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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.

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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

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insight into the communication barriers, facilitators and need for supportive interventions experienced by elderly cancer patients.

2. Method

2.1. 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.

2.2. Quantitative study

2.2.1. 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 (≥ 65 years) and 56 younger patients (18–65 years), to allow for a comparison on age.

2.2.2. 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].

2.2.3. 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).

2.2.4. 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 Chi2. Data were analysed using STATA 13 (2013).

2.3. Qualitative study

2.3.1. Participants

Patients (≥ 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.

2.3.2. 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

Table 1

Barriers to effective communication, as perceived by elderly (≥ 65 years) and younger (<65 years) cancer patients.

Number of barriers	Elderly survey patients (n = 70)	Younger survey patients (n = 56)	P-value*
No barriers	52.6%	56.2%	0.71
One or more barriers	47.4%	43.8%	
Missing (n)	13	8	
Type of barriers	%	%	
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 chi2 (<0.05).

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