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.

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.

Table 1

<table>
<thead>
<tr>
<th>Time since diagnosis</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;6m</td>
<td>5</td>
</tr>
<tr>
<td>&gt;6m</td>
<td>5</td>
</tr>
<tr>
<td>1-2y</td>
<td>3</td>
</tr>
<tr>
<td>3-5y</td>
<td>4</td>
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<tr>
<td>6-10y</td>
<td>4</td>
</tr>
<tr>
<td>11-15y</td>
<td>3</td>
</tr>
<tr>
<td>16-20y</td>
<td>1</td>
</tr>
</tbody>
</table>

* one participant to register for personal characteristics was not available afterwards, only sex and age of diagnoses are shown in focus group data

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

Psychosocial care offers are often unclear

You don’t know what kind of supportive care exists. Meanwhile I now 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)

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)

THEME 2 Care needs and expectations

Comprehensive information

So that you know ‘oh what I experience is normal’… it’s sometimes you almost feel abnormal. If you know that there are a lot of people experiencing those thoughts and feelings you already feel much better. So that expect three 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 doctor expect you to follow them ubiquitously, that you… endure… agree with what they propose. You have to remain mute; setting your limits and standing on principle is taken exception to (FG-23)

Acknowledgement as (ex-)cancer patient

I have difficulties with my own brother in law, who even lives very far… I have difficulties with my other brother-in-law too… when you’re only just coping with your cancer… (FG-07)

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 concern 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.

ACKNOWLEDGEMENTS

We want to thank the participants of our focus group discussions. Funding is provided by Limburg Sterk Merk (LSM).