

BACKGROUND

Cancer is a disease with a huge impact, going far beyond the threat of physical health. Often cancer patients and their loved ones also struggle with cognitive, emotional, social and practical consequences. Internationally guidelines for comprehensive cancer care are written, however the implementation in practice still seems far behind. This study explores cancer patients' experiences with the provided care and the interaction with their caregivers.

METHODS

Sample and sample recruitment

Four focus group discussions were conducted with 26 (ex-) cancer patients recruited from a quantitative study, through a call for participation on the radio and in a newspaper. Four male and 22 female (ex-)cancer patients participated. Mean age for the participants was 56.8 (range 28-78) *. Primary cancer diagnoses were: Breast, Colorectal, Non-Hodgkin Lymphoma, Hodgkin Lymphoma, Lung, Ovarian Brain, Prostate, Thyroid, Maligne melanoma, Pancreas and Liver cancer. The variety in time since last diagnosis or relapse is shown in Table 1.

* one participant forgot to register his personal characteristics and was not reachable afterwards, only sex and type of diagnosis are known from focus group data

TABLE 1 Time since last diagnosis or relapse

Time since diagnosis	Number of participants (n=25)*
<6m	5
>6m	5
1-2y	3
3-5y	4
6-10y	4
11-15y	3
16-20y	1

Procedure

Participants were asked to complete a questionnaire at home prior to the group discussion. With this we collected socio-demographic, medical and some quality of life data. The group discussions were facilitated with key questions. The moderator and observer conducted and followed the discussion while it is audiotaped with prior consent.

Data analysis

The audio file was transcribed verbatim and afterwards thematically analyzed. Questionnaire data were digitalized and statistical analyses were performed using SPSS 21.0.

QUALITATIVE ANALYSIS RESULTS

THEME 1 EXPERIENCES WITH CANCER CARE

→ MEDICAL CARE AND PSYCHOSOCIAL CARE ←

Cancer care has evolved positively however, the ideal of comprehensive care seems to be an aspirational target

If you take into account the psychosocial aspect in hospital care and then the medical ... that's ... the two worlds do not intertwine (FG-13)

The experience I have as a patient... I must admit that there is an enormous progress technically ... but from the patients I have spoken, no one is satisfied with the support...the human aspect, how they are treated as patient (FG-25)

Psychosocial care offer often is unclear

You don't know what kind of supportive care exists. Meanwhile I know it all, but I have encountered that you have to search for it yourself. If you sit on the fence, there will be no one helping you (FG-07)

Bad timing and lack of continuity

Actually in the beginning they overwhelm you with everything...when you're only just coping with your treatment and the fact that you have cancer. But when that phase has passed you expect them to return to you again with their care offer, but then... they don't come (FG-11)

Cost

Since I'm still in treatment in the hospital the support from the psychologist for me is for free. That is luxury for me compared to others that have to pay 50 euro's for one time. I think that is a large difference, I can imagine that it is not possible for everyone to appeal for that kind of support (FG-16)

Brochures

In my view it is difficult...you have a leaflet with support information and contacts on it, but to take it and call someone ...at that point when you are struggling... I can understand that there are people who don't use it, there is still a threshold (FG-21)

→ INTERACTION WITH PROFESSIONAL CARE GIVERS ←

Multidisciplinary collaboration and referral

The second time I went to my doctor... when she came to get me out of the waiting room, she said "you are scared". I said "How do you know that?". "I see it in your eyes...scared for all that is to come". And then she also asked me "Do you want to talk to a psychologist?" and I immediately said yes (FG-20)

Informing the patient

The nurse who accompanied me said "you are only getting an echography". But, that turned out to be incorrect, yet it was a different kind of examination. Well and I was driving from Genk to Lanaken for 14 kilometers and...suddenly it started leaking at my bottom. It was terrible. ...when I came home I was wet to the skin...and they didn't tell me that that could happen (FG-17)

Affinity with psychosocial concerns

Last year I went to the gynecologist for a normal gynecological examination...and he asked me "How are you?" and I said "Fine, I come for my examination". Then he said "No no I'm asking how you are doing? You have been through a lot so...?". He took his time and started asking me how I coped with the cancer psychologically and how I dealt with it (FG-11)

If they would have had attention for my deepest fear at the time I was sick to death of my chemo...the fear that said "What if something goes wrong with me, what with my two sons?...I think I would have been a lot more resilient to cope with the chemo (FG-26)

Take some time

Once in Leuven I had a very emotional morning. I don't know...I can't tell exactly why. One of the nurses noticed and took some time for me. That was fantastic! (FG-21)

There was no time for questions. I stood there with the handle in my hand and uh ... had to dress quickly and the next patient was already there. (FG-24)



Trust

You have trust them fully, but sometimes like with those medications...they damage your confidence. You are scared, worried and you feel disappointed...and yet next time you go back you have to trust them again (FG-26)

Communication style of professional

...the second option was to bring me into the menopause, which would shut down everything for a while. They were not sure what effect it would have on me and well...the oncologist said "It's that option or the other...you don't have to start whining how you will feel about it. We have to start with the chemo so decide." (FG-10)

Familiarity with total health file of patient

Even physical complaints were dismissed. I suffered a lot from nausea and that was dismissed as...well it was not possible. But I was in follow-up with an assistant in the department of radiology and at the same time I got chemotherapy. The nausea was a consequence of the chemo...but the radiology assistant didn't thought about that. I went to another hospital for my further follow-up and thank god it is totally different there. The intestinal specialist is my doctor and he knows my file (FG-21)

THEME 2 CARE NEEDS AND EXPECTATIONS

Comprehensiveness and continuity of care

Next time I want more to be done about... or more attention for support in the period afterwards. Even so going back to work...it's all very difficult (FG-11)

Comprehensive information

So that you know 'oh what I experience is normal'...I...sometimes you almost feel abnormal, but if you know that there are a lot of people experiencing those thoughts and feelings, you already feel much better. So in that respect there also should be given more information, it's always the medical things they talk about (FG-11)

Patient involvement

At the moment you get sick, the doctors expect you to follow them slavishly, that you...ehm...agree with what they propose. You have to remain mute; setting your limits and standing on principle is taken exception to (FG-26)

Acknowledgement as (ex-)cancer patient

I have difficulties with my own brother in law, who even lives very close to me, not knowing I had breast cancer (FG-05)

You almost would be jealous not having breast cancer. I had the feeling...I've had three cancers and no one speaks about that (FG-07)

CONCLUSIONS

The participating (ex-)cancer patients have positive and negative experiences with care. Aspects that contribute to this are trust, personal approach, multidisciplinary cooperation and referral, follow-up, holistic approach, availability/time, communication style, clarity of information and familiarity with patients' medical or personal situation. People often had difficulties to encounter and acknowledge psychosocial concerns because they were overwhelmed, because of the taboo that still is experienced and the difficulties to find psychosocial support and to pay for it.

DISCUSSION

A positive evolution in care is perceived, however still a lot of (ex-)cancer patients deal with unresolved psychosocial concerns. Barriers to address psychosocial concerns could be lowered when the psychosocial topic is standardly raised by care givers, when a central contact would be available throughout the whole care trajectory and appropriate referral is placed if necessary.

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