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ORIGINAL ARTICLE

An explorative study on systematic assessment of QOL and care needs with the CARES-SF in the early follow-up of patients with digestive cancer

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Abstract

Purpose Systematic assessment of QOL and care needs was applied in two gastroenterology departments to support "Cancer Care for the Whole Patient."

Methods Patients with digestive cancer were asked to complete the Cancer Rehabilitation Evaluation System-Short Form (CARES-SF) at the start of treatment and 3 months later. Both times CARES data were processed, and summary reports on the retained insights were sent to the reference nurse for use in further follow-up of the patient. Patients' and reference nurse's experiences with the systematic CARES-assessment were explored with several survey questions and semi-structured interviews, respectively.

Results The mean age of the 51 participants was 63 years (SD11.17), 52.9% was male. With the CARES-SF, a large variety of problems and care needs was detected. Problems most frequently experienced, and most burdensome for QOL are a mix of physical complaints, side effects from treatment, practical, relational, and psychosocial difficulties. Only for a limited number of experienced problems a desire for extra help was expressed. All patients positively evaluate the timing and frequency of the CARES-assessment. The majority believes that this assessment could contribute to the discussion of problems and needs with healthcare professionals, to get more tailored care. Reference nurses experienced the intervention as an opportunity to systematically explore patients' well-being in a comprehensive way, leading to detection and discussion of specific problems or needs in greater depth, and more efficient involvement of different disciplines in care.

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Conclusions Systematic QOL and needs assessment with the CARES-SF in oncology can contribute to more patient-centeredness and efficiency of care.

Keywords Digestive cancer · Systematic assessment · Quality of life · Care needs · CARES

Background

Depending on the type of cancer, the prognosis and other health factors digestive cancers are mostly treated with surgery, chemotherapy or radiation, or a combination of these. Due to the disease and these related treatments, cancer patients can suffer from physical, psychosocial, and practical problems. There is a large interpersonal variability in the resulting supportive care needs [1–3]. When confronted with digestive cancer, patients often face specific challenges such as frequent constipation or diarrhea, weight loss, loss of appetite, stoma care, incontinence, changed body image, problems in sexual, and social functioning [4, 5].

In the pursuit for high quality care, it is important that the care offered adequately matches with the problems and care needs that patients experience. In this context, the Institute of Medicine (IOM) recommended routine assessment of experiences, needs, preferences, and values in all cancer patients [6]. Use of a patient reported outcome measure (PROM) could support standardization of this routine assessment, and so, several studies reviewed the available needs assessment instruments, their characteristics, and psychometric qualities [7–9]. The Cancer Rehabilitation Evaluation System (CARES) was described as a psychometric robust and feasible instrument for the measurement of quality of life (QOL) and care needs. The instrument was developed in the early 1990 [10–12], and subsequently used in clinical practice and in several studies [13–19].

This article describes an explorative pilot study in which systematic assessment of QOL and care needs with the CARES is applied in the early follow-up of patients with digestive cancer. The objectives are to explore (1) the value of the insights that can be obtained with the routine application of this tool in clinical practice, (2) the management of detected problems and care needs, and (3) the feasibility of the systematic QOL and needs assessment intervention for patients and nurses.

Methods

Participants and setting

For this study, participants were recruited from October 2016 until April 2017 in the gastroenterology departments of two general hospitals. Two reference nurses (clinical nurse specialist in one hospital, head nurse of the department in the other) actively worked with the researcher to recruit participants, and received the needs assessment output for use in patient follow-up.

Patients were eligible if they (1) were diagnosed with digestive cancer, (2) started treatment in the gastroenterology department (no former experience with follow-up in this department), (3) were aged 18 years or older, and (4) provided written informed consent. Exclusion criteria were the following: a lack of proficiency in Dutch, cognitive, or other impairment that hinders the person from completing questionnaires.

Instruments

QOL and needs assessment instrument

In an earlier phase, we reviewed the literature on needs assessment tools for cancer patients and compared these on the basis of content and psychometric robustness [20] . This review resulted in the choice to use the Cancer Rehabilitation Evaluation System (CARES) in further research. The CARES is a PROM with good psychometric qualities and broader biopsychosocial content than other tools, that was developed with great involvement of patients and professionals from the clinical field [10–12]. The CARES was translated in Dutch and assessed for cross-cultural validity in focus groups and a cross sectional study in our country (the CARES and its short form) [20–23]. Led by the feedback of participants in these previous studies, we chose to work with the CARES-Short Form (CARES-SF) in the explorative study described in current paper.

With addition of two items, requested for by participants in our validation study, the CARES-SF used in this study counts 61 items (min of 34, and maximum of 59 applicable per person). For each statement, patients are asked to answer the question “How much does this apply to you?” on a 5-point ordinal scale with following answer-options: “not at all” (no problem); “a little,” “a fair amount,” “much,” “very much” (severe problem). Additionally, for any problem experienced patients are asked to answer the question “Do you want help?’ by ticking “yes” or “no.” The tool has an average completion time of 10 min. Based on all items, a CARES-SF-total score and six domain scores (physical, medical interaction, psychosocial, relational, sexual, miscellaneous) can be computed.

Assessment output report

This CARES-report is a short summary of the insights obtained from the patients' CARES-SF completion. The CARES-SF-total score is given as an indication for patients' QOL disruption, followed by a visual overview of the average severity of problems in the six domains, a list of the problems that are indicated as applicable in "a fair amount" to "very much," and a list of the indicated care needs. For the visual overview in subsequent reports, the data of previous assessments is maintained to display the evolution.

Study survey

To explore patients' experiences with the systematic CARES-assessment intervention, a short survey was constructed with multiple choice questions on completion time, frequency and timing of the assessment intervention, and value of the CARES for the discussion of problems with healthcare professionals. Six months after the start of the study, semi-structured interviews were conducted with both reference nurses to explore their experiences with the implementation of the CARES.

Procedure

Participants were recruited by the reference nurses at the start of their treatment (T_0). After informed consent, they received a paper version of the CARES-SF and asked if they preferred to complete following assessments on paper or digitally. This choice, patients' diagnosis, and treatment regimen were registered. Patients were asked to return their filled out questionnaire on sociodemographic characteristics and the CARES-SF with the stamped and addressed envelope provided. The researcher processed the CARES data, set up the output report, and sent it coded to the reference nurse for use in patient follow-up. We choose not to work with reminders when patients did not return the completed CARES-SF, as this would probably not be feasible in the eventual implementation of systematic needs assessment in clinical practice in the future. At 3 months post start of treatment (T_1), a second CARES-SF was sent to participants, by post or with a Qualtrics survey-link by e-mail, according to the preference for paper or digital version. Again, returned questionnaires were processed and an output report was sent to the reference nurse. The full procedure is visualized in Fig. 1. Only the first two CARES assessments are in the scope of this article.

Ethical considerations and study registration

The study procedure and all study materials were submitted to the ethical committees of both hospitals (Committee Medical Ethics AZ Delta and Ethical Review Commission Jessa Hospital) and the university (Medical Ethical Committee Hasselt University). Ethical approval was given by the leading ethical committee (Committee Medical Ethics AZ Delta) on the 14th of March 2016 (B117201627823). The leading ethical committee also reviewed and approved amendments. This pilot study was registered with ClinicalTrialsGov. (ID. NCT02282696). Patients participated after signing for informed consent. Participant data was treated confidentially. Participant codes were used on CARES-SF forms, in data collection and for all correspondence. Only the researcher and reference nurse had access to the file that linked the patients' name with their participant code.

Data analysis

The Statistical Package for Social Sciences (SPSS; Chicago, IL) version 22.0 was used for calculation of CARES scores and further data analysis. The study sample in this explorative study was not large enough to explore statistical significance for group differences based on population characteristics or time points, so simple descriptive statistics were used to analyze all data.

Results

Participants

Patients

Sixty-seven patients consented to participate in this study. Eight of them were lost due to death ($n = 6$) or worsened health condition ($n = 2$) before they returned any questionnaire. With 51 participants of the remaining 59 actually returning one or both completed CARES forms, the response rate was 86.4%. The mean age in the study sample was 63 years (SD11.17), and for 82.4%, the digestive cancer was the first cancer diagnosis they were treated for. Further, sociodemographic and medical characteristics are displayed in Table 1.

Professionals

The reference nurse in AZ Delta was a female clinical nurse specialist, working as the central contact person for the follow-up of cancer patients in the gastroenterology department. She had 21 years of job experience, of

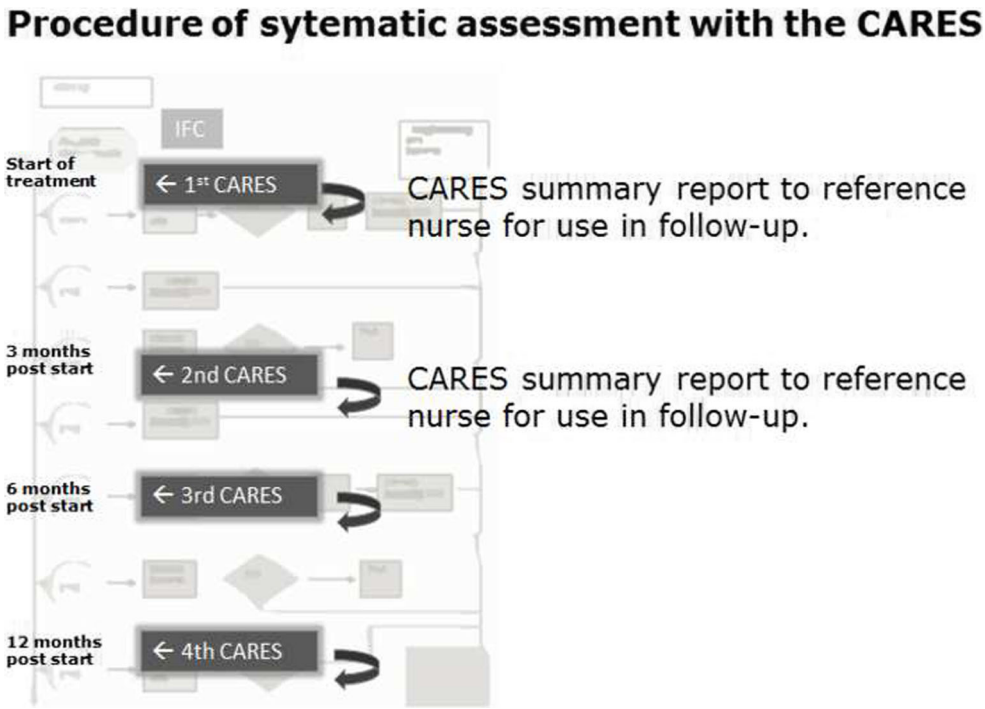

Fig. 1 Procedure of systematic CARES assessment intervention

which 18 years in oncology. The reference nurse in the other site of this pilot study was the male head nurse of the oncology outpatient clinic in the gastroenterology department in the Jessa Hospital. He had 28.5 years of job experience, all in the field of oncology.

Quality of life

In this study sample, all participants experienced problems to a greater or a lesser extent, at the start of treatment, as well as 3 months after the start of treatment. For both time points, the frequency and severity rating of all 61 problems stated in the CARES-SF are presented in Supplementary file 1. The average and total number of problems that are experienced by patients in the several life domains are presented in Table 2.

At the start of treatment, the mean severity of problems was highest in the domain of sexual functioning, followed by physical, marital and psychosocial functioning, miscellaneous aspects, and medical interaction (Table 2). At T_1, this sequence was relatively sexual functioning, miscellaneous aspects, physical, marital and psychosocial functioning, and medical interaction (Table 2).

The relative impact of the cancer experience on QOL at T_0 was highest for sexual, physical and psychosocial functioning, followed by marital functioning, miscellaneous aspects, and medical interaction (Table 2). Three months after the start of treatment, the impact was highest in the domains of physical and sexual functioning, followed by psychosocial and marital functioning, miscellaneous aspects, and medical interaction.

The problems most frequently experienced by patients (by more than half of the sample) at both time points are displayed in Table 3, as well as the problems that have the highest impact on patients' QOL.

Care needs

The percentage of participants indicating to be in need for additional support or assistance was limited with 34.8% and 25.6% at T_0 and T_1, respectively. At the start of treatment, there were 40 types of problems for which participants desire help, and 3 months after the start of treatment, there were 36 types of problems (Supplementary file 1). The number of problems for which patients desire help at the start of treatment ranges from 0 to 7, 0–2, 0–7, 0–2, 0–2, and 0–3, for the physical, medical interaction, psychosocial, marital, sexual, and miscellaneous domain, respectively. This is similar at T_1. The problems for which additional care or support is desired the most at both time points are presented in Table 3.

Feasibility and acceptability intervention

Questionnaire return

Of the 51 participants returning their questionnaire, 46 (90.2%) completed the first CARES-SF at the start of treatment, 43 (84.3%) completed the second CARES-SF 3 months later. Reasons for non-return mentioned to the nurse were lack of time, not feeling into completing a questionnaire, or forgetting. For example, because of these reasons, there were five

Table 1 Sociodemographic and medical characteristics patients ($N = 51$)

Socio-demographic characteristics	*n*	%	Medical characteristics	*n*	%
Sex			Type of cancer[c]		
Men	27	52.9	Colorectal	31	60.8
Woman	24	47.1	Pancreas	7	13.9
Relational status			Esophagus	1	2.0
Single	7	13.7	Stomach	3	5.9
Partner, married, or living together	39	76.5	Liver, gallbladder	7	13.9
Partner, not married, or living together	2	3.9			
Widowed	3	5.9			
Having children	46	90.2	Type of treatment[c]		
Graduation level[a]			Surgery	2	3.9
Elementary school	7	13.7	Surgery + Palliative CT	1	2.0
High school	27	52.9	CT + RT	5	9.8
Graduate school	9	17.6	Adjuvant CT	18	35.3
University	4	7.8	Neoadjuvant CT	5	9.8
Job occupation[b]			Palliative CT	18	35.3
Employed	5	9.8			
Work interruption/on sick leave	6	11.8			
Unemployed	1	2.0			
Disabled	2	3.9	Intention of treatment[a]		
Housewife/houseman	2	3.9	Curative	29	56.9
Retired	34	66.7	Palliative	18	35.3

Abbreviations: CT, chemotherapy; *n*, number of participants; *R*T, radiotherapy

[a] Percentages do not count up to 100%, due to missing data of 4 participants

[b] Percentages do not count up to 100%, due to missing data of 1 participant

[c] Percentages do not count up to 100%, due to missing data of 2 participants

patients who did not complete the CARES-SF at the start of the treatment, but did so 3 months later.

Patients' experience (quantitative data)

All participants that completed the questionnaire at the start of treatment judged the completion time of the CARES-SF to be acceptable. At the start of treatment, 42 participants (91.3%) indicated that repeated assessment with the CARES-SF could contribute to the discussion of problems and needs with healthcare professionals, to get support that was more tailored to their individual needs. One person (2.2%) indicated "no" for this question. After the CARES-SF completion at 3 months, participants were asked to evaluate the frequency and timing of the CARES-assessments. Almost 91% indicated that this was good and had no suggestions for other frequency or timing. After this second CARES-assessment, 65.1% of the participants indicated that the use of the CARES-assessment in follow-up could contribute to problems and needs discussions with healthcare professionals. Eight participants (18.6%) thought this was not the case.

Professionals' experience (qualitative data)

The findings from the semi-structured interviews with the reference nurses are described in this section and illustrated with their quotes in Table 4.

Both reference nurses used the CARES-results on needs as action points in care. The QOL information was used in follow-up for the discussion of patient's well-being and their way of coping with disease and treatment. In AZ Delta, the CARES-report was scanned and placed in the electronic patient file; in Jessa Hospital, the reference nurse included information on detected problems and needs in his discipline specific section of the electronic patient record.

The CARES-SF was experienced by the references nurses as a tool that provides support in patient-communication and follow-up of patients' overall well-being, including medical and psychosocial. On the one hand, the CARES-information confirmed their clinical insights; on the other hand, in several cases, it added extra insights.

The semi-structured interviews with the two reference nurses revealed that use of the CARES can support the completeness, efficiency, and customization of follow-up.

Table 2 Severity scores for problems and impact on QOL in the CARES domains

	Number of problems				Severity of problems[a]				Impact on QOL[a,b]			
	At T_0		At T_1		At T_0		At T_1		At T_0		At T_1	
CARES domains	M	Range	M	Range	M	SD	M	SD	M	SD	M	SD
Physical	5	0–10	5	1–10	1.55	0.57	1.66	0.56	0.89	0.68	1.00	0.76
Medical Interaction	1	0–4	1	0–4	1.21	0.42	1.23	0.42	0.24	0.38	0.20	0.40
Psychosocial	8	1–18	7	0–15	1.45	0.53	1.53	0.58	0.76	0.64	0.75	0.61
Marital	1	0–5	2	0–6	1.50	0.71	1.55	0.57	0.44	0.46	0.58	0.65
Sexual	1	0–3	1	0–3	2.12	0.98	1.87	0.83	0.93	1.08	1.00	1.09
Miscellaneous	3	0–10	3	0–10	1.44	0.58	1.70	0.80	0.40	0.38	0.51	0.48
CARES-SF Total	19	2–37	19	1–41	1.45	0.46	1.51	0.49	0.61	0.43	0.67	0.43

Abbreviations: *M*, mean; *SD* (standard deviation); T_0, at the start of treatment; T_1, 3 months after the start of treatment)

[a] QOL-score range of each CARES-SF item from 0 to 4: 0 = "not at all" (no problem); 1 = "a little," 2 = "a fair amount," 3 = "much," 4 = "very much," on the question "How much does this apply to you?"

[b] This score is weight on the number of items applicable for a person

Besides, it could contribute to the relationship of trust that a care professional has with the patient.

During the interview, the reference nurse of the Jessa Hospital stated "We also should have a questionnaire like that for the patients' partners." In AZ Delta, the reference nurse already asked for such a version during the study period, and used a partner-version of the CARES (not part of the scope in this study, but developed and added on her request), and experienced this as valuable. Problems that remained unnamed before between partners were now exposed. In response to this, the concern not to strain each other, and the problem could be discussed, sometimes resulting in a relief of relational tension.

According to the reference nurses, healthcare professionals can be involved in a more efficient and focused way, better prepared with self-reported problems and needs that are important to patients. Outcomes of the CARES-assessment were discussed with several disciplines.

A physician of the gastroenterology department not actively involved in the study spontaneously sent an email with the message "A lot of our patients complete the CARES, often we get valuable insights from this." A psychologist asked if there was a cutoff value for the CARES to determine whether further care was required.

In reference nurses' experience, most patients were willing to complete the CARES. What struck them was that many problems were indicated in the CARES, but that few patients pointed out that they were in need for help. However, in conversations about these issues, help questions did emerged sometimes. According to both reference nurses, the use of the CARES could contribute to a patient-centered approach in care.

After recruitment for this pilot study, the reference nurse in AZ Delta kept on using the CARES-SF in the follow-up of patients and encouraged colleagues and managers to use the instrument for the wider group of cancer patients in the hospital.

The other reference nurse is also positive about a future implementation of the instrument in practice. And this not only for the benefit of the individual patient, but also because of the value of big data that could be collected in case of larger scale implementation.

Discussion

With the CARES-SF, a comprehensive overview of each patients' overall well-being was obtained in the study sample. The problems most common in the sample and most stressing to patients' QOL consist of a mix of disease symptoms or treatment side effects, physical, practical, relational, and psychosocial problems. As in other studies, only a small group of patients experiencing problems also expressed related care needs (34.8% at T_0; 25.6% at T_1), or is willing to accept a referral [24, 25]. This can be explained by the fact that patients want to cope with the problems and distress on their own, they do not experience their levels of distress as high enough, or they have sufficient social support in their personal context to deal with the situation [26]. This emphasizes that the QOL insights require attention in follow-up, but not necessarily ask for action. However, the indicated care needs do. As in other studies [27], some patients who initially did not experience considerable problems or care needs did report significant problems or care needs in the CARES assessment at 3 months after the start of treatment. This emphasizes the value of repeated needs assessment, to enable us to timely identify and address patients QOL issues.

Table 3 Main problems and care needs in this population of digestive cancer patients

Problems most frequently experienced

At the start of treatment (T_0)			At 3 months post start of treatment (T_1)		
Problem	n[a]	%	Problem	n[a]	%
Worry whether cancer progresses	43	93.5	Reduction in energy	40	93.0
Reduction in energy	39	84.8	Worry whether cancer progresses	37	86.1
Difficulties planning activities	32	69.6	Difficulties planning activities	31	72.1
Worry how loved ones are coping	30	65.2	Uncomfortable with body changes	30	69.8
Uncomfortable with body changes	30	65.2	Cancer interferes ability to work	26	60.5
Cancer interferes ability to work	29	63.0	Food unappealing	25	58.1
Nervous when waiting to see doctor	29	63.0	Worry not being able to care for self	25	58.1
Difficulties sleeping	27.00	58.7	Frequently anxious	24	55.8
Frequently having pain	26.00	56.5	Nervous when waiting to see doctor	24	55.8
Difficulties doing household chores	25.00	54.3	Difficulties to bend or lift	23	53.5
Difficulties asking frnd/rel. for help	25.00	54.3	Difficulties sleeping	23	53.5
Worry not being able to care for self	27.00	58.7	Difficulties concentrating	23	53.5
			Difficulties asking frnd/rel. Help	23	53.5

Problems with the highest impact on patients' QOL

At the start of treatment (T_0)		At 3 months post start of treatment (T_1)	
Problem	Av.sev.[b]	Problem	Av.sev.[b]
Difficulties telling a date about cancer[c]	3.00	Vomit after chemo[c]	2.67
Nauseous/vomit after radiotherapy[c]	3.00	Difficulties telling date about cancer[c]	2.50
Difficulties initiating dates[c]	2.60	Cannot gain weight	2.38
Difficulties to talk about cancer at work[c]	2.50	Not gets along as usual with partner[c]	2.38
Cannot gain weight	2.20	Difficulties initiating dates[c]	2.25
Not interested in having sex	2.16	Other side effect from chemo[c]	2.21
Frequency of sex decreased[c]	2.14	Cancer interferes ability to work	2.19
Does not feel sexually attractive	2.13	Frequency of sex decreased[c]	2.18
Worry whether cancer progresses	2.02	Clothes do not fit	2.11
Not gets along as usual with partner[c]	2.00	Reduction in energy	2.05
Problems ostomy care/maintenance[c]	2.00	Frequent diarrhea	2.00

Care needs most frequently expressed

At the start of treatment (T_0)			At 3 months post start of treatment (T_1)		
Wish for help with…	n[a]	%	Wish for help with…	n[a]	%
Difficulties doing household chores	8	17.4	Difficulties planning activities	5	11.6
Worry whether cancer progresses	5	10.9	Food unappealing	4	9.3
Reduction in energy	4	8.7	Cancer interferes ability to work	4	9.3
Cannot gain weight	4	8.7	Uncomfortable with body changes	4	9.3
Difficulties sleeping	4	8.7	Difficulties concentrating	4	9.3
Worry how loved ones are coping	4	8.7	Worry how loved ones are coping	4	9.3
Food unappealing	3	6.5	Difficulties doing household chores	3	7.0
Frequent diarrhea	3	6.5	Cannot gain weight	3	7.0
Cancer interferes ability to work	3	6.5	Frequent diarrhea	3	7.0
Frequently has pain	3	6.5	Frequently anxious	3	7.0
Uncomfortable with body changes	3	6.5	Difficulties sleeping	3	7.0
Difficulties concentrating	3	6.5	Worry whether cancer progresses	3	7.0
			Nauseated after chemo[c]	3	7.0

Abbreviations: *Av.sev*, average severity; *n* number of participants; *QOL*, quality of life

[a] $n_{T0} = 46$; $n_{T1} = 43$

[b] QOL-score range of each item from 0 to 4: 0 = "Not at all," 1 = "A little," 2 = "A fair amount," 3 = "Much," 4 = "Very Much"

[c] Item not applicable for every participant

All participants were positive on the frequency and timing of the CARES-assessment, and the majority indicated that this could have an additional value in the patient-professional communication and receiving tailored care. That some of the patients do not share this opinion may be in person's personal coping, physical, and social surroundings. As well, communication needs and preferences can change along the care trajectory [28].

The reference nurses experienced the CARES data as a valuable starting point to discuss patients' well-being, and in detecting potential problems and care needs [29]. It stimulates patients to reflect on potential problems and their impact, and supports them in determining for which they desire further discussion or support [30]. The obtained insights provided the nurses guidance in conversations on patients' well-being, enabled them to "come to the point" in less time and to

Table 4 Reference nurses' experiences with systematic CARES-SF assessment

Experiences on content
"*The information is rich…. One of the great strengths of the CARES is that the CARES questionnaire gives a reflection of how people are doing, and that you can use it as a starting point for communication.*" *(Reference Nurse 1).*
"*Putting patients on the IV line is one thing…but everything going beyond that…the questionnaire is perfect for that… the experience, the side effects, and what makes the patient feel comfortable. And the CARES gives you input to address all of these aspects.*" *Reference Nurse 2).*
Experiences of use in patient follow-up
"*I think, if you have to get all of that information that you collect with the CARES, you would need a conversation of three or four hours…and we do not have that time.*" *(Reference Nurse 1).*
"*I think you can navigate care actions a lot better. Plus, I also think that it is a great advantage for the patient, or your trust relationship with that patient, that the patient experiences 'he understands me,','he is aware of the problems I have to face.'*" *(Reference Nurse 2).*
"*Your conversations are going to have a larger variety in topics, because there are actually many different classes of questions answered. (Sums up a series of CARES topics) A huge divergence of opportunities for discussion topics is addressed.*" *Reference Nurse 1).*
"*You can work a lot more proactively ... so that's the benefit.*" *Reference Nurse 2).*
'I have already called a general practitioner with issues from the CARES questionnaire, a treating physician, because there were some questions or patients who indicated "*I want more information, but I do not get that* "*Social services, especially for problems of finance, insurance, practical help at home ... a dietician for nutritional and weight problems.*"*Reference Nurse 1).*
Experiences of patient-centeredness and patient empowerment
"*The patient will complete the questions from his perspective…and then care will be targeted more to individual needs*" *(Reference Nurse 2).*
"*The patient has his responsibility there too ... he completes those questions, but in the end it provides him with more tailored support.*"*(Reference Nurse 2).*
"*You are going to do something with that (insights from the CARES) in collaboration with them…in the end it's all about them.*" *(Reference Nurse 1).*
"*If they refuge things or do not want it, well…it's their way*" *Reference Nurse 1).*
"*50% of our care for the patient is treatment, and the other 50% is the attention for the thing we are talking about… patients' quality of life… and that is important! I am not sure if all doctors are aware of that. Ours are, because they gave me the chance to do this PAN-function and take time for the people, but…other doctors… And with an instrument like this you can indicate what kind of problems and needs patients experience. This is also important for the organization of the healthcare system.*" *Reference Nurse 2).*

involve other disciplines more effectively in care [31]. However, they emphasized that the tool should be used for its supportive value and not to replace clinical contacts. Physicians were not actively queried in this explorative study, and so, it was not possible to evaluate if and how the use of the questionnaire influenced the clinical contact with physicians. However, an oncologist spontaneously sent the researchers an email with the message that a lot of his patients wanted to complete the CARES, and that the assessment resulted in valuable information for their consults with patients.

In addition to these findings, several critical reflections on this study should be mentioned. Firstly, in comparison with other intervention studies, our sample size was rather small. However, this study was set up with an explorative purpose to study the acceptability and feasibility from patients' and nurses' perspective. In subsequent studies, more participants will be recruited. As well, outcome measures will be used to study the concrete effectiveness of the intervention. Secondly, as we worked with two reference nurses that were willing to collaborate for this explorative pilot study, there might have been a bias in their judgements. In studies following on this explorative pilot, more hospitals and departments should be involved in a broader evaluation, with inclusion of additional objective outcomes. Also, it would be interesting to evaluate the clinical use of CARES compared to the European Organization for Research and Treatment of Cancer (EORTC) QOL-schemes frequently used in clinical trials. Thirdly, at the point of data processing, we had some doubts about the question on patients' experience with the potential value of the CARES-assessment for the discussion of problems, and for receiving tailored care. This question was accompanied by the answer options: "yes" and "no." Perhaps, it would have been better to use a rating scale, as this would have allowed more nuance in patients' responses.

Conclusions

It is challenging to implement a systematic assessment with the CARES in daily cancer care. Healthcare professionals have to work with the obtained insights, in good collaboration with other team members: mutual agreements must be made regarding data processing, inclusion of the obtained insights in the patient file, and the actions that have to be taken (and by whom) when certain problems or needs are detected. Also for patients, it requires an effort in terms of time investment to complete the CARES. However, both patients and reference nurses positively evaluated the CARES-assessment. The tool supports patients in providing valuable information on their well-being and care needs and stimulates the comprehensiveness in professionals' follow-up. The obtained insights can be used in clinical conversations, and to efficiently take action in care, in line with patients' preferences and needs.

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Study coordination, data analysis, and drafting the paper: BS.
Revision of the paper: JH, DDJ, JD, MA, DW, PV.
All authors read and approved the final manuscript.

Data availability The datasets analyzed during the current study are available from the corresponding author on reasonable request.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committees.

Informed consent Informed consent was obtained from all individual participants included in the study.

Abbreviations *CARES*, Cancer Rehabilitation Evaluation System; *CARES-SF*, Cancer Rehabilitation Evaluation System-Short Form; *IOM*, Institute of Medicine; *PROM*, patient reported outcome measure; *QOL*, quality of life

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