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## Patient participation during oncological encounters: barriers and need for supportive interventions experienced by elderly cancer patients

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### ABSTRACT

**Objective:** To enhance patient participation during (oncological) encounters, this study aims to gain insight into communication barriers and supportive interventions experienced by elderly patients with cancer.

**Method:** A mixed method design, including both quantitative (secondary survey data analysis) and qualitative (interviews) methods. Survey data were used to identify communication barriers and need for supportive interventions of elderly cancer patients, compared to younger patients. Next, interviews provided in-depth insight into elderly patients' experiences and underlying mechanisms.

**Results:** A majority of the 70 participating elderly cancer patients (53%) felt confident in communicating and participating during medical encounters. However, 47% of patients experienced barriers to effectively communicate with their healthcare provider and felt the need for supportive interventions. The 14 interviewed patients mentioned barriers and facilitators related to attributes of themselves (e.g. feeling sick, self-efficacy), the provider (e.g. taking patient seriously) and the healthcare system (e.g. time constraints).

**Conclusions:** Although many elderly cancer patients feel confident, offering support to patients who feel less confident in communicating with their provider is recommended.

Practice implications: The outcomes of this study can be used as a first step for developing interventions for elderly cancer patients to overcome communication barriers, and help providers to facilitate this process.

## 1. INTRODUCTION

Patient participation during (oncological) encounters is beneficial for both patients and providers. It can lead to more patient satisfaction, more informational and emotional need fulfilment and more effective information exchange [1-3]. However, research shows that communication and participation within (oncology) encounters are not optimal; information provision is often not tailored to patients' needs [4], providers have difficulty implementing shared decision-making [5] and patients' emotional concerns often remain unnoticed [6]. While many patients prefer an active role, their actual contribution during consultations is often limited [7]. This is especially true for elderly cancer patients, as they have difficulty expressing their informational needs or preferences, ask fewer questions and show less active behaviour than younger patients [8-11]. Compared to younger patients, communication with elderly cancer patients is also more challenging because of cognitive (memory), sensory (vision and hearing loss), mental (resilience, loneliness), social (smaller network) and functional (co-morbidity, performing daily activities) decline [12-14]. As cancer is frequently a disease of elderly people (i.e. more than 60% is 65 years or older [15]), it is advocated on a European level that "older people should be encouraged to express themselves and should get more opportunities to communicate" [16]. In order to speed this development we first need to get insight into the barriers which older cancer patients experience in their communication with their healthcare provider (HCP). Currently, there is a gap of knowledge with respect to this topic. Previous studies on this topic do not focus specifically on elderly cancer patients [e.g.17-20]. This study aims to gain insight into the communication barriers, facilitators and need for supportive interventions experienced by elderly cancer patients.

## 2. METHOD

### Design

A mixed methods design was chosen [21]; both quantitative (secondary survey data analysis) and qualitative (interviews) methods were used. The survey provided the starting point, whereas the subsequent interviews provided in-depth insight into patients' experiences and underlying mechanisms [22]. The quantitative and qualitative study include two different patient samples. However, both samples include Dutch patients with a cancer diagnoses of 65 years and older. Similar questions were asked to patients in both samples.

### Quantitative study

#### *Participants*

Secondary analysis was performed on data resulting from a survey study conducted by Henselmans et al. [23] including 1314 chronically ill patients who participated in the National Panel of people with Chronic illness or Disability (NPCD) [24]. For the secondary analysis a selection was made of all adult patients with cancer (n=126), of which 70 elderly ( $\geq 65$  years) and 56 younger patients (18-65 years), to allow for a comparison on age.

### *Recruitment*

Patients were recruited for the NPCD from a random sample of general practices drawn from the Netherlands registration of general practice. Eligible patients (inclusion criteria:  $>15$  years; diagnosis of a somatic chronic disease; being non-institutionalized; not being terminally ill; being aware of the diagnosis; being mentally able to participate and sufficient mastering of Dutch) were invited by their GP to fill out questionnaires twice a year. The NPCD is a representative sample of the non-institutionalized Dutch chronically ill population [24]. The NPCD is registered with the Dutch data Protection Authority. For more details about the panel and survey, see [23,24].

### *Procedure*

Respondents were asked about their perceived barriers in their communication with their main HCP. The barriers were introduced with: "I sometimes find it difficult to say something in a conversation with my care provider, because...". They could choose from seventeen perceived barriers, by answering 'yes' or 'no' or add another experienced barrier. Barriers included emotions, skills, values and beliefs (Table 1). The list of perceived barriers was created based on previous studies [19,25] and literature research [26,27]. Next, patients were asked about their interest in communication support. A list of seven possible supportive interventions was generated, based on previous studies and literature research [19,25]. By answering 'yes' or 'no' to "I would benefit from...." participants could choose from possible supportive interventions such as 'having a list of questions' or 'video-modelling' (Table 2).

### *Data analysis*

Patients' background characteristics, perceived barriers and need for supportive interventions were described using descriptive statistical techniques (e.g. frequencies, mean, SD). Differences between elderly and younger cancer patients were tested with Pearson's Chi<sup>2</sup>. Data were analysed using STATA 13 (2013).

## **Qualitative study**

### *Participants*

Patients ( $\geq 65$  years) who were being treated or controlled for cancer (irrespective of tumour type) were included. Patients in the diagnostic or palliative phase and patients who did not master the Dutch language were excluded.

### *Recruitment*

Patients were recruited through the patient organisation 'NFK' by email. Fifteen patients initially responded to the invitation. To recruit a diverse patient sample (i.e. more female patients) we asked oncological HCPs representing three hospitals to invite eligible female patients; these attempts failed.

The number of participants eventually invited for an in-depth interview was based on thematic saturation, defined beforehand as when the final three patient interviews generated no new topics [28]. We first invited 6, then 5 and then the final 4 patients out of the 15 (one of these 4 dropped out). The final 3 interviews yielded no new themes. Interviews took place in May and June 2015, at patients' home, at the office of NIVEL (Netherlands institute for health services research) or in a public place, as preferred by the patient.

### *Procedure*

Semi-structured face-to-face interviews with patients were conducted by one researcher (JN). Patients were invited to bring a companion and their informed consent was obtained to audio-record the interview. The interview scheme contained three main themes: needs, barriers and supportive interventions regarding the communication with oncological HCPs. In addition, questions were asked about their experiences and participatory role during consultations.

Approximately one week prior to the interview, patients were sent a short questionnaire. Apart from questions about patients' background they were asked about their perceived barriers in their communication with their oncologist or nurse, with the same questions as used in the quantitative study. Patients could select the barrier(s) which applied to their situation and could add other barriers.

### *Data analysis*

The interviews were transcribed verbatim and were coded by one researcher in MAXQDA11 (JV). Concepts and themes were discussed with three other researchers (JD, SvD & JN) and in case of differences agreement was reached by discussion. Interviews were 'openly coded'; initial codes were given to fragments in the transcripts. By reviewing the interviews several times, codes were developed into concepts ('axial coding'). Concepts were developed based on the frequency of patients' quotes.

The main themes that were derived from the interviews were barriers and supportive interventions or facilitators related to 'the patient', 'the provider' and 'the healthcare system'. Some overlap and interactions between themes exist (e.g. 'taking time' can be related to the provider as well as related to the system).

### 3. RESULTS

#### Characteristics of survey participants

Seventy elderly cancer patients ( $\geq 65$  years) participated, with an average age of 74 years, 59% was male and 79% suffered from comorbidity. Most patients were diagnosed with prostate cancer (36%), followed by breast cancer (19%). 52% of the patients reported that the medical specialist was their main HCP, 35% their general practitioner and 13% a nurse. Illness duration was on average 10.6 years (31% 1-5 years ill, 56% 5-15 years and 13%  $>15$  years). Younger cancer patients ( $n=56$ ,  $<65$  years) were on average 56 years, 39% was male and 63% suffered from comorbidity. Most patients were diagnosed with breast cancer (32%), followed by colon cancer (14%). 74% of the patients reported that the medical specialist was their main HCP, 17% their general practitioner and 9% a nurse. Illness duration was on average 10.7 years (36% 1-5 years ill, 43% 5-15 years and 21%  $>15$  years). The gender ( $P=0.03$ ) and main HCP ( $P=0.04$ ) differed significantly between elderly and younger cancer patients.

#### Characteristics of interview participants

Fourteen elderly (former) cancer patients ( $\geq 65$  years) were interviewed. Patients were on average 73 years old and eleven patients were male. Most patients were diagnosed with prostate cancer (71.4%), followed by colon cancer (21.4%). The medical specialist was reported as main HCP by thirteen patients, one patient mentioned his general practitioner as main HCP. Illness duration was on average 8.1 years (range 2-31 years). Interviews lasted on average 40 minutes (28-87 min). Three patients brought a companion (spouse) to the interview.

#### Barriers

Table 1 shows the barriers concerning effective communication with their main HCP that were reported by the survey participants.

47% of elderly patients experienced communication barriers. This is comparable to the experienced barriers by younger patients ( $P=0.06 - 0.9$ , see Table 1).

The type of barriers largely overlap between the quantitative and qualitative samples. Often reported barriers were that patients do not want to be bothersome, remember topics only afterwards, feel nervous and have the perception that there is too little time. Interview participants also reported additional barriers (see below).

#### [TABLE 1]

##### *Barriers related to the patient*

During the interviews, several patients reported the 'impact of cancer' as a barrier to effective communication and participation during the encounter. They mentioned that it influenced their ability to ask questions or discuss emotions.

*You have cancer. And that has such an impact, that hits you. I was really taken aback. And yeah, I did not ask enough" (patient 2).*

*“It has such a huge impact, the moment you hear the words: sir, you have cancer (...).*

*And also the fact that you’re on the street immediately after diagnosis. It has such an impact”* (patient 9).

Some patients mentioned that being too modest or feeling shy hindered effective communication. Also, patients felt uncomfortable talking to younger HCPs of the opposite sex, in particular when having to talk about intimate issues or quality of life.

*“I felt a bit uncomfortable there, you know. All those women there, and of course all younger than I am as well”* (patient 3).

Some patients also mentioned that they forgot to ask questions during consultations and ending up having more questions afterward (e.g. because the situation was new to them).

*“You do not know, what you do not know, so to ask the right questions, is difficult. I find that hindering”* (patient 11).

The majority of patients preferred bringing a companion to the consultation. Two patients mentioned that bringing a companion could also be difficult, as the companion could be overwhelmed by emotions because of the illness of their loved one.

#### *Barriers related to the provider*

Some patients do not feel a connection with their provider, resulting in inefficient communication and participation during encounters. As one patient mentioned: *“Before you can really commit, you need to have a relationship, you have to build something together. It would be nice if they could pay more attention to that* (patient 2). Reported barriers include ‘not taking me and my needs seriously’, ‘not offer the opportunity to express freely’ and ‘not see me as a human being’.

Several patients expressed barriers allied to topics or emotions not being discussed by the provider. For example, not discussing patients’ quality of life.

*“The question is, what is going to happen and how does that feel? What will happen to my quality of life, how many years will I lose or gain if I decide whether or not to do it?”* (patient 14).

According to six out of fourteen patients, their provider did not give the (appropriate) information. Patients mentioned not being informed (enough) about (other) treatment options and not given enough time to reflect on choices, hindering shared decision making.



*“Yes, I took the decision way too fast. But they should have pointed that out to me. Like, ‘patient, keep the negative consequences of this treatment in mind. Think about it for a while’.” (patient 7).*

*“And then, for the first time, I was confronted with making decisions. And that was not easy I can tell you. (...) Because it is a profound choice you have to make. And that is crazy, as it is something medical, and you have to make the decision yourself.” (patient 3)*

Other barriers that were mentioned: the provider immediately started to talk about difficult or intimate subjects; topics passed too quickly; the provider did not answer patients’ questions; the provider did not give patient access to their personal file.

#### *Barriers related to the healthcare system*

Health system-related barriers include time constraints and communication between HCPs. With respect to time constraints patients mentioned that the short time available for a consultation and the long waiting lines before (important) consultations.

*“I have been waiting for 1.5 hours one time. Well, you’re in a cancer situation and you don’t know anything about that yet, so you’re extremely nervous” (patient 6).*

*“People do not take enough time for me and when I come, they only look at their watch or computer” (patient 1).*

Several patients mentioned inefficient (or no) communication between different providers of the same hospital or between hospitals, resulting in patients having to explain the situation over and over again or being confronted with different opinions of professionals.

*“What I would like to see improved, is that when two departments are involved – as in my case –they speak as one. And that I am not being pulled back and forth between their opinions” (patient 3).*

#### Facilitators and supportive interventions

53.3% of the survey participants indicated that they do not need an intervention to support effective communication or participation during healthcare encounters (see Table 2). The others prefer ‘Question prompt lists’ (QPS) (for personal use and use by the doctor) and ‘Information about how to prepare and communicate’ as

interventions. Less frequently reported interventions include ‘Modelling videos’ and ‘Personal advice and practice’.

No significant differences ( $P=0.06-0.9$ ) were found in the need for supportive interventions of elderly cancer patients ( $n=70$ ) compared to younger cancer patients ( $<65$  years;  $n=56$ ).

## [TABLE 2]

Patients who were interviewed were also asked about communication facilitators and their need for supportive interventions (see below).

### *Facilitators and supportive interventions related to the patient*

Patient-related facilitators for effective communication and participation during encounters include patients’ self-efficacy, personality or coping skills.

*“Yes, I can just say anything I feel” (patient 9).*

*“I am very open and able to ask anything I want” (patient 5).*

The majority of patients preferred to prepare the consultation, using a list of questions and topics as supportive intervention.

*“Yes well, I still think I prepare everything on paper, what I want to ask and what items I want to discuss. I find that very pleasant. In this case, that is something that works for me” (patient 11).*

Also, the majority of patients thought it was or would be helpful to bring a companion to consultations. Interviewed patients mentioned reasons, such as ‘support’ and ‘two can hear more than one’.

*“Then things go through your head. And that’s why it is good to bring someone with you. Who can objectively listen to it, yes” (patient 5).*

Other facilitators that were mentioned were: ‘finding it easy to talk about emotionally difficult or intimate subjects’, ‘being verbally strong’, ‘knowing where to find information’, ‘asking for answers to questions’ and ‘searching for the right treatment and a suitable provider’.

### *Facilitators related to the provider*



Reported facilitators included taking time, knowing the patient, being open and honest and taking questions and complaints seriously.

*“I know my provider is busy, but he always knows how to create an atmosphere like: take all the time you need”* (patient 13).

*“I have a surgeon who is great. He knows how I will respond (.). And he will not sit behind his desk with a monitor. No, he will go and sit in front of you on his desk and starts his conversation”* (patient 8).

*“Yeah, attention for the human being. I have to say I found that very pleasant”* (patient 2).

Patients mentioned that the provider creates opportunities to ask questions, talks about possibilities and expectations and openly discusses difficult and intimate issues.

*“I notice that there is room to ask my questions, where he simply replies to, where he gives answers to”* (patient 13).

#### *Facilitators related to the healthcare system*

A frequently mentioned system-related facilitator was the accessibility of the hospital or provider.

*“If there is anything wrong, I can call, just to discuss. So yes, that makes you calmer as well”* (patient 4).

Some patients expressed the communication with nurses as supportive.

*“Often, contact with a nurse is better, better education, better information, often more focus on practice than the doctor”* (patient 10).

Other patients stated that they experienced no difference in communication between nurses and other (oncological) care providers; they all take the patient seriously.

## **4. DISCUSSION AND CONCLUSION**

### **4.1 Discussion**

This study showed that a majority of elderly cancer patients felt confident in communicating and participating during medical encounters. Yet, 47% of the elderly

cancer patients experienced at least one communication barrier. A similar percentage felt the need for support in this respect.

Patients mentioned barriers and supportive interventions related to attributes (values, emotions, skills, beliefs, needs) of themselves, the provider and the healthcare system. Patient-related attributes included e.g. patients' self-efficacy, personality and coping skills. These patient-related attributes hindered the communication for one person (e.g. being shy or modest), while supporting the communication for another (e.g. being open or verbally strong).

This also applied to several attributes related to the provider (e.g. (not) taken seriously) and the system (e.g. too little or sufficient time).

Frequently reported barriers by elderly patients with cancer were: not wanting to be bothersome, remembering topics only afterwards, feeling nervous and having the perception that there is too little time. The impact of cancer was also frequently mentioned as a barrier to effective communication and participation. Another study [14] also found that patients tend to get confused and forget information due to the impact of cancer, which can hinder effective communication.

Facilitating factors, such as a good relationship with the provider or the provider properly adjusting his or her communication could decrease feelings of anxiety. Preferred supportive interventions, according to survey patients, were the use of a 'question prompt list' and information about how to prepare and communicate. Only few survey-patients preferred modelling videos to facilitate communication and participation. However, this could have been due to the non-familiarity with (the principle of) modelling videos.

The survey and interviews both yielded similar barriers. The interviews added barriers and provided more insight into patients experiences and underlying mechanisms. The survey participants choose from a list of possible supportive interventions, whereas the interviewed patients reported mainly communication facilitators instead of supportive interventions, like provider-related facilitators such as taking time, knowing the patient, being open and honest and taking questions and complaints seriously. An exception was 'the use of a list of questions' as supportive intervention which was mentioned by several interviewed patients. As we openly asked patients about supportive interventions it is possible that they were not familiar with what kind of supportive interventions exist. However, we did provide some examples when asking about it.

Furthermore, the barriers and need for supportive interventions experienced by elderly cancer patients are comparable with those of chronically ill patients in the larger survey [23]. In both studies patients reported the following top-4 barriers: not wanting to be bothersome, remembering subjects only afterwards, feeling tense, and having the perception that there is too little time. The reported interventions were also quite similar in both studies; with the QPS for personal use on top of the list. However, elderly cancer patients least preferred 'personal advice and practice', while the larger group of chronically ill patients least preferred 'modelling videos' to support communication and participation.

Another recent study found that older cancer patients attach value to 'affective communication', 'treatment-related and rehabilitation information' and 'discussion of realistic expectations' [29]. Affective communication aspects (e.g. taking the patient seriously and taking time), the need for treatment-related information (especially related to decision making) and the discussion of realistic expectations

(i.e. being open and honest) were also mentioned by elderly patients with cancer in our study.

Similar to a previous study [18] we found that many communication barriers and facilitators were not disease-specific, e.g. the facilitating role of bringing a companion and preparing the consultation, are relevant for all patients. However, the importance and manifestation of specific barriers and interventions can differ across cancer type, stage of disease and topic (to be) discussed [18,30]. Cancer patients are likely to benefit most from support when communicating about difficult topics [30]. The age of the patient can be an additional factor. For example, in our study several elderly patients indicated that discussing 'quality of life' and 'psychological support' are important for all cancer patients, but especially for elderly cancer patients. Some interviewed elderly patients also mentioned the barrier of talking to younger providers of the opposite sex. This could be an age or/and gender related barrier. No significant differences were found in the survey with respect to experienced barriers and supportive interventions of elderly cancer patients compared to their younger counterparts. However, some background characteristics (i.e. gender, main HCP) of the elderly and younger survey patients differed significantly. The absence of an age difference could imply that supportive interventions do not need to be tailored or specifically designed for elderly cancer patients. Other factors like personality, experience, comorbidity or education could be more significant concerning communication barriers. However, previous studies did show that elderly cancer patients participate less during consultations than younger ones [8-11]. Furthermore, elderly cancer patients often have other considerations when choosing a treatment (or no treatment) than younger patients [31], e.g. preferring quality of life over intensive chemotherapy treatment.

### *Strengths and limitations*

A strength of this study is that we included mixed methods; survey data were used to get insight into barriers and supportive interventions of elderly cancer patients, interviews provided in-depth insight and additional communication barriers and facilitators. As the focus of our study is on elderly cancer patients, we decided to only invite elderly cancer patients for the interviews. Furthermore, we aimed to include a wide range of elderly cancer patients, with different (stages of) disease and different levels of participation (e.g. active, passive). However, patients diagnosed with prostate cancer, and therefore male patients, were overrepresented, as our efforts to include female patients failed. As patients volunteered to partake it is possible that the results of this study represent the more 'active' patients; those who feel confident in participating during medical encounters.

It is furthermore possible that our pre-constructed list of barriers steered the interviews. However, patients also reported additional barriers during the interviews. In addition, we did not use the pre-constructed list of interventions before the interview, but provided some examples (e.g. modelling videos, bringing a companion) as possible facilitators or supportive interventions. Lastly, a limitation is the relatively small sample size of this study, although it is comparable to similar studies [32-34] and it was sufficient to reach thematic saturation [28]. For the quantitative part of the study we included all cancer patients of a national representative panel.

## 4.2 Conclusion

A slight majority of elderly cancer patients felt confident in communicating and participating during medical encounters. However, still a large amount of elderly cancer patients experienced barriers to effectively communicate with their HCP and felt the need for support. Patients mentioned barriers and facilitators related to attributes (values, emotions, skills, beliefs and needs) of themselves, the provider and the healthcare system. Overall, enhancing patient participation during (oncological) encounters should never be a goal in itself. However, offering support to patients who feel less confident in communicating with their provider should always be available.

## 4.3 Practice implications

The study outcomes can be used as a first step in developing an intervention for elderly cancer patients to overcome communication barriers [35]. Bringing a companion and preparing a consultation were frequently mentioned as facilitators. A QPS or modelling videos can be used as an intervention for elderly cancer patients to prepare their consultations, especially for newly diagnosed patients. However, further research should investigate if perceived communication barriers and facilitators differ between newly diagnosed elderly cancer patients and more experienced elderly patients. Potential gender differences need to be taken into account, as well as including low-literate patients and patients with different educational backgrounds [23].

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**TABLES**

Table 1. Barriers to effective communication, as perceived by elderly ( $\geq 65$  years) and younger ( $< 65$  years) cancer patients

<b>Number of barriers</b>	<b>Elderly survey patients (n=70)</b>	<b>Younger survey patients (n=56)</b>	<b>P-value*</b>
No barriers	52.6%	56.2%	0.71
One or more barriers	47.4%	43.8%	
Missing (n)	13	8	
<b>Type of barriers</b>	<b>%</b>	<b>%</b>	
Not wanting to be bothersome	25.4%	13.2%	0.10
Remembering subject only afterwards	24.6%	24.5%	0.99
Feeling tense	18.5%	14.3%	0.54
Perception there is too little time	18.2%	18.9%	0.92
Not knowing how to discuss subject	16.9%	5.7%	0.06
Belief subject not important enough	15.6%	13.2%	0.71
Belief provider cannot provide solution/answer anyway	11.3%	5.8%	0.30
Uncertainty about own understanding	11.1%	5.5%	0.27
Not knowing what to ask	9.5%	7.4%	0.68
Looking up to the provider	9.4%	1.9%	0.09
Not finding the right moment to bring something up	7.9%	7.5%	0.94
Not knowing what is expected of me	6.5%	3.9%	0.55
Burdensome to talk about subject	6.3%	7.4%	0.82
Belief subject is not part of this provider's task	6.3%	11.3%	0.34
Expecting an annoyed /offended response of provider	6.2%	9.4%	0.50
Feeling embarrassed about a subject	1.6%	1.9%	0.92
Fearing the answer to my questions	1.6%	5.7%	0.23

\*(significant) differences between experiences of elderly cancer patients and younger cancer patients, tested with Pearson's chi<sup>2</sup> (<0.05).



Table 2. Interventions and facilitators for effective communication, according to cancer patients

<b>Number of facilitating interventions</b>	<b>Elderly patients (n=70)</b>	<b>Younger patients (n=56)</b>	<b>P-value*</b>
No facilitating interventions	53.3%	51.9%	0.88
One or more facilitating interventions	46.7%	48.1%	
Missing (n)	10	4	
<b>Type of interventions to facilitate communication</b>			
Question prompt list for personal use	45.3%	40.0%	0.56
Information about how to prepare and communicate	36.5%	20.4%	0.06
Question prompt list provided to doctor prior to consultation	34.9%	20.4%	0.08
Preparatory conversation with nurse prior to consultation	22.6%	13.0%	0.18
Personal coach to prepare, accompany and evaluate	18.0%	18.9%	0.91
Modelling videos	11.7%	5.7%	0.26
Personal advice and practice	9.8%	3.7%	0.20

\*(significant) differences between experiences of elderly cancer patients and younger cancer patients, tested with Pearson's chi2 (<0.05).