

Mr. and Mrs. Patient Speaking: Patients' preferences on psychosocial screening and their impression of the CARES.

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BACKGROUND

Screening for distress and psychosocial well-being in cancer care is recommended. However, the value and applicability are discussed. As part of a larger mixed-methods study, this study explores (ex-) cancer patients' experiences with and preferences on the application of psychosocial assessment in clinical practice. Likewise, patients' view on the content validity and feasibility of the CARES (Cancer Rehabilitation Evaluation System), a comprehensive quality of life and needs assessment tool, is explored.

METHODS

- Four focus group discussions were conducted with 26 (ex-) cancer patients recruited from a quantitative validation study of the CARES and through a call for participation in the newspaper.

- Participants were asked to complete the CARES at home prior to the group discussion to get familiar with assessment tool.

The CARES contains 139 items; however, not all items apply to all patients (min. 93 – max. 132).

- The focus group discussions were audiotaped and transcribed verbatim. Thematic content analysis was used to analyze the collected qualitative data.

How much does it apply to you?	Not at all	A little	A fair amount	Much	Very much	Do you want help?
1. I have difficulty walking	0	1	2	3	4	Y (N)
2. I find that food tastes bad	0	1	2	3	4	Y (N)

SAMPLE

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, Lung, Ovarian, Non-Hodgkin Lymphoma, Hodgkin, Lymphoma, 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

QUALITATIVE ANALYSIS RESULTS

Difficulties and concerns cancer patients

memory problems, change of personality and vision in life, emotional sensations: being overwhelmed, fear, sorrow, feelings of loneliness, anger, shame, guilt, insecurity.

lack of energy, reduced physical condition, pain in muscles or joints, bodily changes: scarves, gain weight, loss of taste, loss of fertility, brittle skeleton.

pushing others away, losing social contact, lack of understanding for ones situation, temporarily increase of social context.

discrepancy in emotional coping, relational tension, difference in sexual needs.

negative and positive experiences in interaction with caregivers and medical procedures.

loss of income, health expenditure, problems with financial benefits.

getting fired, hard to get a new job, temporarily losing large part of social context, expectancy to function at a 100% when returning to work.

Wellbeing of loved ones

! MATCH !

Content validity CARES

Summary and subscales CARES

- Physical:** Ambulation, Activities of daily living, Recreational activities, Weight loss, Difficulty working, Pain, Clothing
- Medical Interaction:** Problems obtaining info from medical team, Difficulty communicating with medical team, Control of medical team
- Miscellaneous:** Compliance, Economic barriers, Dating*, Chemotherapy-related problems*, Radiation-related problems*, Ostomy*, Prosthesis*, Miscellaneous items
- Marital*:** Communication with partner, Affection with partner, Interaction with partner, Overprotection by partner, Neglect of care by partner.
- Psychosocial:** Body image, Psychological distress, Cognitive problems, Difficulty communicating with friends/relatives, Friends/relatives difficulty interacting, Anxiety in medical situations, Worry, Interaction with children*, At work concerns*.
- Sexual:** Sex interest, Sexual dysfunction*.

*does not apply to everyone

Feasibility CARES

- Long questionnaire, but acceptable considering the importance to capture people's all over wellbeing rigorously to be useful in cancer care (when used in stepped care).
- Everything was clear for participants, could be more difficult for immigrants who lack proficiency in Dutch.
- Items on death and testament: realistic but confrontational, reformulation of the items could solve this.
- The 'yes'/'no' response categories linked to the question 'Do you want help?' posed some problems, an option 'maybe later' needed.

Experience with psychosocial screening in practice

Only three participants had former experience, namely the Distress Thermometer (DT). This was a positive experience, although not comparable with the CARES since the DT seemed more a crude measure.

Preferences on psychosocial screening in practice

Throughout the care trajectory, with every contact. Differentiate between signaling, screening and assessment to avoid overshooting and tailor to the individual patient.

Experiences and preferences on Psychosocial Screening

Value of psychosocial screening in practice

The use of a screening instrument could sensitize on psychosocial wellbeing, normalize the psychosocial topic, facilitate communication and give input for designated action in care if used actively.

CONCLUSIONS

The CARES has a good content validity containing topics that are relevant, important and comprehensive for the experience of cancer patients. It is a feasible instrument only lacking the question for the wellbeing of loved ones. Use of such an instrument according to the (ex-)cancer patients could normalize psychosocial concerns and facilitate communication.

Participants emphasize that concerns and needs differ according to one's personal situation and phase in the care trajectory, requiring a tailored psychosocial screening stepped care approach. Screening should be applied repeatedly and could be continued with a more comprehensive instrument if needed.

RESEARCH IMPLICATIONS

The results of this study confirm the content validity and feasibility of the CARES. It is a comprehensive tool useful to gain insight in cancer patients overall wellbeing. Likewise the results of this study underline the importance of research on psychosocial screening in cancer care. Whereas a lot research in the past has focused on screening tools and the effect of screening, future research should aim at the implementation and evaluation of care approaches using screening and assessment as a tool to gain input from patient-perspective for designated action in care. In clinical practice, screening should be organised as a stepped care approach differentiating between signaling, screening and assessment. The CARES appears an excellent assessment tool for this purpose.

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