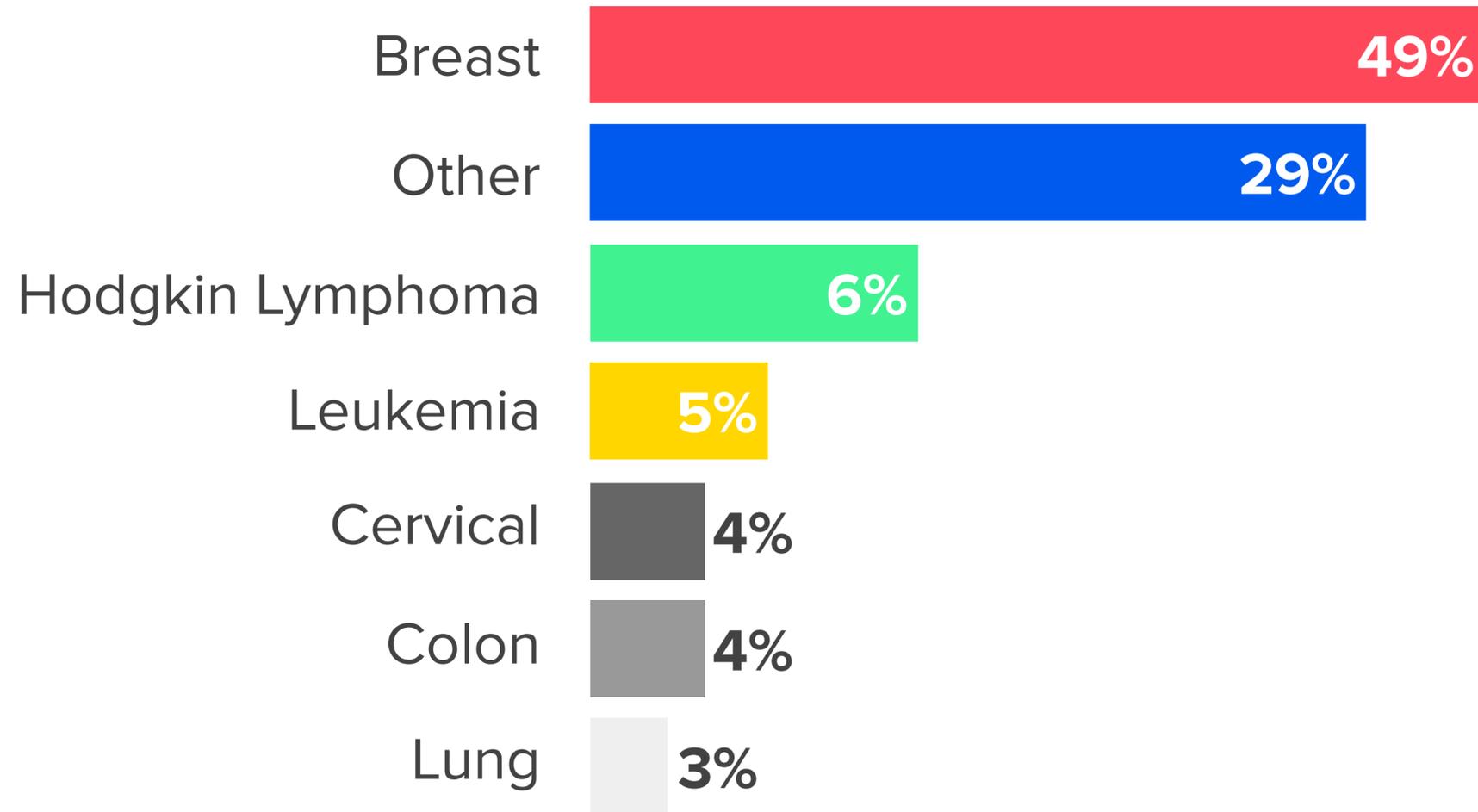
n = 348

9%

Other

n = 80

Type of cancer



3.7 years

average time
since diagnosis

75% had 4 or less years of cancer

Category 'Other' consists of 53 additional cancer types (each <3% of total)

“ I feel that my mental health battle is a bigger one than my physical battle.



experienced

mental health
decline

need for mental
health support

since receiving the
cancer diagnosis

“ I was not offered any help regarding my mental health during or after treatment. I found my mental health declined after treatment ended and I struggled to come to terms with my new normal. Since then I have been diagnosed with anxiety and PTSD as I live in complete fear to relapse or others I love receiving a diagnosis. Any help I’ve received has been sought out by me.

Q1 How has your mental health been affected since being diagnosed with cancer?

Q8 I need or needed mental health support because I was...

Q12 Is there anything you would like to add regarding how cancer care is currently addressing your mental health needs?

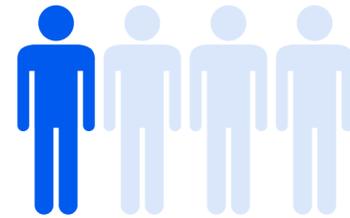
Just over half received a referral to a therapist/psychologist...



Q3 Since I was diagnosed with cancer, I have been referred to and have visited a therapist or psychologist about my mental health
Q8 I need or needed mental health support because I was...

... and many were not even recommended any mental health tools

“ While most of my care has been great I've never been asked if I would like counseling. I feel I'd need to actively seek it out if it was something I needed.



“ No one, not one person has offered to help me with my mental health throughout this. I have had to try and find options for myself.

“ I find the questions are not asked around mental health and as a typical male I do not express myself freely. I find myself fall into despair on occasions, becoming tearful at times.

Almost
1 in 4
were not even
**offered any suggestions
for therapies and tools
to support mental health**

“ Although all the health professionals involved in my care were very caring and kind not one ever addressed the possibility that a diagnosis and treatment may affect my mental health. All the focus was on physical aspects of diagnosis and treatment.

Counseling is the most suggested mental health service

6 out of 10

states that their
healthcare provider
suggested counseling

but many

felt dissatisfied with the
services offered

“ I didn't receive the support I asked for. Was told I could not meet a psychologist. The counselors were not helpful for my anxiety and worry. They did not want to speak about it and certainly not about death, which was now part of my life.

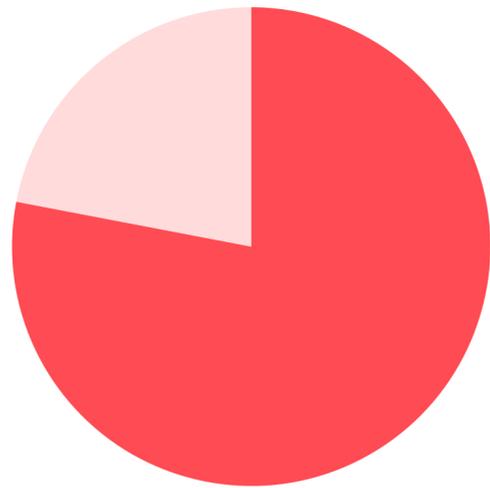
“ After my hematologist visit I had phone consultation with a counselor, but I experienced that it quickly turned into stating “acceptance” and closing the case.

“ I would have wished for more than a counsellor, preferably a psychologist/therapist.

“ Have spoken a few times with a counsellor but it was rather pointless.

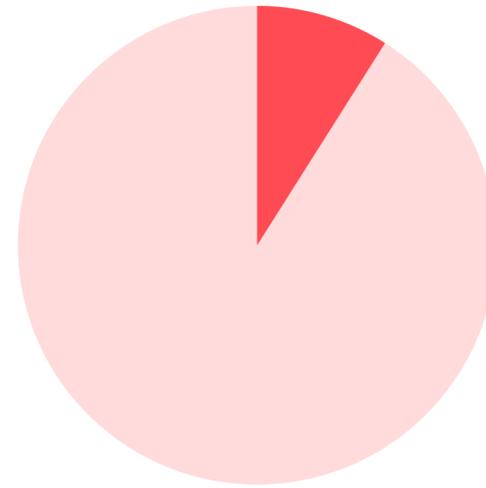
Acceptance of services

Among patients who needed mental health support and received a referral



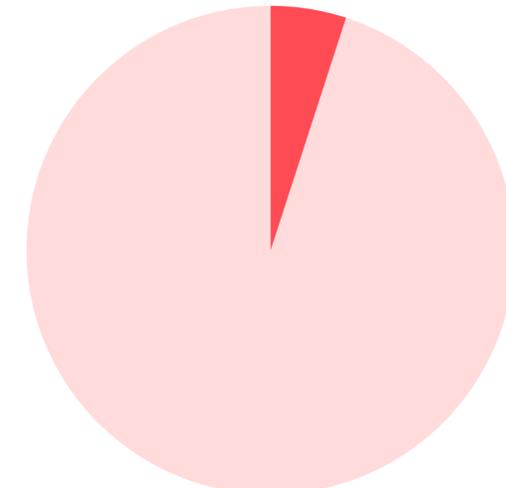
92%

accepted referral for
mental health services



9%

were not ready to
deal with it



5%

had other tools and
ways to help

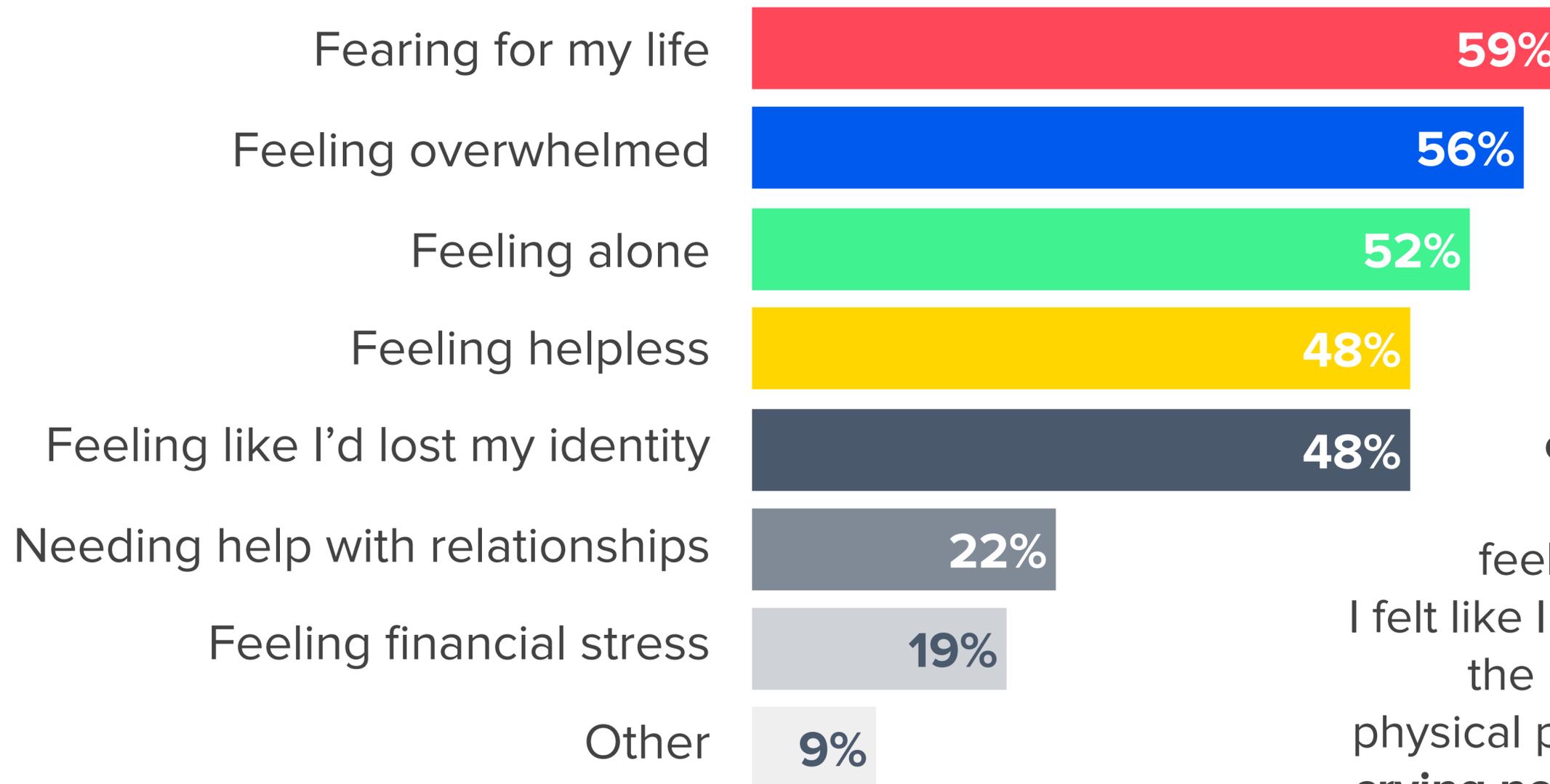
To access services some rely on private health insurance or pay themselves

“ I had to look for a psychologist myself and now am undergoing trauma therapy because of the trauma associated with the diagnosis and treatment of childhood cancer. Unfortunately the trauma therapy is not reimbursed and I have so far paid more than SEK 30,000 for this and I am not done yet.

“ After chemotherapy I have privately sought a psychologist and payed for it myself.

“ I have a [private] health insurance and it was during examinations via this that the tumor was found – this meant that I also received support in the form of 10 phone consultations, which probably would not have been offered otherwise.

Reasons for needing mental health support



“
Over Christmas when my treatment finished I was **totally alone** and **completely overwhelmed** by everything and understood how people end up feeling like **there's no point to it all**. I felt like I couldn't call anyone because all the numbers I'd been given were for physical problems and all I was doing was **crying non stop**, I had no number for that.

Q8 I need or needed mental health support because I was...

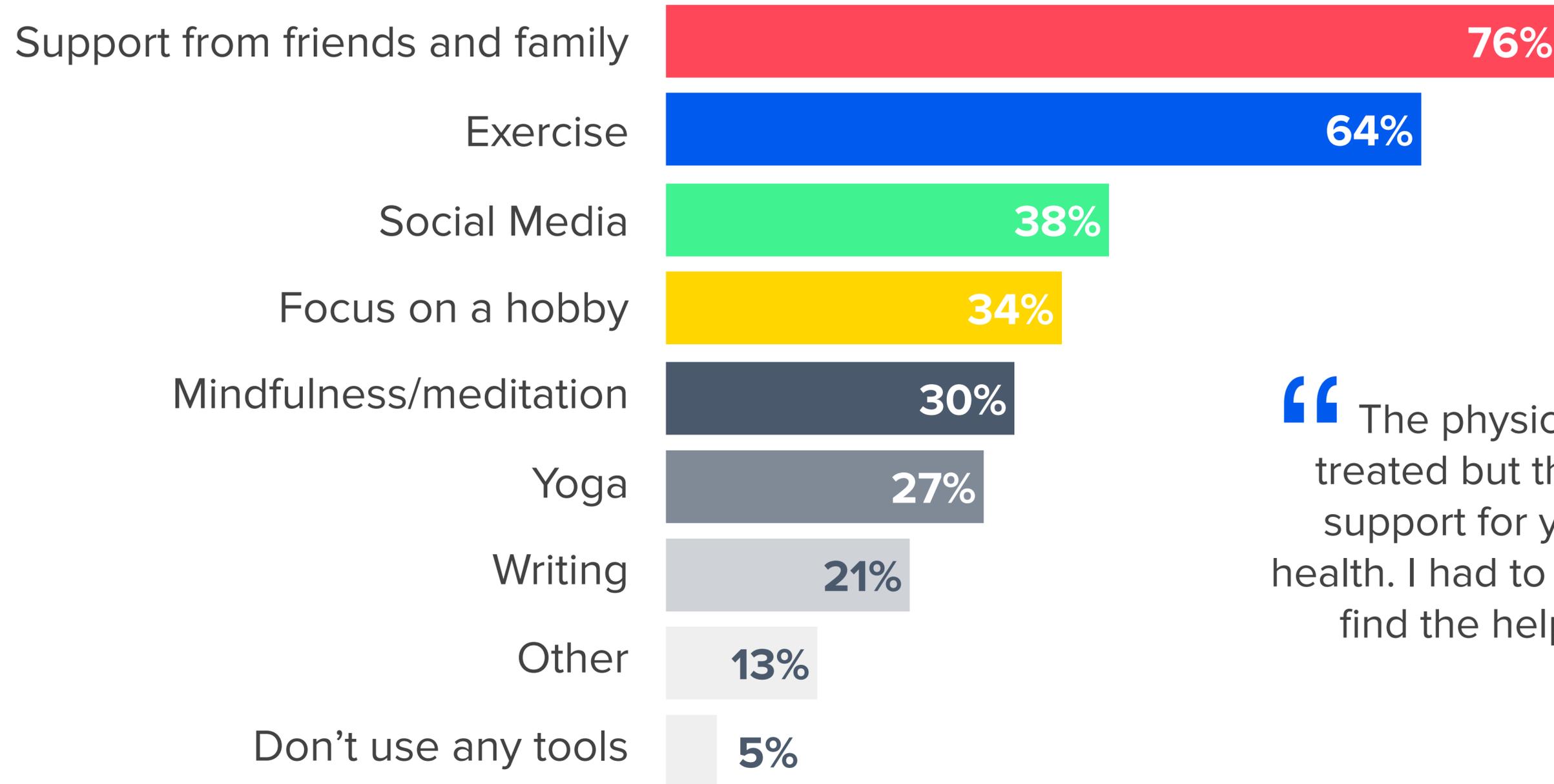
Q12 Is there anything you would like to add regarding how cancer care is currently addressing your mental health needs?

“

I think life after cancer is a lot harder than during active treatment. People may not think they need mental support/help for afterwards as I think you have an overwhelming naive expectation that you will just go back to normal once treatment ends, but you don't. I don't think doctors realize how hard life after cancer is, but also don't think the diagnosed-cancer realizes that either until they do.

52% had no discussion with cancer care professionals about what life may be like after cancer treatment

Patients take own initiative to self-manage their mental health



“ The physical health is treated but there is little support for your mental health. I had to go out and find the help I needed.

“ Psychological support should be a routine part of cancer care.

“ I was not offered any help regarding my mental health during or after treatment. I found my mental health declined after treatment ended and I struggled to come to terms with my new normal. Since then I have been diagnosed with anxiety and PTSD as I live in complete fear to relapse or others I love receiving a diagnosis. Any help I've received has been sought out by me.

88%

believe that
healthcare should
refer **all cancer patients** to
a therapist or psychologist

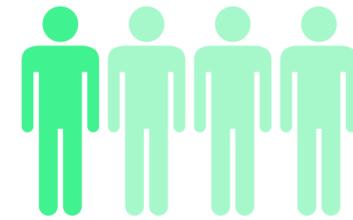
A family approach is needed – everyone is affected



I got the question: “Do you have children?” – “Yes, a 6-year old.” – “Okay, it’s good to tell the child that you are sick.” But how do I do that when I have death anxiety?



I would have needed them to ask about my children. They needed help. I was unable to help and comfort them. More than ten years later I still suffer much.



**Only
1 in 4**
reported that
their loved ones
were offered
counseling



What layperson knows how to talk to their kids about a chronic and life-threatening disease?



No one offered my child help. [...] during my last two rounds of treatment they told me a therapist will contact me but it never happened. I have a death sentence and need to fight for everything. Help for my loved ones has not even been discussed.



I find it overwhelming that much of my mental health needs are left to my own assessment. Sometimes people aren't aware that they need help.



In collaboration with

