Patients' interpretation of Patient-Generated Subjective Global Assessment (PG-SGA) Short Form

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Abstract

Background: The Patient-Generated Subjective Global Assessment (PG-SGA) is a patient-reported instrument for assessment of nutrition status in patients with cancer. Despite thorough validation of PG-SGA, little has been reported about the way patients perceive, interpret, and respond to PG-SGA. The aim of this study was to investigate how patients interpret the patient-generated part of PG-SGA, called PG-SGA Short form

Methods: Purposive sampling was used to identify participants that had experienced weight loss and/or reduced dietary intake and/or had a low body mass index. Data was collected from 23 patients by combining observation of patients filling in PG-SGA Short Form, think-aloud technique and structured interviews, and analysed qualitatively using systematic text condensation.

Results: Most of the participants managed to complete PG-SGA Short Form without problems. However, participant-related and questionnaire-related sources of misinterpretation were identified, possibly causing misinterpretations or wrong/missing answers. Participants either read too fast and skipped words, or they struggled to find response options that were suitable for covering their entire situation perfectly. The word 'normal' was perceived ambiguous, and the word 'only' limited the participants' possibility to accurately describe their food intake. Long recall periods in the questions and two-pieced response options made it difficult for patients to select only one option.

Conclusion: The results of this study provide a unique patient perspective of using PG-SGA Short Form and valuable input for future use and revisions of the form. The identified sources of misunderstanding could be used to develop a standardized instruction manual for patients and health care personnel using PG-SGA Short Form.

Keywords: Validation studies; nutrition assessment; qualitative research; patient involvement; patient reported outcome measures

Introduction

Patients living with cancer may have different nutritional challenges; early identification and treatment of malnutrition and disturbed metabolism are of critical importance. European Society for Clinical Nutrition and Metabolism (ESPEN) guidelines strongly recommend to screen for risk of malnutrition in all cancer patients and further perform a nutritional assessment in patients at risk to identify those who are malnourished.[1]

The Patient-Generated Subjective Global Assessment (PG-SGA) is well recognized in clinical research as the reference method for assessing nutrition status in patients with cancer,[2-10] and is a modified version of the nutritional assessment instrument Subjective Global Assessment (SGA).[11,12] The first part of PG-SGA is completed by the patients, and have been used as a screening instrument for nutritional risk/deficit and is referred to as PG-SGA Short Form.[8,13,14]

The PG-SGA (full and Short Form) has been validated on various levels. A high construct validity, ie sensitivity and specificity to predict nutritional status compared to a reference method, has been reported.[4,13] Numerous studies have shown PG-SGA's ability to predict clinical outcomes (predictive validity), such as survival,[6,13,15] postoperative complications[16] and reduced tolerance to chemotherapy.[17] A recent systematic review reported that PG-SGA (including Short Form) was among very few (four out of 37) instruments covering all the domains in the ESPEN and American Society for Parenteral and Enteral Nutrition (ASPEN) definition of malnutrition (content validity).[18]

Despite the extensive use and validation of PG-SGA, very little has been reported about the patients' perspective, ie about the way patients perceive, interpret, and respond to the items in

the patient-generated part constituting PG-SGA Short Form.[19] Validity of an instrument relies also on a common understanding of the meaning of the questions and the response options. Patients might interpret questions in different and unexpected ways, compared to what was intended.[20] Data gathered from self-report instruments are only useful to the extent that people make sense of the questions in the intended manner.[21] If a questionnaire fails to represent the patients' perspective, it may result in patients failing to complete the questionnaire properly and consequently a possible negative impact on the validity.[22]

Experiences from the use of PG-SGA Short Form in clinical trials have questioned how well it works with regard to patient use and understanding. Challenges regarding patients' understanding of the form were observed in a feasibility study of a multimodal intervention for cachexia[23] and in a cross-sectional study examining the prevalence of cachexia and areas of unmet need in patients with cancer.[24] Therefore, the aim of this study was to investigate how patients interpret the patient-generated part of PG-SGA.

Methods

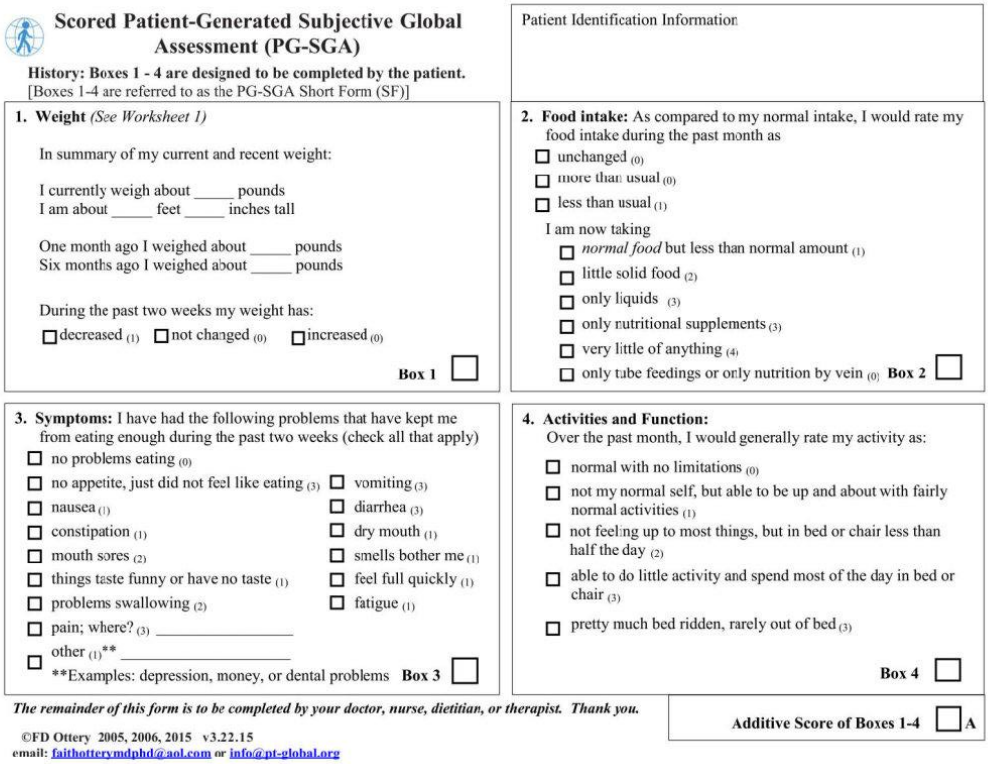
Ethics approval and participants

The Regional Committee for Medical and Health Research Ethics evaluated the protocol and concluded that no formal ethical approval was required for this study (Reference 2017/979 REK) since the study was not within the scope of the Norwegian Health Research Act. The study was therefore ethically approved by Norwegian Centre for Research Data (Reference 54934/3/STM) and the internal review board of the Cancer Clinic, St. Olavs hospital, Trondheim University hospital. Participants were recruited from the inpatient clinics at the Cancer Clinic, St. Olavs hospital, Trondheim University hospital between August and December 2017. All participants provided written informed consent. Purposive sampling was used to identify participants that during the last week had experienced weight loss and/or

reduced dietary intake and/or had a BMI<20.5 as identified by Nutrition Risk Screening 2002.[25] Inclusion criteria included a verified cancer diagnosis, 18 years or older, ability to understand Norwegian language and to provide written informed consent.

PG-SGA Short Form

The PG-SGA Short form (consisting of four text boxes), patients report on current and former body weight (Box 1); changes in food intake and current type of food/nutritional intake (Box 2); nutritional impact symptoms and other factors that negatively influence food intake/absorption/utilization of nutrients (Box 3); and activities and function based on Eastern Cooperative Oncology Group (ECOG) performance status,[26] converted to layman's language (Box 4)[14] (Figure 1). The PG-SGA Short Form numerical scoring range from 0 (no problems) to 36 (worst problem), whereof Box 1 has a maximum score of 5, Box 2 has a maximum score of 4, Box 3 has a maximum score of 24, and Box 4 has a maximum score of 3. Multiple answers where only one answer is intended (applies to all boxes) by eg ticking "no problems eating" in Box 3 in combination with other symptoms, the sum of problems scores are reported. The Norwegian version of PG-SGA Short form 155-004 v01.18.17 was used in this study.



Scored Patient-Generated Subjective Global Assessment (PG-SGA)

History: Boxes 1 - 4 are designed to be completed by the patient.
[Boxes 1-4 are referred to as the PG-SGA Short Form (SF)]

Patient Identification Information

1. Weight *(See Worksheet 1)*

In summary of my current and recent weight:

I currently weigh about _____ pounds
I am about _____ feet _____ inches tall

One month ago I weighed about _____ pounds
Six months ago I weighed about _____ pounds

During the past two weeks my weight has:
☐ decreased (1) ☐ not changed (0) ☐ increased (0)

Box 1 ☐

2. Food intake: As compared to my normal intake, I would rate my food intake during the past month as
☐ unchanged (0)
☐ more than usual (0)
☐ less than usual (1)

I am now taking
☐ *normal food* but less than normal amount (1)
☐ little solid food (2)
☐ only liquids (3)
☐ only nutritional supplements (3)
☐ very little of anything (4)
☐ only tube feedings or only nutrition by vein (0) **Box 2** ☐

3. Symptoms: I have had the following problems that have kept me from eating enough during the past two weeks (check all that apply)
☐ no problems eating (0)
☐ no appetite, just did not feel like eating (3)
☐ nausea (1)
☐ constipation (1)
☐ mouth sores (2)
☐ things taste funny or have no taste (1)
☐ problems swallowing (2)
☐ pain; where? (3) _____
☐ other (1)** _____
☐ vomiting (3)
☐ diarrhea (3)
☐ dry mouth (1)
☐ smells bother me (1)
☐ feel full quickly (1)
☐ fatigue (1)
**Examples: depression, money, or dental problems
Box 3 ☐

4. Activities and Function:
Over the past month, I would generally rate my activity as:
☐ normal with no limitations (0)
☐ not my normal self, but able to be up and about with fairly normal activities (1)
☐ not feeling up to most things, but in bed or chair less than half the day (2)
☐ able to do little activity and spend most of the day in bed or chair (3)
☐ pretty much bed ridden, rarely out of bed (3)

Box 4 ☐

The remainder of this form is to be completed by your doctor, nurse, dietitian, or therapist. Thank you.

Additive Score of Boxes 1-4 ☐ **A**

email: faithotterymdphd@aol.com or info@pt-global.org

Figure 1 English language version of the Patient-Generated Subjective Global Assessment (PG-SGA) Short Form

Data collection

A combination of observation, think-aloud technique and structured debriefing interviews was selected to identify how the patients interpreted the items in and layout of PG-SGA Short Form, and whether problems occurred during the completion.[27] Patients were asked to complete the PG-SGA Short Form and verbalize what they think while completing the form. Observation notes were taken based on a template with broad categories addressing how the participants navigate in the form; whether they read fast or slowly; misreadings; whether and where they hesitated before answering; and words that seemed of particular interest for the participant, or to cause problems or frustration. The categories were partly predefined based on previous research on participants' interpretation of self-reported questionnaires [28,29] and on empirical experience of patients' use of PG-SGA in clinical trials [23,24]. Also, any other

behavior of relevance was registered, which were the basis for also generating new categories of behavior during data collection. Whether patients read slowly or fast were based on the two researchers' subjective interpretations. After completing the form, the patients were interviewed based on a structured interview guide containing questions about the participants' subjective evaluation of the questions and response options, their choice of reading strategies, whether questions were found to be easy or difficult, and how they selected response options. The questions were repeated for each of the four sections of the form (Box 1–4). Additionally, observed patient behavior and/or patients' comments during the completion of the form were addressed in the interviews when relevant. The interviews were conducted by a nurse (CRSJ). Two researchers (one nurse (CRSJ) and one communication researcher (KS)) were present during each data collection session. Observations and interviews were audio recorded. Demographic and medical background data were collected from medical journals. Performance status was assessed using Karnofsky Performance Score (KPS).[30]

Data analysis

The audiotaped material was transcribed verbatim and combined with the observation notes before analysis. The analysis followed the principles of systematic text condensation,[31] which is a four-step procedure for analysis of qualitative data. A condensation approach implies to identify patterns and diversity within the participants' accounts, and not quantifications. The unit of analysis is experiences, not individuals.[32] First, two researchers (CRSJ and KS) read and reread transcriptions to obtain an overall impression of the material, and preliminary themes were identified inductively (eg "did not notice all the words", "selecting more than one response option", "assistance from family member", "negative thoughts", "changing their mind"). In the second step, units of meaning – ie all pieces of the transcripts of relevance for the research aim, in this case aspects of how patients filled in PG-SGA Short Form – were

identified. A detailed coding scheme was developed based on the preliminary themes, and all meaning units were coded by use of this. In the third step, the coded material was condensed into code groups (eg the codes “asked for help from family”, “asked what a word mean” and “asked for confirmation from researcher” were combined into the code group “did not want to do anything wrong”). The code groups were classified into two overall categories: participant-related and questionnaire-related sources of misinterpretation and associated sub themes (eg “reading fast and skipping words”, “the need to tell the whole story” as participant-related sub-categories and “imprecise words” and “two-pieced response options” as questionnaire-related sub-categories”). In the last step, the condensates were summarized and illustrative quotes were selected for all themes. The phases of developing preliminary themes, codes, sub-categories and categories were continuously reflected on and discussed between two researchers (CRSJ and KS). The researchers continuously returned to the original text to ensure that the core meaning was preserved.

Results

A total of 46 patients were approached, and of these 23 wanted to participate in the study. Twenty-two participants were in-patients and one was an out-patient. Eleven patients were included from the palliative care unit at the Cancer Clinic, eleven participants were included at the general oncology unit at the Cancer Clinic, and one was included from the Gastro surgery unit. All interviews took place at the hospital, either in patients’ rooms or in a conference room. None of the participants had filled in PG-SGA Short Form before their participation in this study. Patient characteristics and results from PG-SGA Short Form are presented in Table 1. Almost half of the patients (n=11, 48%) had gastric cancer and according to tumor staging, eight had local disease (35%), nine had locally advanced disease (39%) and six had metastatic disease (26%). All patients except one received anti-cancer

174 treatment, most commonly chemotherapy. Patients' performance status ranged from KPS 30–
175 90 whereof half of the group had KPS ≥ 70. Weight loss last six months reported in PG-SGA
176 showed a mean (SD) % weight loss (kg) of 10.6 (10.4) %, ranging from -13.0 % (increase in
177 weight) to 29.2 %. When calculating the score of PG-SGA Short Form, the median (IQR)
178 total score was 13 (8), ranging from 3 to 28 (Table 1). One patient had a score of 3, three
179 patients a score from 4 to 8 and the remaining 19 patients had a score ≥ 9. Six patients chose
180 more than one response in single response questions and/or no response at all in two or more
181 of the boxes, 11 chose more than one response in single response questions and/or no
182 response at all in one of the boxes, and the remaining five patients completed the form as
183 intended. More specifically, in Box 1 data regarded previous weight were missing, or
184 multiple responses on weight loss last two weeks were given; in Box 2 patients selected
185 several options when they were supposed to select only one item in their answer to 'I am
186 currently taking'; in Box 3 patients selected the option 'no problems eating' in combination
187 with several symptoms that had kept them from eating; and in Box 4 patients selected several
188 options about their level of activity and function when they were supposed to select only one.
189 One patient did not report body weight last month, and one did not report weight six months
190 ago, and therefore weight loss could not be calculated from those time points.
191
192 Table 1. Patient characteristics

Variables	**n =23**
Age, years, mean (SD)	64.4 (11.9)
Sex (n)	
Woman	9
The highest completed level of education (n)	
College/University	11
Secondary school/High school	11
Primary school	1
Year of diagnosis (n)	

2016 or 2017	16
Before 2016	7
Type of cancer (n)	
Digestive tract	11
Hematological	5
Lung	3
Bladder	2
Breast	1
Bone	1
Metastasis (n)	6
Present anti-cancer treatment (n)	
Ongoing chemotherapy	13
Ongoing radiotherapy	8
Other cancer therapy	8
Ongoing hormone therapy	5
No ongoing	1
Karnofsky performance score (n)	
30 *Almost completely bedfast*	2
40 *In bed more than 50% of the time*	3
50 *Requires considerable assistance and frequent medical care*	3
60 *Requires occasional assistance but is able to care for most of his needs*	3
70 *Cares for self; unable to carry on normal activity or to do active work*	8
80 *Normal activity with effort; some signs or symptoms of disease*	3
90 *Able to carry on normal activity; minor signs or symptoms*	2
Weight loss last six months (%), mean (SD)*	10.6 (10.4)
PG-SGA Short Form (total score, median (IQR))	13 (8)
Box 1 (weight and weight loss) (median (IQR) score)	4 (4)
Box 2 (food intake) (mean (SD) score)	2 (2)
Box 3 (nutritional impact symptoms) (median (IQR) score)	6 (7)
Box 4 (activities and function) (median (IQR) score)	2 (2)

n=number of participants; SD=standard deviation; PG-SGA=patient generated subjective global assessment; IQR= interquartile range; *n=22

Most of them had no problem filling in the form or understanding the words used in it. The mean (SD) time spent on the entire session (ie filling in PG-SGA Short Form while verbalizing their thoughts and participating in the interview) were 25 (10) minutes, ranging from 9.5 to 49.5 minutes. Thirteen of the participants read and filled in the form in the

intended order, ie starting with Box 1, going on to number 2, 3 and finally number 4, while ten filled in Box 3 before number 2, ie in a vertical direction.

Even if the form were perceived and evaluated by the patients as relatively easy and straightforward to complete, some sources of misinterpretation were identified causing participants to answer the questionnaire in an unintended manner, or for them to struggle finding sufficient response options. These sources of misinterpretation were categorized in two main categories: participant-related or as questionnaire-related.

Participant-related sources of misinterpretation

One reason for misreading or giving wrong answers, was that the patients read the questions and answered quickly. Box 1 asks about current weight and weight history, but most participants read neither headlines nor the question. They started right on the answer in the third line and wrote only their current weight. In boxes 2–4, most participants seemed to read the questions before they answered. However, during the subsequent interviews, it became apparent that several of them had not read the question or response options well enough. When they were asked specific questions about the content of the form, or how they selected their responses, they realized that they had neither noticed all the words in the questions nor in the response options, as the following quotes illustrates:

> *When I read it now, I find the question a little bit long. But I didn't think about it when I read it the first time. I didn´t notice it, because you only read every third word. But now that I had to go over each word, it turned out to be a long sentence* (Participant 22, man).

> *I had to go back, because I didn´t give a precise answer. I need to write 'Pain in left shoulder' here* (Participant 8, man).

Now I have to see if I have responded correctly, I started to think a little more (Participant 9, woman).

Some participants spend more time than others on completing PG-SGA Short Form because they strived to give precise answers covering their unique situation. They reported that they had to think thoroughly to understand the question and to find one correct answer. Often, they felt that more than one response option was needed to allow for a better description of their situation, such as one participant explained regarding the question about food intake in Box 2:

My food intake has changed because now I eat several and smaller meals. What do I do? 'More than usual'? 'Less than usual'? Perhaps I eat what I normally eat, but in smaller portions. In total, perhaps half the amount of food compared to what I usually would have eaten. What do I choose in order to get it correct? 'Less than usual'? 'More than usual'? You can't throw a dice, you know (Participant 18, man).

Thirteen of the patients selected more than one response option on questions in Box 1 (body weight and weight history), 2 (food intake) and 4 (activities and function). For instance, in Box 1, one participant checked off that his weight had both 'decreased' and 'increased' during the past two weeks.

I kind of had to read the question twice in order to figure out what suited best for me. And it was easier when I realized that I could select more than one option. But still, I was not able to illustrate my special situation. I think it is very special (Participant 12, man).

When participants had trouble selecting a response option, they often sought a confirmation of their choice from the researchers or from present family members:

I don't know if this is how you wanted me to answer this question? (Participant 7, man).

The content of the PG-SGA Short Form made some of the patients more aware of their body weight, reduced food intake and/or reduced level of activities, and this was observed to be distressing for them. Some of them became sad when they had to talk about their weight loss or reduced level of activity due to their disease.

Oh my God, I want to avoid this! [refers to question about weight loss]. The hardest thing is when you lose weight when you actually don't want to (Participant 13, woman).

When the form asked about aspects of the participant's situation, such as functional decline and weight loss, it was difficult for some patients to answer honestly. One participant, who had always been active, also as part of his work, found it very hard to admit that he had to select the last response option in Box 4: *'*Pretty much bed ridden, rarely out of bed*'*. In the interview, he hesitated before he commented:

I wish I could have selected 'able to do little activity and spend most of the day in bed or chair'. But to be honest, I have been lying in bed (Participant 16, man).

Questionnaire-related sources of misinterpretation

In general, the words used in PG-SGA Short Form were easy to understand for most participants. Still, it was difficult to interpret the meaning of some of the words as they were used in the form. The most frequent word causing misunderstandings was 'normal', used in phrases such as 'normal food' (Box 2 (food intake)) and 'not my normal self" (Box 4 (activities and function). The phrase 'normal food' was found to be ambiguous, since it could

refer to ‘the type food I normally eat’, ‘the amount of food I normally eat’, or ‘normal food in general / in my culture’.

> *‘Normal food’, is it hotdog, pizza, what is it?* (Participant 24, man).

> *I wonder if enteral nutrition is normal food, but I concluded that it isn’t* (Participant 5, woman).

In Box 2 (Food Intake), the second item consists of the heading ‘I am now taking’ followed by a list of six response options regarding nutritional intake (‘normal food but less than normal amount’; ‘little solid food’; ‘only liquids’; ‘only nutritional supplements’; ‘very little of anything’; ‘only tube feedings or only nutrition by vein’). The word ‘only’, used in four of the options, limited the participants’ possibility to convey what they wanted, since it prevented them from telling that they ingested both solid food and oral nutritional supplements. It was commented by some that they chose to ignore the word ‘only’ when they answered. One of the participants even drew a line through the word to delete it.

> *If it hadn’t said ‘only tube feedings’, if it had said ‘tube feeding or nutrition by vein’ as a response options for ‘I am now taking’, then it would be suitable for me. But when it says ‘only’, it doesn’t fit, because it is in combination with something else* (Participant 23, man).

In three of the four text boxes of PG-SGA, no instructions are given regarding how many options one is supposed to select, while in Box 3 (nutrition impact symptoms) it is stated that one is to ‘check all that apply’. When filling in the form, some participants asked the researcher to clarify how many options they were supposed to select. For some, it seemed to be regarded mandatory to select only one, indicating that this is how it is usually done, or this

is what they were most used to do filling in questionnaires in general, even if they felt that one option was not sufficient, as the following quote illustrates:

> *Although I do not see that it's written, you do not allow yourself to fill in more [than one option], it's not common* (Participant 3, woman).

The relatively long recall periods caused challenges for the participants. During the past month (the recall period used in Box 2 (food intake) and Box 4 (activities and function)), several of the participants had experienced variations that made it impossible for them to select only one response option. Consequently, some participants checked off for more than one option. The variations over a month could be so extensive that most of or all the response options were appropriate.

> *Yes, the last month, it feels like cycles. First, I don't eat much and then I eat a lot when I'm feeling better. During one month, it's really going through all phases from usable to good intake to minimal like intravenous* (Participant 17, man).

> *It changes daily, I choose two options, 'little solid food' and 'only liquids' because I eat bread in the morning and receive parenteral nutrition as well* (Participant 1, man).

Four of the five response options in Box 4 (activities and function) are two-pieced, for instance: 'not my normal self, but able to be up and about with fairly normal activities' or 'not feeling up to most things, but in bed or chair less than half of the day'. Consequently, half of one option and half of the other could be suitable, and consequently it was difficult to select only one.

> *But when it says that I 'spend less than half the day in bed or chair' that's correct [option 3], but I also feel familiar with option number two 'up and about with fairly normal activities'* (Participant 4, man).

Discussion

When participants in this study interpreted and used PG-SGA Short Form, most of them had no problem reading the questions and answering them. However, some sources of misinterpretation were identified. Many of the participants read and responded to the questions quickly. For some this resulted in failing to notice all the words, such as the recall period in the question or all the response options. Another source of misinterpretation was phrases participants found to be imprecise, such as 'normal food' or 'normal activity level'. More than half of the participants also selected more than one response option in questions where they were supposed to select only one. Reasons for this were that the recall periods were perceived as long that only one option did not capture the entire period, and that the options in Box 4 (activities and function) were too unspecific.

The challenges with long recall period in some of the questions in the PG-SGA Short Form raised the question of whether it would be easier for patients to relate to for example 'now' than 'past month'. However, in a previous study of the patient-rated instrument Edmonton Symptom Assessment Scale, in which the assessed time frame was 'now', it was found that this was not an unambiguous term that patients easily related to. Patients answered either how they felt yesterday or how they thought they would feel in the future. They experienced that the intensity of symptoms varied and if they answered how they were at the moment, then the situation could be different in the next moment.[28] The need to tell the whole story seems to be so important for patients that it is difficult to relate to predefined recall periods.

Many of participants in our study read too fast and ignored words. A possible consequence of this is that the form is not filled in as intended, and the results / total score could thus be

incorrect or misleading. There are different reasons for patients reading the questions inaccurately. Some of the participants were frail, malnourished, tired, sad, and/or had lack of concentration due to their disease and/or medication, which could make it difficult for them to read and answer all the questions properly. For others, however, answering questionnaires is familiar and an easy task, and they probably found it unnecessary to read thoroughly to be able to respond.

Patient responding to a questionnaire is not a neutral task where one just gives a mark and move on to the next question. When a patient answers a questionnaire, it involves a separate interaction between the patient and the questionnaire, which can start a thinking process, either for the better or for worse for the patient.[33] Answering a questionnaire can make the patient more aware of his/her situation, either positively or negatively. We observed that some patients became more aware of the negative aspects of their situation, and such negative thoughts may have affected their motivation for or ability to answer questions on such topics.

That the content of PG-SGA Short Form seemed to provoke negative thoughts among some of the participants, was something we were not sufficiently prepared for before the study started. For some, for example, it was hard to be reminded of how much weight they had lost, while others were very tired of a constant focus on food. In future similar studies, consideration should be given to whether participants should be offered a consultation with, for example clinical dietitian, nurse or doctor after participation.

Patients in this study were very eager to tell their own unique story and many experienced that it was not possible to tell it completely by use of PG-SGA Short Form in its current form. However, since questionnaires never could be individually customized for each patient, we

362 suggest, based on the results of this study, that a standardized manual for instruction to
363 patients is developed, addressing examples of what the healthcare provider and/or researchers
364 could explain to patients who are asked to fill in PG-SGA Short Form. Such a manual could
365 be useful as beforehand instructions and/or as assistance if patients want help during the
366 complementation.[34]

367 **Box 1**. Ideas for content in a PG-SGA instruction manual

It could be necessary to explain to the patient that:

- it is worthwhile to read the questions and options carefully before giving an answer since it has happened that someone has skipped important words;
- only one option is required if nothing else is stated;
- if he/she finds two options suitable, the healthcare professionals can assist in finding the one that represents the recall period best;
- if he/she selects two options, only the ”worst” counts in the calculation of total score;
- in Box 2, the word ‘normal food’ may be ambiguous, and healthcare professionals can explain what is meant.

368 In able to give these instructions to patients, the healthcare professionals need to have
369 sufficient knowledge of the form and to be familiar with the instrument’s use.

370

371 Due to advances in medical nutritional therapy, combination of treatments such parenteral
372 nutrition support in addition to using oral nutritional supplements and eating some food, is
373 more common. Such a treatment combination is difficult to express in when answering the
374 current question about food intake in PG-SGA (Box 2, second half), since you cannot express

a combination treatment by use of the current available response options. Therefore, PG-SGA should be amended and elaborated accordingly.

The present study is to our knowledge the first study to evaluate patients use and interpretation of PG-SGA Short Form, an under-researched field in development of nutritional screening and assessment instruments. A high number of patients were included in this qualitative study, which strengthen our findings. Combining observation with the think-aloud technique and interviews made it possible to obtain more detailed and complete data from the participants, than by using only retrospective debriefing interview. Nevertheless, this study had some limitations such as single-site inclusion, inclusion of a relatively frail cancer population predominantly included at inpatient units. Our results are not necessarily transferable to an outpatient population. Still, questionnaire-related sources of misinterpretation, such as the phrase "normal food" being ambiguous, could have been identified in outpatient population as well. ESPEN guidelines strongly recommend to screen for (risk of) malnutrition in patients with advanced cancer, thus it is essential to have a valid tool that fits all. In general, qualitative data are limited by the possibility for losing information and nuances when oral data are transcribed into written text, and also when translating quotes.

Conclusion

The PG-SGA Short Form was found to be easy to use and understand for the majority of the participants in this study. However, sources to misinterpretations were also identified, both participant-related and questionnaire-related sources. In order to reduce misinterpretation and missing/wrong answers when using PG-SGA, a standardized instruction manual could be used as guidance and training of patients and healthcare professionals. All future revisions of

PG-SGA Short Form should be based on regular patient involvement in order to maintain and increase comprehensibility and relevance of the form.

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Disclosure

All authors declare that they have no conflict of interests.

Authors' contributions

All authors designed the study. CRSJ and KS conducted the data collection, and analysed the data with assistance from TRB. TRB and KS wrote up the study with the support of CRSJ, AB, LT and TSS. All authors critically reviewed the article and approved its final version.

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