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Tailored communication for older patients with cancer: Using cluster analysis to identify patient profiles based on information needs



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ABSTRACT

Introduction: Understanding how information needs of older patients with cancer vary is essential for patient-centered communication. Little research has considered the potential complex patterns in information needs among older patients with cancer. This study aims to identify profiles of older patients with cancer based on differences in their information needs.

Materials and Methods: Two-hundred and twenty-three patients with cancer and survivors aged 70 years or older completed an online survey. Based on an extensive scoping review, we included measures on information needs (i.e., monitoring coping style and type of information needs as measured with QUOTE) and related factors (i.e., psychological distress, ability, motivation, participation in decision making, and demographics). Profiles were identified using *k*-means cluster analysis.

Results: Analysis revealed three profiles of older patients with cancer exhibiting differences in monitoring coping style and type of information needs: the so-called “information seeker” (38.8%), the “listener” (47.2%), and the “information avoider” (14.0%). Besides differences in information needs, the profiles differed on psychological distress (i.e., intrusive thinking, cancer worry, and intolerance of uncertainty), ability (i.e., self-efficacy in interaction with physician), and motivation (i.e., information goals and future time perspective).

Discussion: Our findings revealed a nuanced perspective to information needs of older patients with cancer by combining two measurements of information needs with factors contributing to these needs. Clinicians could use these results to increase their awareness of the complexity and heterogeneity of information needs in older patients with cancer and to tailor their information to the needs of older patients.

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1. Introduction

Providing information to patients suffering from cancer is essential for delivering high quality care [1]. Fulfilling patients' need for information is key for informed decision making, coping with illness, and managing the disease in daily life [2]. This may be even more true for older (70+) patients as they often deal with multiple diseases at the same time [3]. However, age-related changes – such as cognitive and sensory decline – often complicate cancer communication, making older patients at risk for poor communication with health providers [4]. Thereby, within the older patient population, there is a lot of variation in the amount as well as in the type of information preferred, making it difficult for clinicians to adapt their communication to older patients' specific needs, often resulting in high amounts of unmet information needs [5,6]. As the world population is rapidly aging [3], there is an

urgent need to invest in enhancing our knowledge of individual differences in information needs of older patients with cancer to guide high-quality information provision that aim to reduce unmet information needs and improve health outcomes.

One effective approach to take individual differences into account in clinical encounters is tailoring. Tailoring refers to creating communications individualized for their receivers, with the expectation that this individualization will lead to larger intended communication effects [7]. Although interpersonal interactions between two individuals have the potential to be tailored, older patients with cancer often have unmet information needs after having had a consultation with their health care provider [5,6]. One explanation for this could be that older patients with cancer run the risk of being treated as a homogenous group due to age stigma or stereotypes associated with aging [8]. Although research suggests that they in fact have very heterogeneous information needs [5], there is little understanding of what these information needs precisely look like and how this information can be used by clinicians to adapt their information provision in a relatively easy way.

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The current study combines two approaches to increase our understanding of older patients' information needs and how to translate these to tailored communication. First, we enhance and nuance our knowledge about older patients' information needs by focusing on two related, yet distinct concepts of information needs: monitoring coping style and type of information needs. In dealing with potentially threatening information, such as being diagnosed with cancer, patients can differ in their coping style. Actively seeking for information as a way of coping is referred to as monitoring coping style, i.e., the tendency to seek threat-relevant information. In contrast, low monitors refrain from engaging in information seeking behavior [9]. Although monitoring coping style provides an interesting distinction between those seeking for and those avoiding information, it does not yet explain what type of information older patients with these coping styles need to cope with illness. We therefore combine monitoring coping style and type of information needs to provide a better, more comprehensive understanding of the information needs of older patients with cancer.

Second, this study enhances our understanding of how to translate older patients' information needs to tailored communication by exploring factors related to older patients' information needs. Research on such potential predictors of information needs in older patients with cancer is scarce [6], while insight therein is exactly what can help to reduce unmet needs. If we can identify different types of older patients with cancer based on their information needs and other related characteristics, such as their degree of psychological distress [10], ability and motivation to seek information [11], participation in medical decision making [12], and their demographics [13], we can create potentially effective tools for clinicians to adapt their communication to older patients with cancer.

Therefore, this paper aims at shedding a new light on older patients' information needs by truly considering the heterogeneity in their needs and preferences with regard to information about cancer. To do so, this study will (1) identify different profiles of older patients with cancer based on their information needs, and (2) examine differences among these information need profiles in terms of associated factors. With our results, we aim to contribute to better cluster the information needs of older patients, which can be used as a starting point for clinicians to tailor their medical consultations.

2. Materials and Methods

2.1. Participants and Procedure

The study protocol was approved by the institutional review board of the University of Amsterdam (reference number: 2015-CW-66) and meets the requirements for protection of human subjects. Patients with cancer and survivors aged 70 years or older were recruited via the online panel company FlyCatcher. Due to its length, the online survey was divided in two parts.

2.2. Measures of Information Needs

2.2.1. Monitoring Coping Style

An adapted version of the shortened validated Threatening Medical Situation Inventory (TMSI) was used to measure the participants' monitoring coping style [14,15]. Participants were asked to indicate the extent to which three items were applicable to them when they learned that they were diagnosed with cancer. These were assessed on a 5-point scale (1 = "not at all applicable to me," 5 = "strongly applicable to me"). Items included: "I planned to read as much as possible about my disease" (Cronbach's $\alpha = 0.85$).

2.2.2. Type of Information Needs

The type of information preferred was assessed by looking at cancer-specific issues and generic issues, using a 37-item adapted version of the validated Quality Of care Through the patients' Eyes (QUOTE) importance questionnaire [16,17]. This questionnaire was originally developed to measure the information needs of patients with cancer regarding chemotherapy, but was adapted to general cancer-related information needs for this and earlier studies. This questionnaire assesses how significant information about a specific health care aspect is to patients with cancer. Patients rated the extent to which they considered cancer-specific and generic issues important on a 4-point scale (1 = "not important," 2 = "fairly important," 3 = "important," 4 = "very important"). Table 1 offers an overview of all information needs subscales and Cronbach's α measures.

Table 1
Description and internal consistency of the monitoring coping style and QUOTE constructs (cancer-specific and generic issues).

Construct	Number of items	Content	Cronbach's alpha	Mean (SD)
Monitoring coping style	3	Planning to start reading about cancer; determining to inform oneself about cancer; planning to ask questions to a specialist.	0.85	3.52 (1.00)
Cancer-specific issues				
Disease and diagnostic test-related information	5	Diagnosis; purpose and results of diagnostic tests; logistic information, tests and procedures; cancer staging.	0.86	3.51 (0.49)
Treatment-related information	7	Purpose of treatment; side effects; when to report side effects; how providers can reduce side effects; expected result of treatment; physical effects of treatment; adequate information about how treatment works.	0.90	3.49 (0.48)
Prognosis information	3	Realistic expectations: life span or survival rate; effect on life plan or long-term goals in the future; outcome if no treatment.	0.84	3.42 (0.62)
Daily life information	5	Preventing and reducing side effects; influence cancer on daily life; influence of treatment (e.g., fatigue); influence of treatment on sexuality.	0.88	3.11 (0.69)
Generic issues				
Coping information	4	Worries and fear; emotional reactions; community counseling or support; support from other patients or support groups.	0.87	2.90 (0.79)
Interpersonal communication	3	Effect of treatment on significant others, i.e., family members or friends; attention to (questions of) significant others; discuss how significant others can support patient.	0.88	3.02 (0.80)
Tailored communication	5	Knowledge of and adaptation to patients' personal situation and preferences.	0.84	3.05 (0.67)
Affective communication	5	Empathizing, giving attention and emotional support; listening; inviting to express concerns.	0.83	3.10 (0.59)

Note. Higher means indicate higher information needs. Monitoring coping style ranges from 1 to 5, QUOTE constructs on cancer-specific issues and generic issues range from 1 to 4.

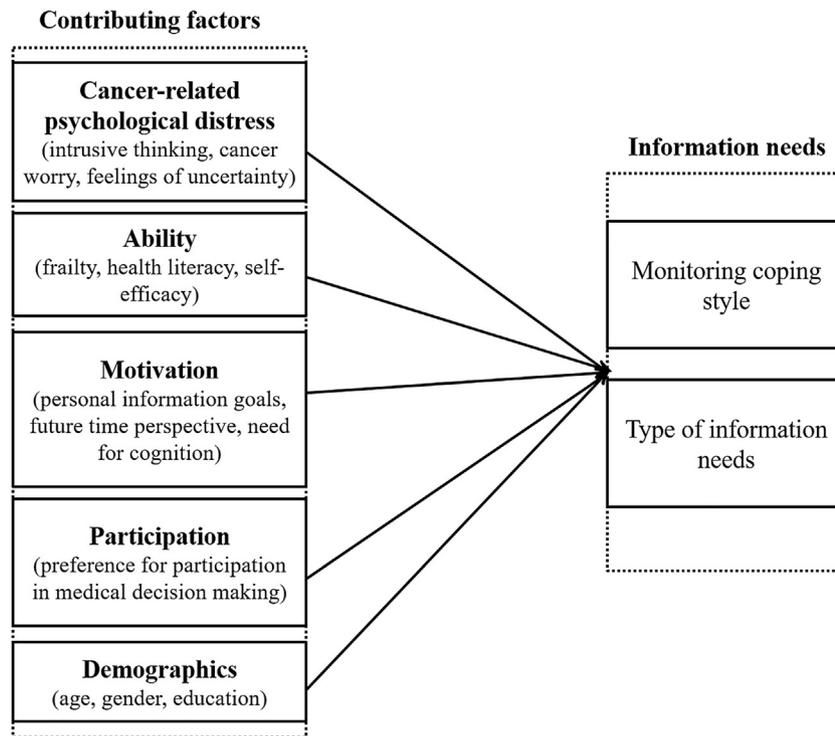


Fig. 1. Conceptual model of older patients' information needs and their contributing factors.

2.3. Measures of Factors Associated with Information Needs

Based on an extensive scoping review, we identified several relevant factors that might be associated with information needs of older patients with cancer (see Fig. 1). Their measurements are described below.

2.3.1. Cancer-Related Psychological Distress

Cancer-related psychological distress has been associated with information needs [10], and was measured by three concepts: intrusive thinking, cancer worry, and intolerance of uncertainty. Intrusive thinking was measured using the 7-item Impact of Events Scale (IES) [18], e.g., “I thought about the cancer when I didn't mean to,” using a 4-point scale (ranging from 0 = “not at all,” 1 = “rarely,” 3 = “sometimes,” and 5 = “often,” Cronbach's $\alpha = 0.91$). Cancer worry was measured with 6 items of the cancer worry scale [19], e.g., “How often have you thought about your chances of getting cancer (again)?”, assessed on a 4-point scale where higher scores indicated more cancer worry (Cronbach's $\alpha = 0.88$). To measure intolerance of uncertainty a shortened Dutch version of the Intolerance of Uncertainty Scale (IUS) was used (12 items) [20,21], including “Unforeseen events upset me greatly,” measured on a 5-point scale (1 = “strongly disagree,” 5 = “strongly agree,” Cronbach's $\alpha = 0.90$).

2.3.2. Ability

To assess how well patients were able to engage in information gathering and processing activities, we assessed patients' frailty, health literacy, and self-efficacy in interacting with physicians. Frailty in the physical, cognitive, social, and psychosocial domain was assessed using the Groningen Frailty Indicator (GFI) [22]. Scores range between 0 and 15, where higher scores indicate higher levels of frailty. Functional health literacy was measured with the SAHL-D [23], consisting of 22 health-related words, such as palliative, adrenaline, and schizophrenia, of which the correct meaning could be selected out of four multiple choice options, including the answer option “I don't know.” One point was allocated for each correct answer (range 0 to 22). Patients' perceived self-efficacy in interacting with physicians was measured with

the PEPPi-5 [24], and included 5 items beginning with “How confident are you in your ability to...” followed by, e.g., “know what questions to ask your doctor?” (rated on a 5-point scale: 1 = “not at all confident,” 5 = “very confident,” Cronbach's $\alpha = 0.94$).

2.3.3. Motivation

We measured whether patients were motivated to engage in knowledge acquisition about their cancer with three concepts: information goals, future time perspective, and need for cognition (i.e., the tendency to which an individual is intrinsically motivated to engage in effortful information processing [25]). Information goals were assessed by 4 items, such as “My goal is to better understand my illness and treatment,” [26] to be scored on 5-point scales (1 = “not at all true,” 5 = “completely true,” Cronbach's $\alpha = 0.93$). Future time perspective was measured by the Future Time Perspective (FTP) scale that consisted of ten items, such as “As I get older, I begin to experience that time is limited” (7-point Likert scale with 1 = “not at all true,” 7 = “very much true,” Cronbach's $\alpha = 0.90$) [27]. Higher scores indicate more perceived time left in life. Need for cognition was assessed by a shortened version of the Need for Cognition (NFC) scale [25], and included items such as “I like to have the responsibility of handling a situation that requires a lot of thinking” (7-point scale with 1 = “strongly disagree,” 7 = “strongly agree,” Cronbach's $\alpha = 0.66$).

2.3.4. Preference for Participation in Decision Making

The Control Preferences Scale (CPS) was used to assess patients' role preferences in medical decision-making [28]. Patients were able to indicate whether they preferred an active role (e.g., “I prefer to make the final selection about which treatment I will receive”), collaborative role (i.e., “I prefer that my doctor and I share responsibility for deciding which treatment is best for best”), or a passive role (e.g., “I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion”) by picking one of five options presented.

2.3.5. Demographics

Sociodemographic characteristics included age, gender and education level.

2.4. Statistical Analysis

A *k*-means cluster analysis was used as a statistical method to identify patients that are similar to each other with regard to specific characteristics, but different from patients in other groups [29]. Patients' scores on their information needs (i.e., monitoring coping style and QUOTE measures) were standardized and used as clustering variables. Patients with mean scores deviating more than 3 standard deviations from the sample average (*z*-scores above +3 and below -3) were not considered in the cluster analysis, since *k*-means clustering is very sensitive to outliers [29]. Three-, four-, and five-cluster solutions were investigated with regard to their interpretability. To compare the cluster solutions, one-way analyses of variance (ANOVAs) with Tukey's post hoc comparisons were conducted to compare clusters on cancer-related psychological distress, ability, motivation, and demographic. Chi-square tests were used to compare clusters on preference for participation in decision making, gender, and educational level. Data were analyzed using SPSS version 24 (SPSS, Inc., Chicago, IL).

3. Results

3.1. Respondents

A total sample of 4478 people aged 70 years or older were approached, of which 1145 responded to the survey invitation (response part I = 25.6%). Of those, 263 respondents were eligible (i.e., had been diagnosed with cancer), and completed the first part of the survey assessing demographic characteristic, patients' information needs (i.e., monitoring coping style and type of information needs), and the first contributing factors (i.e., frailty, information goals, self-efficacy, preference for participation in medical decision-making). After one week, part II of the survey continued with measures of the following contributing factors: intrusive thinking, cancer worry, future time perspective, uncertainty intolerance, need for cognition, health literacy. In total, 223 respondents with an average age of 74 years (SD = 3.81) fully completed both surveys (response part II = 84.8%). Men were slightly overrepresented (63.1%), and almost half of the respondents reported a low level of education (46.7%).

3.2. Clusters of patients' Information Needs

K-means cluster analysis identified a three-cluster solution that provided the best theoretical fit. The identified clusters differed in their monitoring coping style and the type of information preferred. The first cluster comprised 38.8% of the patient sample (*n* = 83), and included those characterized by relatively high levels of information needs (both in terms of monitoring coping style and type of information needs). We labeled this cluster 'information seekers'. The second and largest cluster included 47.2% of the patients in the study sample (*n* = 101). Patients in this cluster also had a high need for information based on monitoring coping style, but had a lower need for information based on type of information, i.e., attributing less importance to specific information topics. We labeled this patient group 'listeners'. The third cluster comprised the minority of older patients with cancer in this study sample (*n* = 30, 14.0%). Patients in this cluster reported relatively low information needs (both in terms of amount and type of information), and were labeled 'information avoiders'. Fig. 2 provides a visualization of the three patient clusters.

3.3. Differences in Patient Profiles Based on Factors Associated with Information Needs

To address our second aim – that is, to better understand the composition of the three-cluster solution – we compared the subgroups on the different predictors, i.e., cancer-related psychological distress, ability, motivation, preference for participation in decision making, and demographics. Table 2 presents an overview of the differences between patient clusters.

With regard to *cancer-related psychological distress*, we found significant differences between patient clusters on intrusive thinking, cancer worry, and intolerance of uncertainty. Patients in cluster one ("information seekers") indicated relatively higher levels of intrusive thinking (*p* = .003), cancer worry (*p* = .001), and intolerance of uncertainty (*p* = .022) compared to patients in cluster three ("information avoiders"). Patients in cluster two ("listeners") also reported higher levels of cancer worry compared to patients in cluster three (*p* = .007).

Our analyses did not reveal any cluster differences with regard to *ability* (i.e., frailty, health literacy). The clusters, however, differed on perceived self-efficacy, such that patients in cluster one felt more self-efficacious in interacting with physicians than patients in cluster two (*p* = .040) and three (*p* = .001).

With respect to *motivation*, patients in cluster one and patients in cluster two significantly differed from patients in cluster three in terms of information goals. Patients in clusters one and two reported

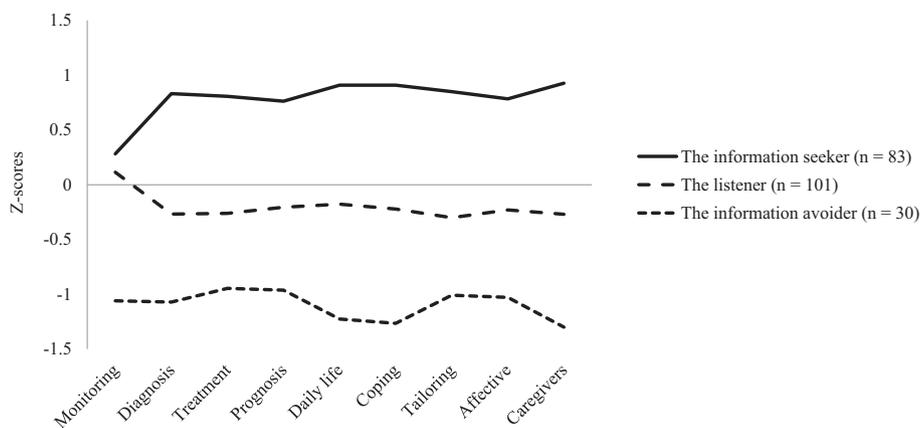


Fig. 2. Patient profiles for the three clusters identified within the three-cluster solution. The x-axis indicates the different information needs categories (i.e., monitoring coping style and type of information as measured by QUOTE). The y-axis indicates whether patient clusters scored relatively higher (above 0) or lower (below 0) on information needs compared to other clusters.

Table 2
Comparison of the three-cluster solution on cancer-related psychosocial distress, ability, motivation, preference for participation in decision making, and demographics ($N = 214$).

	The information seeker ($n = 83$)	The listener ($n = 101$)	The information avoider ($n = 30$)	F-test/Chi-square (df), p-value
Cancer-related psychosocial distress				
Intrusive thinking, M (SD)	16.37 (9.13) ^{a**}	14.24 (8.26) ^{ab}	10.27 (8.62) ^b	5.58 (2, 211), $p = .004$
Cancer worry, M (SD)	11.77 (3.61) ^{a***}	11.35 (3.63) ^{a**}	9.13 (2.60) ^b	6.43 (2, 211), $p = .002$
Intolerance of uncertainty, M (SD)	35.64 (7.43) ^{a*}	34.10 (7.69) ^{ab}	31.37 (6.90) ^b	3.67 (2, 211), $p = .027$
Ability				
Frailty, M (SD)	2.73 (2.18) ^a	3.06 (2.29) ^a	2.63 (2.22) ^a	0.68 (2, 211), $p = .508$
Health literacy, M (SD)	16.05 (4.31) ^a	15.76 (4.02) ^a	16.23 (4.52) ^a	0.19 (2, 211), $p = .827$
Self-efficacy, M (SD)	4.17 (0.75) ^a	3.92 (0.68) ^{b*}	3.65 (0.58) ^{b**}	7.03 (2, 211), $p = .001$
Motivation				
Information goals, M (SD)	4.04 (0.72) ^{a***}	3.77 (0.92) ^{a***}	2.84 (0.97) ^b	21.72 (2, 211), $p < .001$
Future time perspective, M (SD)	4.37 (1.08) ^{a***}	3.69 (1.15) ^b	4.00 (1.17) ^{ab}	8.36 (2, 211), $p < .001$
Need for cognition, M (SD)	4.06 (0.69) ^a	4.22 (0.74) ^a	3.89 (0.82) ^a	2.60 (2, 211), $p = .077$
Participation				
Preference for participation in decision-making				3.14 (4), $p = .535$
Active role, n (%)	12 (14.5) ^a	7 (6.9) ^a	3 (10.0) ^a	
Collaborative role, n (%)	49 (59.0) ^a	64 (63.4) ^a	17 (56.7) ^a	
Passive role, n (%)	22 (26.5) ^a	30 (29.7) ^a	10 (33.3) ^a	
Demographics				
Age, M (SD)	73.51 (3.35) ^a	74.44 (4.30) ^a	73.80 (3.16) ^a	1.40 (2, 211), $p = .249$
Gender (male), n (%)	47 (56.6) ^a	68 (67.3) ^a	20 (66.7) ^a	2.43 (2), $p = .296$
Educational level				3.50 (4), $p = .479$
Low, n (%)	45 (54.2) ^a	41 (40.6) ^a	14 (46.7) ^a	
Middle, n (%)	16 (19.3) ^a	24 (23.8) ^a	6 (20.0) ^a	
High, n (%)	22 (26.5) ^a	36 (35.6) ^a	10 (33.3) ^a	

Note. Differing superscripts indicate significantly different mean scores within a row. Chi-square statistics are reported for role preferences in medical decision-making, gender, and education levels. For all other factors, F-statistics are reported.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

being more engaged in information goals than patients in cluster three ($p < .001$). We also found cluster differences in terms of future time perspective. Patients in cluster one perceived relatively more time left in life than patients in cluster two ($p < .001$). No differences were found for need for cognition.

Furthermore, with regard to *preference for participation in decision making*, there were no differences between patient clusters in preferring an active, collaborative, or passive role in medical decision-making.

Last, with respect to *demographics* (i.e., age, gender, education level) our analyses did not reveal any cluster differences.

4. Discussion

This study used cluster analysis to provide a better understanding of cancer-related information needs among older patients with cancer, thereby considering the heterogeneity in their needs and preferences. With this approach, we identified three profiles of older patients with cancer based on their information needs and differences among these profiles in terms of several related factors. Besides the well-known “information seeker,” characterized by high levels of information needs, and “information avoider,” characterized by low information needs, a third group appeared to be the largest group within our sample of older patients with cancer, that is the “listener.” This group presented a somewhat different pattern: although characterized by a high monitoring coping style, patients in this group showed at the same time lower perceived importance for the different cancer-related information topics as compared to the “information seeker.” Whereas earlier research has described the distinction between monitoring coping style (i.e., information seeking) and blunting coping style (i.e., information avoiding) [14], our study suggests an important third group (the “listeners”), which nuances our understanding of older patients’ information needs. This group has, as far as we are aware, not been identified in the literature before.

The three information need profiles differed on several related factors, which contribute to better grasp these profiles and thus help to better understand where clinicians could start to tailor their medical interactions with different types of older patients. Important differences between “information seekers,” “listeners,” and “information avoiders” mainly concerned those in terms of psychological distress and motivation. More specifically, the “information seeker” generally experienced higher levels of intrusive thinking, cancer worry, and intolerance of uncertainty than the “information avoider,” while at the same time reporting higher self-efficacy in interacting with a physician compared to the “listener” and “information avoider.” These characteristics pose important implications for clinical practice.

4.1. Clinical Implications

This research points to some fruitful directions for clinical practice. The results of this study can be used by oncology nurses and physicians to increase their awareness of the complexity and heterogeneity of information needs among older patients with cancer. Importantly, it can support clinicians during consultation to explore the different information needs patients have, and to adapt the information provision accordingly.

In light of this, we developed communication advises based on previous research that can be used to understand the different profiles and corresponding information needs, and to tailor communication accordingly.¹ In these one-page paper sheet communication advises, we offer clinicians a brief overview of the patient profiles’ characteristics to encourage clinicians to use these profiles as a starting point to tailor information. When clinicians encounter a possible “information seeker,” it is important to address these patients’ possible concerns, as these concerns might be responsible for patients’ above-average need for

¹ More information about this tool can be obtained from the first author upon request.

information [10]. As “information seekers” cope with their concerns by seeking for information, it is important that clinicians help such patients to prioritize information. Moreover, “information seekers” have difficulty dealing with uncertainty. Although uncertainty is intrinsic to the medical setting and cannot be fully reduced, it is important that clinicians focus on the challenging task of focusing less on information per se and more on how to assist patients in managing uncertainty [30].

When encountering a possible “listener,” we advise clinicians to encourage patients to ask questions, as these patients might have difficulties expressing questions and concerns and might not be active participators during consultations. Similar to the “information seeker,” patients’ information needs can be the result of concerns. However, different from the “information seeker,” the “listener” might be probed more to be actively involved during the consultation. Responding to patients’ emotions could be a way to engage them and improve consultation outcomes, such as information recall [31]. Therefore, it is important to discuss the possible concerns patients have, even if the patient does not express these spontaneously.

Last, when encountering a possible “information avoider,” we advise clinicians to discuss the main points as this type of patient scored low on information needs. Providing additional information to those who prefer little information could feel overwhelmed and recall less of the information presented by their doctor [32]. Additionally, it is important to structure the consultation and to be clear about the aim of the consultation to help the patient gain a clear focus. As these patients perceive difficulties expressing themselves and participating during a consultation, it is important to encourage the patient to be involved in the decision-making process.

4.2. Study Limitations

One of the limitations of this study is that the results of the cluster analysis are dependent on interpretation, the sample size and composition, and statistical cluster approach. Although the validity of our cluster solution was theoretically plausible, it could be that the cluster solution might represent this sample only. As we limited our study to including patients with cancer aged 70 years or older, we lack knowledge on whether the three profiles would also be represented in different (cancer) patient populations. It would be interesting to include younger patients to explore if other profiles exist that were not present in our sample. Additionally, it is important to note that the different profiles scored high or low relative to the other profiles. This does not necessarily mean that certain profiles have extremely high or low scores on information needs and the contributing factors. Nevertheless, this study extends previous research by combining two approaches of measuring patients’ information needs, which presents a unique and more nuanced perspective on how much and what type of information older patients with cancer need.

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Author Contributions

NB Study concept and design, data collection and analysis, manuscript preparation and editing; AL Study concept and design, data collection, manuscript preparation and editing; ES Study concept and design; manuscript review; MV Data analysis and interpretation; JvW Study concept and design, manuscript editing and review.

Declaration of Competing Interest

None declared.

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