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Needs, barriers, and eHealth

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Enhancing patient participation of older migrant cancer patients: needs, barriers, and eHealth

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ABSTRACT

Objectives: To gain insight into (1) the unfulfilled instrumental and affective needs of Turkish-Dutch and Moroccan-Dutch older cancer patients/survivors, (2) the barriers perceived by healthcare professionals in fulfilling these needs, and (3) how the *Health Communicator*, a multilingual eHealth tool, can support the fulfillment of patients'/survivors' needs, and decrease professionals' barriers.

Design: We conducted a pre-implementation study of the *Health Communicator* using semi-structured interviews with Turkish-Dutch ($n = 10$; mean age = 69.10) and Moroccan-Dutch ($n = 9$; mean age = 69.33) older cancer patients/survivors, and held two focus groups with general practitioners (GPs; $n = 7$; mean age 45.14) and oncology nurses (ONs; $n = 5$; mean age = 49.60). Topic list consisted of questions related to needs and perceived barriers. Analysis was based on grounded theory. The acceptance of the *Health Communicator* was inquired by questions based on the concepts of the Technology Acceptance Model, and analyzed deductively.

Results: Patients/survivors reported unfulfilled needs concerning: (1) information about cancer (treatment), (2) information about the healthcare system, (3) possibilities regarding psychosocial support, and (4) doctor-patient relationship. Among professionals, the main perceived barriers were: (1) patients'/survivors' low health literacy and language barrier, (2) cultural taboo, (3) lack of insight into patients' instrumental needs, and (4) patients'/survivors' lack of trust in Dutch healthcare. Both patients/survivors and professionals thought that implementing the *Health Communicator* could be effective in fulfilling most of the needs and decreasing the barriers. However, a majority of the patients/survivors were hesitant regarding the use of it, because they found it too difficult to use. Professionals showed a positive intention towards using the *Health Communicator*.

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Conclusions: To enhance patient participation among older migrant cancer patients/survivors, the *Health Communicator* is, under certain conditions, a promising tool for fulfilling patients'/survivors' unfulfilled instrumental and affective needs and for bridging barriers perceived by professionals.

Introduction

Ethnic minority cancer care is increasing due to the rise in cancer incidence (WHO 2018), ongoing migration waves (Smith et al. 2009), and ageing of the world's population (Nolen et al. 2017). In the Netherlands, the incidence of ethnic minority cancer patients is expected to rise from 1.8% in 2005–6% in 2030 (KWF 2006). This increase is partly caused by Turkish-Dutch and Moroccan-Dutch migrants – two major non-Western ethnic minority groups in the Netherlands (Hosper et al. 2007) – adopting the Western lifestyle (KWF 2006; Arnold, Razum, and Coebergh 2010), and by the ageing of first generation Turkish-Dutch and Moroccan-Dutch migrants (KWF 2006; Hosper et al. 2007; Arnold, Razum, and Coebergh 2010).

In Western societies active patient participation, i.e. 'the extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction as well as the health care professional's beliefs and behaviors' (Street and Millay 2001) (hereafter called 'participation'), is highly encouraged and is considered a standard for adequate doctor-patient communication and quality of care (Vahdat et al. 2014; Clayman et al. 2016). More active participation is associated with positive health outcomes like greater satisfaction, less distress, less depression, better treatment adherence, and a higher quality of life (Luckett et al. 2011; Vahdat et al. 2014; Brandes et al. 2015; Faller et al. 2016). However, both older patients (Levinson et al. 2005; Kiselev et al. 2018) and patients with an ethnic minority background (Levinson et al. 2005; Gordon et al. 2006; Schouten et al. 2007) participate less actively during medical encounters compared to younger patients and patients with no migration background. The same holds for Turkish-Dutch and Moroccan-Dutch patients (Schinkel et al. 2015). Less active participation among them is partly caused by the language barrier: Dutch language proficiency is lowest among Turkish-Dutch, followed by Moroccan-Dutch inhabitants (Huijnk and Dagevos 2012). Additionally, low (health) literacy contributes to less active participation among migrant inhabitants (Sudore et al. 2009).

In order to enhance participation among older Turkish-Dutch and Moroccan-Dutch cancer patients, three important issues have to be addressed. First, their unfulfilled instrumental (i.e. information about disease-related and treatment-related topics) and affective (e.g. support and partnership building (Deveugele et al. 2004)) needs should be identified (Soothill et al. 2001; Wen and Gustafson 2004; Chen et al. 2010; McDowell et al. 2010), because fulfilling patients' needs is found to increase participatory behavior among patients (Vahdat et al. 2014). Ethnic minority patients in general have wide-ranging, high instrumental needs (Fujimori and Uchitomi 2009; Yilmaz et al. 2019) and affective needs (Fujimori and Uchitomi 2009), and they experience unfulfilled needs more frequently compared to ethnic majority patients (see for instance (Schinkel, Schouten, and van Weert 2013)). However, older ethnic minority cancer patients/

survivors are often underrepresented in these studies. Consequently, there is a lack of knowledge regarding their specific needs, which could partly explain why the fulfillment of their needs remains suboptimal. Hence, the first aim of this study was to explore the unfulfilled instrumental and affective needs of Turkish-Dutch and Moroccan-Dutch older cancer patients/survivors.

Second, more insight should be gained into potential barriers faced by healthcare professionals in fulfilling ethnic minority cancer patients'/survivors' needs. A recent study showed a mismatch between patients' perceived unfulfilled needs and healthcare professionals' views on these unfulfilled needs (Marcusson-Rababi et al. 2019). For example, ethnic minority cancer patients reported that they are not always able to attend their appointment with the healthcare professional because they are too ill. Professionals, however, reported that migrant cancer patients are simply reluctant to attend the consultation, and, therefore, they do not perceive an urge to support the patients' needs. These kind of mismatches might reflect barriers (e.g. cultural differences) experienced by healthcare professionals to identify and fulfill ethnic minority cancer patients'/survivors' needs. Not fulfilling patients'/survivors' needs, in turn, might results in less participation (Yilmaz et al. 2019). Therefore, the second aim of this study was to explore barriers perceived by healthcare professionals' in fulfilling patients'/survivors' reported instrumental and affective needs.

Third, one way to enhance patient participation among older ethnic minority cancer patients/survivors might be the implementation of eHealth interventions, because these interventions can relatively easily be tailored to the needs of patients/survivors (Ritterband et al. 2009), and can be made available in the mother tongue of the patient/survivor, thereby decreasing the language barrier (Kreuter and McClure 2004; Lang 2006; Ritterband et al. 2009). These features make eHealth interventions potentially effective in reducing barriers that might impede the identification and subsequent fulfillment of ethnic minority patients'/survivors' needs (Kreuter and McClure 2004; Lang 2006; Ritterband et al. 2009). An example of a Dutch eHealth intervention used by Dutch general practitioners (GPs) is the *Health Communicator*. The *Health Communicator* is a multilingual (e.g. Dutch, English, Turkish, Arabic, Berber, Spanish, Polish) eHealth tool in which ethnic minority patients can fill out questions (i.e. medical anamnestic information and Question Prompt Lists (QPLs)) and receive audiovisual patient education in narrative format in their own mother tongue. QPLs are simple communication tools that consist of structured lists of questions which stimulate information-gathering and encourage active participation during consultations (Brandes et al. 2015). As patients can either read or listen to the QPLs in the *Health Communicator*, the tool is also suitable to illiterate patients. Patients' health-related information gathered through the *Health Communicator* is pre-translated into Dutch, and sent to the physician to prepare for the consultation.

The acceptance of eHealth among (intended) end-users is an important prerequisite for its implementation and adoption. According to the Technology Acceptance Model (TAM), potential end-users of a new technology who perceive the technology as useful and easy to use, will show a more positive attitude towards using the new technology (Davis 1985; Bolle et al. 2016), which, in turn, is predicted to result in a positive intention towards adoption, eventually leading to actual use (Davis 1985). However, because there is a dearth of research on older ethnic minority cancer patients'/survivors' acceptance of

eHealth interventions, the third aim of this study was to explore how the unfulfilled instrumental and affective needs of older Turkish-Dutch and Moroccan-Dutch cancer patient can be fulfilled by exploring their beliefs, attitudes, and intentions towards using the *Health Communicator*. As healthcare professionals should implement the *Health Communicator*, their perceptions regarding the potential of the *Health Communicator* in supporting the fulfillment of patients' needs were also explored.

In sum, to enhance patient participation among older migrant cancer patients/survivors, the current pre-implementation study aimed to gain insight into 1) the unfulfilled instrumental and affective needs of Turkish-Dutch and Moroccan-Dutch older cancer patients/survivors, 2) the barriers perceived by healthcare professionals in fulfilling these needs, and 3) how the Health Communicator can support the fulfillment of patients'/survivors' needs, and decrease professionals' barriers.

Materials and methods

Design

This study contained an exploratory qualitative study design. First, semi-structured interview data with a purposive sample of older Turkish-Dutch and Moroccan-Dutch cancer patients/survivors were collected and analyzed, followed by focus group data with a purposive sample of general practitioners (GPs) and oncology nurses (ONs). Data collection took place between April and November 2017. Prior to data collection, ethical approval was obtained from the ethical committee of our University (W16_218#16.256).

Procedure

Interviews with patients/survivors

Older Turkish-Dutch and Moroccan-Dutch cancer patients/survivors were recruited purposively, striving for diversity regarding age, country of origin, and educational level. Patients/survivors were recruited through hospitals, general practitioners, health centers and patient organizations. In addition, flyers were distributed in places often visited by older Turkish-Dutch and Moroccan-Dutch cancer patients/survivors (e.g. mosques, community centers), and posted on social media (e.g. Facebook). Inclusion criteria were that participants (1) were aged 60 years or older, (2) were born in either Turkey or Morocco, and (3) were under treatment for cancer at the moment of the study or were a cancer survivor. Inclusion went on until theoretical data saturation was reached. The interviews took place at a time and place that was chosen by the participants, often at their home, and were audiotaped. The interviews lasted approximately one hour, and were conducted in Turkish, Arabic, or Berber by four native speakers or bilingual research assistants. Interview training was done face-to-face with each interviewer; they were also provided with a written procedure on conducting the interviews. Patients received a gift card of €20 for their participation. Member checks (i.e. checking with the interviewee whether their responses were interpreted correctly by the interviewee) were conducted with six participants. All six participants declared to be in agreement with the results.

Before starting the face-to-face interviews with patients/survivors, the aim, content, and procedure of the study were explained and informed consent was obtained. An

open-ended and semi-structured interview guide was used for the interviews. First, open-ended questions about unfulfilled instrumental needs, and unfulfilled affective needs were asked. After these questions, the existing diabetes module of the *Health Communicator* was demonstrated to the patients. Then, semi-structured questions related to *Health Communicator* acceptance were asked based on the TAM-concepts (i.e. questions about 'Perceived ease of use', 'Perceived usefulness', 'Attitude towards use', and 'Behavioral intention to use'). Finally, questions regarding participants' demographics were asked (e.g. age, level of education, and language proficiency in Dutch and in their mother tongue). For the complete patient interview guide, see *Appendix A*.

After finalizing the interviews with patients/survivors, the interviews were analyzed (see *'Data analysis*'). The unfulfilled instrumental and affective needs of patients/survivors, and their views concerning the *Health Communicator* were summarized in order to be discussed with the healthcare professionals. Then, the focus groups with GPs and ONs were organized.

Focus groups with healthcare professionals

The GPs were purposively recruited through the researchers' personal networks and the ONs were recruited through a key figure in a Dutch hospital. The inclusion criterion was that professionals were recently (i.e. less than a year ago) involved in the treatment of at least one Turkish-Dutch or Moroccan-Dutch cancer patient. The focus group with ONs took place at the hospital, while the focus group with GPs took place at our university. Healthcare professionals and patients were not ethnically matched. Both focus groups were audiotaped, and lasted approximately two hours. The focus groups were conducted in Dutch by the last author (BS), who is experienced in conducting focus-groups. The second author (HS) was also present to make notes. Participating GPs and ONs received a monetary incentive for their participation.

The focus groups with GPs and ONs were held separately, and consisted of four parts. Before starting the focus groups, the aim, content, and procedure of the study were explained. Then, professionals were invited to tell about their experiences with providing care to older Turkish-Dutch and Moroccan-Dutch cancer patients. Second, professionals were asked what information about older Turkish-Dutch and Moroccan-Dutch cancer patients would help them to better prepare for the consultations. Third, professionals were asked to comment on the patients' interview findings (i.e. unfulfilled instrumental and affective needs of older Turkish-Dutch and Moroccan-Dutch cancer patients/survivors), in order to identify their perceived barriers in fulfilling these needs. Finally, professionals were asked what they thought about the *Health Communicator*, what the oncological module should look like, what content should be in the module, and what the requirements would be to implement the oncological module in practice. Questions regarding professionals' demographics (i.e. age, gender, ethnic background, and work experience) were asked at the end of each focus group. For the focus group guide, see *Appendix B*.

Data analysis

All audiotaped interviews and focus groups were transcribed verbatim by the first author and two bilingual research assistants. Atlas.ti version 8.3.0 was used to analyze the data

qualitatively. The transcripts were coded by three researchers (NGY, HS, BS). Five (out of 19) interviews and one (out of two) focus groups were double-coded independently. Subsequently, the codes of the three researchers were assessed on their similarity. Disagreement about the codes was discussed and after mutual agreement was achieved, researchers agreed on the final codes. As mentioned, both the interview and focus group guide encompassed an open-ended and a semi-structured part. Data from the two parts were analyzed by two different qualitative approaches.

Analyzing open-ended data

The open-ended questions of the interviews with patients/survivors concerned their unfulfilled instrumental and affective needs and healthcare professionals' perspectives. Data analysis of this part was based on grounded theory (Charmaz and Belgrave 2007). This method entails inductive approaches for data analysis in which conceptual categories are being developed from the analysis of individual interviews. The conceptual categories, in turn, enable the researcher to combine, explain and understand the data, and to map patterns in the relationships between concepts (Charmaz and Belgrave 2007).

Analyzing semi-structured data

The semi-structured questions were related to *Health Communicator* acceptance, and was coded deductively according to the TAM-concepts (i.e. 'Perceived ease of use', 'Perceived usefulness', 'Attitude towards use', and 'Behavioral intention to use').

Results

Sample characteristics

The participants were Turkish-Dutch ($n = 10$; 3 male and 7 female, $M_{age} = 69.10$) and Moroccan-Dutch ($n = 9$; 3 male and 6 female, $M_{age} = 69.33$) older cancer patients ($n = 8$) and survivors ($n = 11$). All patients reported to be Muslim. The majority of the participants had a low level of education, a low level of self-reported Dutch proficiency, and most were diagnosed with breast cancer or colon cancer.

The participants were GPs and one internist ($n = 7$; 4 male and 3 female, $M_{age} = 45.14$) and ONs ($n = 5$; all female, $M_{age} = 49.60$). The ONs were all Dutch, but four of the seven GPs had a non-Dutch ethnic background (i.e. Moroccan and Middle-Eastern). Table 1 provides an overview of the sample characteristics.

Unfulfilled instrumental needs of patients/survivors

Two main themes emerged during the interviews regarding unfulfilled instrumental needs: (1) information about cancer (treatment) and (2) information about the healthcare system. The majority of both Turkish-Dutch and Moroccan-Dutch patients/survivors reported to have wide-ranging unfulfilled instrumental needs. A few patients/survivors, mostly Moroccan-Dutch patients/survivors, had no unfulfilled instrumental needs.

Table 1. Sample characteristics.

	Patients	
	Moroccan-Dutch ($n = 9$)	Turkish-Dutch ($n = 10$)
Age ($M \pm SD$)	69.33 ± 8.99	69.10 ± 4.97
Gender (%female)	6 (66.7%)	7 (70%)
Educational level		
Low (n (%))	7 (77.8%)	5 (50%)
Moderate (n (%))	2 (22.2%)	4 (40%)
High (n (%))	–	1 (10%)
Self-reported Dutch proficiency		
• Low (n (%))	6 (66.7%)	2 (20%)
• Moderate (n (%))	1 (11.1%)	4 (40%)
• High (n (%))	2 (22.2%)	4 (40%)
Type of cancer (first diagnosis)		
• Breast (n (%))	3 (33.3%)	4 (40%)
• Colon (n (%))	3 (33.3%)	3 (30%)
• Kidney (n (%))	–	1 (10%)
• Leukemia (n (%))	2 (22.2%)	–
• Lung (n (%))	–	1 (10%)
• Skin (n (%))	1 (11.1%)	–
• Stomach (n (%))	–	1 (10%)
Current health status		
• Patient (n (%))	3 (33.3%)	5 (50%)
• Survivor (n (%))	6 (66.7%)	5 (50%)
	Professionals	
	General practitioners ($n = 7$)	Oncological nurses ($n = 5$)
Age ($M \pm SD$)	45.14 ± 10.85	49.60 ± 12.16
Gender (%female)	3 (42.9%)	5 (100%)
Ethnic background		
• Dutch (n (%))	3 (42.9%)	5 (100%)
• Non-Dutch (n (%))	4 (57.1%)	–
Work experience		
• 0–5 years (n (%))	1 (14.3%)	–
• 5–10 years (n (%))	2 (28.6%)	–
• 10–15 years (n (%))	1 (14.3%)	2 (40%)
• 15–20 years (n (%))	1 (14.3%)	–
• 20–25 years (n (%))	–	1 (20%)
• >25 years (n (%))	2 (28.6%)	2 (40%)

Information about cancer (treatment)

The majority of patients/survivors wanted to know as much as possible about cancer, including both good and bad news about their disease:

> And I also told him [oncologist] to tell me everything, 'do not hide anything from me'. [Moroccan-Dutch, Male].

They also had unfulfilled instrumental needs concerning the symptoms of cancer, treatment options and their side-effects, prognosis, and recurrence. Besides, many patients/survivors mentioned that they needed more information about the role of food, physical activity, and alternative medicine in cancer care.

Information about the healthcare system

Turkish-Dutch patients/survivors said that they needed more information about their patient rights, such as the right to say 'no' to treatment. Moroccan-Dutch patients/survivors did not mention this. In addition, Turkish-Dutch patients/survivors reported multiple times to lack information about the aim and outcomes of clinical trials:

> They didn't provide me with any information about the results of the research, while I was very curious about it. I wanted to know which drug was more effective. [Turkish-Dutch, Female].

Factors related to unfulfilled instrumental needs of patients/survivors

Underlying reasons for patients'/survivors' unfulfilled instrumental needs that emerged from our analysis can be distinguished in patient-related and healthcare professional-related factors. With regard to patient-related factors, there seemed to be a taboo on the word 'cancer', leading patients/survivors to not discussing their instrumental needs. Besides, lower educated patients/survivors had less unfilled instrumental needs and seemed to be more easily satisfied with the (amount of) information they received than higher educated patients/survivors. Some patients/survivors were convinced that they already knew everything that is relevant to know about their disease, because they were informed by their informal caregiver or their healthcare professional. Last, some patients/survivors were afraid to know more about their disease and seemed to see being uninformed as a way to cope with their illness.

With regard to healthcare professional-related factors, patients/survivors reported that they needed healthcare professionals to provide them with reliable and unambiguous health-related information. Often contradicting information was provided/found, which was confusing for these patients/survivors. Information pollution, especially (negative) information on the Internet, caused anxiety in this group of patients/survivors. For instance, one patient mentioned:

> The deeper your search, the worse it gets. So I stopped […] I just stopped at a certain moment and told myself 'I just have to listen to and take the information from the doctor'. [Moroccan-Dutch, Female].

Unfulfilled affective needs of patient/survivors

Two main themes emerged during the interviews regarding unfulfilled affective needs: (1) possibilities regarding psychosocial support, and (2) doctor-patient relationship. The

majority of patient/survivors reported unfulfilled affective needs, but a few Turkish-Dutch and Moroccan-Dutch patients/survivors did report to have no unfulfilled affective needs at all. Moroccan-Dutch patients/survivors reported less unfulfilled affective needs regarding the doctor-patient relationship compared to Turkish-Dutch patients/survivors.

Possibilities regarding psychosocial support

Both Turkish-Dutch and Moroccan-Dutch patients/survivors indicated unfulfilled needs for psychological support for themselves and their family members. The majority of both Turkish-Dutch and Moroccan-Dutch patients/survivors told that not only themselves but also their close family members (e.g. spouses, children) were affected greatly by the bad news (i.e. cancer diagnosis). To cope with the burden of the disease, patients/survivors reported to need psychosocial support, as illustrated by this patient:

> There are times that I manage to cope with the disease, but my wife can't. Psychological support to the family would be good. I need that. It would relief my burden. [Turkish-Dutch, Male].

In addition, Turkish-Dutch patients/survivors often mentioned that they need peer support groups or encouragement from their friends.

Doctor-patient relationship

Respondents often reported a need for communication with their healthcare professionals in which they are taken more seriously or in which they are respected more than is currently the case:

> She [nurse] thought that I could not speak or understand Dutch. She told another woman 'These Moroccans are always crazy'. I could not sit on the MRI table because of the pain and she forced me to sit on it by myself, without help. I told her that I cannot, that somebody has to help me. She told me 'No you should do it by yourself'. [Moroccan-Dutch, Female].

Besides, some Turkish-Dutch patients/survivors said that they wanted to be seen as a 'whole' person, and not merely a statistic or a case. Hence, they expected a holistic approach from their healthcare professional. This need was not mentioned by Moroccan-Dutch patients/survivors.

Factors related to unfulfilled affective needs of patients/survivors

Turkish-Dutch and Moroccan-Dutch patients'/survivors' unfulfilled need for psychosocial support seemed to be associated with their fear for the disease, diagnosis, and death, leading patients/survivors to not discussing their affective needs. Besides, patients/survivors who reported to have an unfulfilled need for doctor-patient relationship mentioned that trust in the professional, which often was missing, is very important in their relationship with the professional. The lack of a doctor-patient relationship seemed to instigate a lack of trust in Dutch healthcare professionals among patients/survivors, which in turn seemed to strengthen the unfulfilled need for a doctor-patient relationship. The main reason for having no unfulfilled affective needs was religiosity. Patient/survivors with less affective needs often explained this by their strong faith in Allah:

> I didn't need it [psychosocial support]. I said 'Allah is great'. [Turkish-Dutch, Female].

Barriers perceived by healthcare professionals: instrumental needs

Three main themes regarding perceived barriers in fulfilling patients'/survivors' instrumental needs emerged during the focus groups: (1) language barrier and low health literacy, (2) cultural taboo, and (3) lack of insight into patients' instrumental needs.

Language barrier and low health literacy

A major barrier for professionals to fulfill patients'/survivors' instrumental needs is the language barrier. Dutch language proficiency is often low among older Turkish-Dutch and Moroccan-Dutch patients/survivors, leading to communication problems between patients/survivors and professionals. In order to tackle the language barrier, patients/survivors frequently bring along family members to interpret for them. However, professionals questioned whether informal interpreters translate everything said by either the patient or the professional. They mentioned that informal interpreters often seem to hide bad news like the diagnosis because they are often overconcerned and overprotective. As professionals do not understand the mother language of the patients, they are not able to monitor whether all information is translated adequately.

Besides the language barrier, professionals mentioned that they inform patients/survivors about, among others, patient rights and alternative medicines. However, they perceive the low health literacy of Turkish-Dutch and Moroccan-Dutch patients/survivors as the main cause of not being able to understand this information. According to GPs, low health literacy among Turkish-Dutch and Moroccan-Dutch patients/survivors was an even bigger problem than low language proficiency:

> But even more low health literacy. That is, next to the language barrier, very important to us. Low health literacy. [GP, Male].

Cultural taboo

Professionals mentioned the cultural taboo about cancer as a barrier to informing patients/survivors. Dutch professionals are used to openly discussing all facets of cancer, from diagnosis and symptoms to (bad news about) prognosis, with the patient. In the Turkish and Moroccan culture, however, cancer is often still associated with death. Therefore, professionals feel that they can often not reveal, for example, the diagnosis to the patient:

> Well, sometimes we are not allowed to name the diagnosis, we are not allowed to name the treatment, we have to say other things because otherwise they lose hope. [ON, Female].

Also, some information about symptoms, for example related to stool, is deemed culturally inappropriate to give and, hence, is often not discussed with Turkish-Dutch and Moroccan-Dutch patients/survivors.

Lack of insight into patients' instrumental needs

Professionals reported that they lack information about the patient's/survivor's instrumental needs. They were uncertain about whether Turkish-Dutch and Moroccan-

Dutch patients/survivors want to be informed about their disease, and, if yes, to what extent:

> Well, I would at least want to know what information the patient himself/herself would like to know and not to know concerning his/her disease. [ON, Female].

Factors related to barriers perceived in fulfilling instrumental needs

The role of informal interpreters and other family members of the patient is seen as a substantial factor in the barrier regarding fulfilling patients' instrumental needs. Often these family members tell the professional not to reveal, for example, the diagnosis to the patient. Therefore, professionals try to communicate indirectly about the disease by using euphemisms like *'a bad disease'*, without openly discussing topics like diagnosis, treatment options, and prognosis. It remains unclear to professionals, however, whether patients really do not want to hear this information or whether family members are deciding on behalf of the patient. Family members also are perceived to play a significant role in the 'lack of information' barrier. Professionals reported that Turkish-Dutch and Moroccan-Dutch families are often big families with multiple family members getting involved in the care process. While the professionals expect one family member to be the contact person and main decision-maker, it often remains unclear who this one person is. As a result, one professional said:

> Frequently the family is surrounding the patient severely, so you can't even reach the patient. [GP, Male].

Barriers perceived by healthcare professionals: affective needs

Three themes regarding perceived barriers in fulfilling patients'/survivors' affective needs emerged during the focus groups: (1) cultural differences in non-verbal affective behaviors, (2) uncertainty about patients' affective needs, and (3) lack of trust in the healthcare system. No factors related to barriers perceived in fulfilling affective needs were identified.

Cultural differences in non-verbal affective behaviors

Both GPs and ONs told that they know that Turkish-Dutch and Moroccan-Dutch patients/survivors often describe them as 'hard' and 'cold'. However, professionals mentioned that it is not inherent to the Dutch culture and practice to show much non-verbal affective behaviors, such as hugging a patient. Besides, professionals reported to think that not all Turkish-Dutch and Moroccan-Dutch – especially female – patients are open to physical contact due to religious reasons:

> For me it's, I don't dare, I don't know whether they [female patients], maybe they are not allowed to touch a man at all. [GP, Male].

Uncertainty about patients' affective needs

Professionals reported that Turkish-Dutch and Moroccan-Dutch patients/survivors often do not discuss their affective needs with them if they do not actively enquire

about these needs. This is especially the case for their need for psychosocial support. Besides, professionals perceived Turkish-Dutch and Moroccan-Dutch families as big and caring, and thought that religiosity has a positive role in fulfilling patients'/survivors' emotional needs:

> Well, and the need for psychosocial support. I can imagine that we always back off, because there is already such a big network. [ON, Female].

As a result, professionals mentioned that they remain uncertain about the extent to which (professional) psychosocial support is needed by patients/survivors. Nevertheless, some professionals told that they were already trying to support patients in fulfilling their affective needs by taking some actions in their current practices, such as referring patients to peer support groups, and putting patients with the same ethnic background in the same hospital room in order to foster interaction and support between them.

Lack of trust in the healthcare system

Professionals mentioned that especially Turkish-Dutch, but also Moroccan-Dutch, patients/survivors frequently negatively compare Dutch professionals and the healthcare system to professionals and systems abroad (e.g. in Belgium or Turkey). While the Dutch healthcare system is focused on maintaining patients' current quality of life instead of extending low quality of life, and treatment to palliative patients is being ceased, these patients often get treated to the very end by professionals in hospitals abroad. Patients perceive these professionals as providing better care and taking them more serious compared to Dutch professionals. Besides, professionals in patients' home countries are often perceived as warmer than Dutch professionals. Altogether, professionals think that all these factors cause a lack of trust in the Dutch healthcare system and professionals:

> They do not trust the treatment, that we won't heal them anyway. [ON, Female].

Technology acceptance

Perceived usefulness, ease of use, attitudes and intentions towards Health Communicator use among patients/survivors

All Turkish-Dutch and Moroccan-Dutch patients/survivors believed that the *Health Communicator* could be useful in providing univocal and reliable information about cancer, such as the symptoms of cancer, the side-effects of treatment options, the role of food and alternative medicine in cancer care, and the healthcare system, such as patient rights. As for the affective needs, patients/survivors believed that the *Health Communicator* could be useful in relieving their emotional burden by, e.g. facilitating peer support and getting in touch with their healthcare professionals. Patients/survivors believed that the *Health Communicator* would let them feel taken more seriously:

> If you can email once a month with questions, and receive a response, you would feel taken seriously. [Turkish-Dutch, Male].

Despite the positive perceived usefulness, almost half of the patients/survivors – mostly Moroccan-Dutch – perceived the *Health Communicator* as difficult to use. They often explained this by their inability to use technology, their older age, and their low level

of education. Furthermore, the majority of patients/survivors showed a negative attitude and intention towards using the *Health Communicator*. Patients/survivors mentioned that the *Health Communicator* would be more suitable for younger patients, or when patients are being trained in using it. Patients/survivors who showed a negative intention often said that they doubt whether they can use the *Health Communicator*, and/or that they will not need it because they already get sufficiently informed by their professional or informal caregiver.

Points of improvement according to patients/survivors

In order to make the *Health Communicator* easier to use, patients/survivors mentioned that the tool should be: (1) simpler to navigate (e.g. using big buttons and colors), and (2) in auditory format (e.g. read questions and answer option out loud). Patients/survivors mentioned that they would have higher intentions to use the *Health Communicator* if it would offer options to: (1) make or keep track of appointments, (2) email their GP, (3) watch videos about cancer treatment, and (4) chat with peers/other patients/survivors.

Perceived usefulness, ease of use, attitude and intention towards Health Communicator use among professionals

According to professionals, the *Health Communicator* could be useful in supporting the fulfillment of patients' instrumental needs by providing information about cancer, such as different cancer types and treatment options, and the healthcare system, such as patient rights. Besides, professionals mentioned that the *Health Communicator* would be useful in bridging barriers they perceive by creating more openness and honesty between patients/survivors and professionals. On the one hand, prior to the medical encounter patients/survivors could provide information about their instrumental and affective needs through the *Health Communicator*. On the other hand, patients could be provided the option to email the professional, which could reinstall trust in Dutch professionals and the healthcare system.

As for the ease of use, the majority of professionals mentioned that the *Health* Communicator would not be suitable for this specific target group, mainly due to their age and little experience with using technological tools:

> But I can't imagine older Moroccan-Dutch and Turkish-Dutch people working with such an app. [ON, Female].

Nevertheless, they reported that the use of the *Health Communicator* would be easy for professionals. Precondition for this ease was that it would be ensured that the tool would run without problems on all operating systems, which is currently not always the case. Most professionals also mentioned that they can see the benefits of using the *Health Communicator* in supporting patients' need fulfillment, and therefore intended to use the *Health Communicator*.

Points of improvement according to professionals

In order to make the *Health Communicator* easier to use and to enhance intention to use the tool, professionals mentioned some pre-requisites the *Health Communicator* should satisfy at the level of 'use by patients' and some at the level of 'use by professionals'. At the level of patients, professionals mentioned that the *Health Communicator* would be easy

to use if: (1) it is simpler to navigate, (2) pictograms, smileys, and other visual materials are used, (3) it will contain videos with information in a narrative style, (4) it will have the option to log into a personal account, and (5) it will be available on smartphones. At the level of professionals, professionals told that the *Health Communicator* should be: (1) easy to navigate, (2) connected to patients' electronic health records, (3) guarantee safety and privacy of patients, (5) take little time and effort to use, and (5) implemented top-down (i.e. first embraced by management).

Table 2 illustrates the main findings by providing an overview of quotes per subtheme.

Discussion

Both Turkish-Dutch and Moroccan-Dutch older cancer patients/survivors reported wide-ranging unfulfilled instrumental and affective needs, although Moroccan-Dutch cancer patients/survivors reported to have less unfulfilled needs than Turkish-Dutch patients/survivors. As for instrumental needs, they specifically needed more information about cancer (treatment) and the healthcare system. Our results on their wide-ranging instrumental needs are in line with findings of a recent review study on non-Western migrant cancer patients' information needs and preferences, which showed that non-Western migrant cancer patients/survivors needed and/or preferred to receive more information about their disease than they get (Yilmaz et al. 2019).

Barriers to fulfilling patients'/survivors' instrumental needs, i.e. the language barrier and low health literacy, cultural taboo, and lack of insight into patients' needs, correspond with findings of previous studies (Watts et al. 2017). For instance, Watts et al. (2017) showed that professionals often feel uncertain, especially when dealing with Muslim patients, because they lack both information about and understanding of this group of patients, and because they experience cultural and linguistic differences. In our study, however, professionals frequently attributed the barriers to fulfilling patients'/survivors' instrumental needs solely to the patients' family members. Their involvement as informal interpreters, decision-makers, or contact person was being perceived as hindering professionals in inquiring the instrumental needs of patients/survivors. Professionals frequently blamed the family members of the patient/survivors for not being able to reach the patient/survivor. This perceived hindrance of family involvement has also been reported in previous literature (Shepherd, Tattersall, and Butow 2008; Laidsaar-Powell et al. 2016; Zendedel et al. 2016; Watts et al. 2017).

In our study, one of the main factors related to the barriers to fulfill patients'/survivors' instrumental needs seems to be a mismatch between perceptions of patients/survivors and professionals. For example, patients/survivors reported several unfulfilled instrumental needs while professionals mentioned that they already inform patients/survivors. Besides, patients/survivors requested their healthcare professional to share all information with them, while professionals mentioned that they do not sufficiently know the extent of the needs of their patients. Hence, it seems likely that on the one hand some of the information provided by professionals is not being understood by patients/survivors, while on the other hand professionals underestimate or misunderstand information they receive from the patient/survivor regarding his/her instrumental and affective needs (Schinkel et al. 2016). Linguistic and cultural differences seem to underlie this mismatch between perceptions. Due to low language proficiency, and

Table 2. Quotes per theme.

Patients			Professionals	
	Turkish-Dutch	Moroccan-Dutch		
Unfulfilled instrumental needs			Perceived barriers in fulfilling instrumental needs	
• *Information about cancer (treatment)*	*'I said 'I've one request: you're going to tell me even the smallest thing about my illness. 'You've this long to live', or 'We are not able to treat this anymore', or 'I can treat this'.'* [Male, 69 years]	*'I asked if I am going to be better or will the disease come back? That's a very important question for me to keep me updated about my health.'* [Female, 60 years]	• *Language barrier and low health literacy*	*'Well, the problem is that even if you can discuss a topic with the patient, due to the language barrier the patient cannot easily communicate with you.'* [General practitioner]
• *Information about the healthcare system*	*'All three drugs you [the oncologist] recommended are drugs that are recommended by the pharmacological industry. Don't you have other things that you would like to recommend, other than these drugs, like food or yoga?' She said 'No.''* [Female, 64 years]	***No unfulfilled needs for information about the healthcare system mentioned by Moroccan-Dutch patients/survivors***	• *Cultural taboo*	*'Well, sometimes we are not allowed to name the diagnosis, we are not allowed to name the treatment, we have to say other things because otherwise they lose hope.'* [Oncological nurse]
			• *Lack of information*	*'It's also the question whether they [patients] want to know their diagnosis or not. Could that be discussed at all?'* [General practitioner]
Unfulfilled affective needs			**Perceived barriers in fulfilling affective needs**	
• *Possibilities regarding psychosocial support*	*'Even if it's not a psychiatrist, someone with relevant education [would help]. For instance, you could email once a month, ask your questions and receive the answer. The patient would then feel more appreciated and it would stimulate the wellbeing so much.'* [Male, 61 years]	*'That is why I told you we need psychiatrists; everyone has to have one, just like a general practitioner.'* [Male, 69 years]	• *Cultural differences in non-verbal affective behaviors*	*'In particular, here we sometimes say 'Well, we can't do anything from now on, so we're choosing for quality of life, hence, enjoy the last moments to the fullest' in a very confrontational way.'* [General practitioner]
• *Doctor-patient relationship*	*'What I want is that they have a holistic view. I don't want them to only focus on the tumor, I want them to pay attention to my whole body.'* [Female 64 years]	*'Well they say it is colon cancer, but I still have my doubts if it is really cancer'* [Female, 75 years]	• *Uncertainty about patients' affective needs*	*'I often think 'It's so hard for him/her' about the elderly from ethnic minority background, but I can't reach the pain, I can't reach that emotionality of the patient. They [patients] isolate themselves because they think they should bear with their destiny.'* [Oncological nurse]
			• *Lack of trust in the healthcare system*	*'Moroccan patients have very little trust in Moroccan doctors […] In Turkish patients, it is the complete opposite. They go to Turkey for a*

(*Continued*)

Table 2. Continued.

Unfulfilled instrumental needs	Patients Turkish-Dutch	Moroccan-Dutch	Professionals Perceived barriers in fulfilling instrumental needs	
				second opinion, they highly trust the ability of the doctors there.' [General practitioner]
Technology acceptance			**Technology acceptance**	
• *Perceived usefulness*	*'It is nice, for sure. It is useful, for sure.'* [Male, 76 years]	*'Well, yes, I believe that it would be useful for people who understand it and are going to use it.'* [Male, 81 years]	• *Perceived usefulness*	*'I think that you would create a lot of peace for Turkish-Dutch and Moroccan-Dutch people if you implement something like this. More peace because they can read it, get the feeling that they are thought of.'* [Oncological nurse]
• *Perceived ease of use*	*'Well, it's easy to understand. I might be a bit old and can forget, but if you pay attention to it […] I could use it.'* [Female, 74 years]	*'I could use it at home.'* [Female, 57 years]	• *Perceived ease of use*	*'But doesn't it take much of the GP's time to prepare this, or at least to go through the survey?'* [General practitioner]
• *Attitude towards use*	*'Of course I would love to use it, but I can't open it or install it.'* [Female, 69 years]	*'I am not really interested because I am not good at it.'* [P14, Female, 60 years]	• *Attitude towards use*	*'I absolutely see the benefit. Otherwise, I wouldn't be siting here.'* [Oncological nurse]
• *Behavioral intention to use*	*'No […] I can't do it. First, I have to get a training on how to use it.'* [Male, 76 years]	*'No [I will not use it], all the information I get is from the specialist personally. He is the one who gives me the information.'* [Male, 76 years]	• *Behavioral intention to use*	*'Well, we would like to use it, we would like to deploy it more often, but we experience some small technical problems in practice.'* [General practitioner]

maybe even low health literacy as mentioned by professionals, patients probably do not understand all information provided by the healthcare professional, but are also not able to formulate their needs adequately. Besides, low language proficient ethnic minority patients might feel ashamed for not being able to speak the professional's language (Schinkel et al. 2019), and nod even when they do not understand information. It is likely that, as a result, professionals misunderstand or underestimate patients'/survivors' needs.

As for affective needs, our findings showed that Turkish-Dutch and Moroccan-Dutch cancer patients/survivors need more psychosocial support and doctor-patient relationship. It is an interesting finding that these patients/survivors were much more open about their affective needs than expected based on previous literature. For instance, speaking about mental difficulties is often reported to be taboo among non-Western migrant patients (Fassaert et al. 2009; Zandi et al. 2010). In our study, however, both Turkish-Dutch and Moroccan-Dutch patients expressed a vast need for (professional) psychosocial support. This finding is also surprising because professionals in our study told that they have to explicitly inquire about these patients' psychosocial needs, because otherwise these patients do not discuss them. A possible reason why patients/survivors in our study were this open about their psychosocial needs might be that they were interviewed by an interviewer with the same ethnic background and in their own language, thereby creating sufficient rapport and trust to open up about psychosocial issues.

Barriers to fulfilling patients'/survivors' affective needs, i.e. cultural differences in non-verbal affective behaviors, uncertainty about patients' affective needs, and lack of trust in the healthcare system, also correspond with findings of previous studies (Watts et al. 2017). Watts et al. (2017) showed that the emotional needs of ethnic minority patients are often not explored extensively, and that professionals experience difficulties in recognizing both verbal and non-verbal emotional cues of ethnic minority patients. Prior research indeed showed that Dutch GPs and ethnic minority patients with low Dutch language proficiency face difficulties in terms of affective talk during consultations (Schouten and Schinkel 2014). Cultural differences in the way and extent of showing affective behaviors seem to underlie the mismatch between professionals' verbal affective responses and patients'/survivors' need for non-verbal affective communication (Schouten and Schinkel 2015).

Our findings indicate that the *Health Communicator* could be useful in fulfilling patients'/survivors' instrumental and affective needs, and in bridging professionals' barriers. From the professionals' point of view, the *Health Communicator* could be useful in bridging the language barrier, gaining more information about the needs of the patient/survivors, and enhancing trust among patients. The majority of patients/survivors, however, perceived the tool difficult to use, and, ultimately, did not intend to use it. This finding fits the findings of a previous study in which respondents from Turkey showed a positive attitude in general, but did not intend to use eHealth technologies because they perceived the use of technologies as too difficult (Wilkowsk, Ziefle, and Alagoz 2012). Nevertheless, our result should be interpreted cautiously because despite the negative attitude and intention of the majority of our sample, technological tools like the *Health Communicator* might be suitable for ethnic minority patients/survivors who are able to use technology, younger, higher educated, or being trained in using the tool.

Based on these insights, an oncological module which can be integrated in the Health Communicator that consists of question prompt lists (QPLs) and narrative patient education videos has been developed. After several pilot tests with patients and healthcare professionals, a prototype of the oncological module was tested among patients and healthcare professionals. The content (i.e. QPLs and videos) was evaluated positively. Both patients and healthcare professionals perceived the oncological module as useful and intended to incorporate it in consultations. The details of the findings of the development process and evaluation of the oncological module can be found elsewhere (Sungur et al. 2020).

Strengths, limitations, and suggestions for future research

Our study had some strengths and limitations. The major potential source of bias is that the positive reactions (i.e. attitude and intention) towards the *Health Communicator* among a minority of patients/survivors in our sample might be a result of social desirability. Patients/survivors were interviewed by people who shared the same ethnic background. The interviews also lasted relatively long. A strength of this study is the shared background and relatively long time spent together. This probably led to a high degree of trust during the interviews, ultimately leading to openly discussing, for instance, psychosocial needs. However, simultaneously, this same aspect could also have led to socially desirable answers to other interview questions. Repeating this study with interviewers and participants who do not share the same ethnic and linguistic background, might give more insight into whether or not patients/survivors tend to be more open about their psychosocial needs when they talk to someone they can culturally relate to. As for the need for affective communication, a study similar to ours could be performed with Turkish and Moroccan cancer patients/survivors in their own country to gain insight into whether or not unfulfilled needs for affective communication are also present among patients/survivors in their own country.

Another limitation of our study might be that we did not ethnically match healthcare professionals with patients. Ethnic matching between healthcare professionals and patients might lead to better patient outcomes, such as higher patient participation (Schinkel et al. 2016), because less barriers exist in ethnic concordant doctor-patient dyads compared to ethnic discordant doctor-patient dyads (e.g. language or cultural barrier). Hence, if we had ethnically matched healthcare professionals and patients in our study, this could have led to different results, such as more fulfilled patient needs or less barriers perceived by healthcare professionals. As there is a dearth of research on this topic, future studies are needed to investigate the influence of ethnic matching on patients' and healthcare professionals' needs and perceived barriers.

Another strength of our study is that we studied both the patients'/survivors' perspective and the professionals' perspective. These two parties are both crucial to an adequate doctor-patient relationship, and gaining insight into perspectives of both parties sheds light on which unfulfilled needs and which barriers should be addressed in order to enhance doctor-patient relationship. As family members are perceived as one of the major barriers by healthcare professionals, gaining more insight into why family members do not want the patient to know which types of information in which

circumstances, might contribute to an enhanced understanding of communication in intercultural medical encounters where family members are present. For example, an interview-study among family members of migrant cancer patients/survivors might reveal their specific motives for not wanting certain information to be shared with the

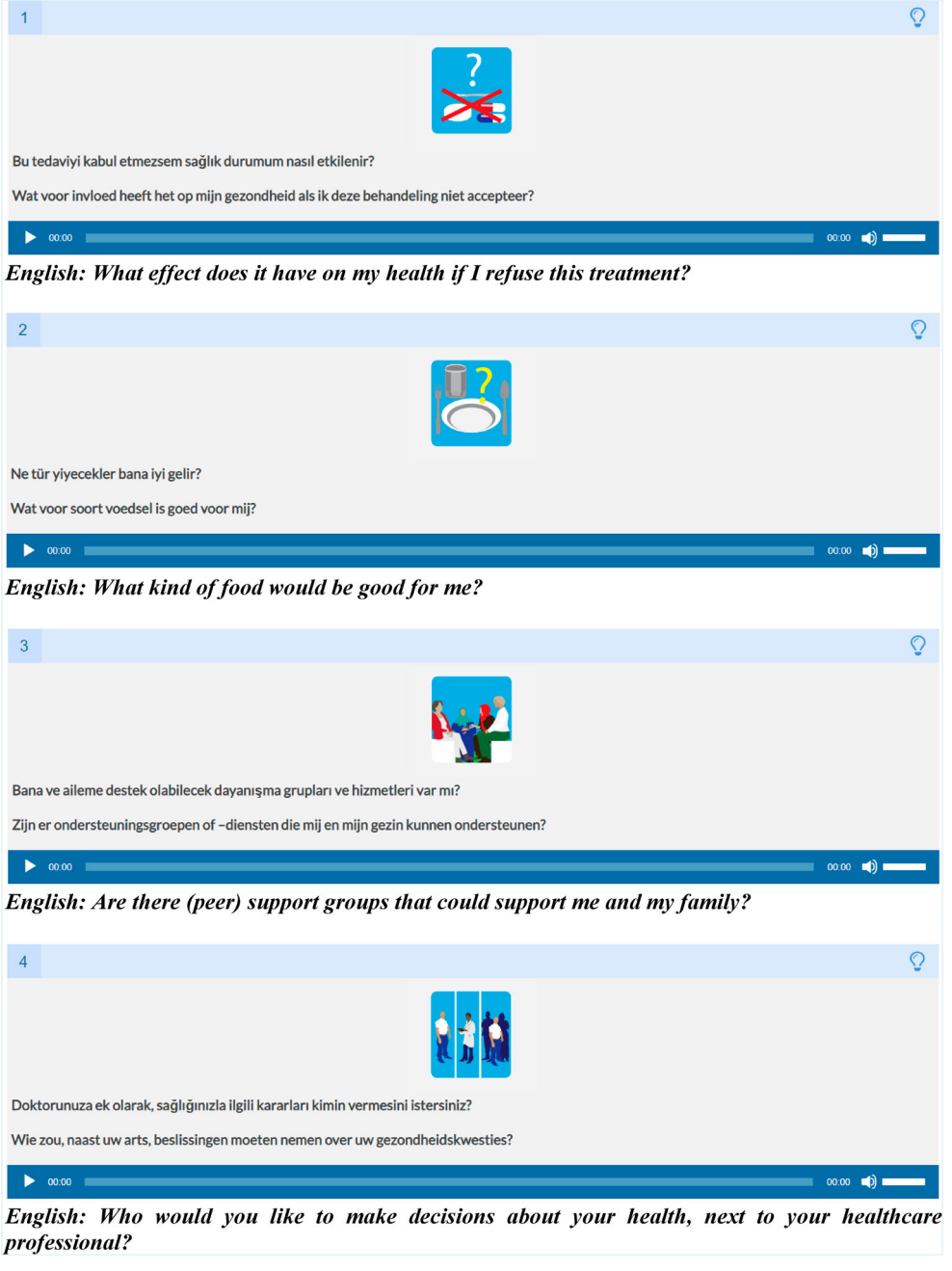

Figure 1. Screenshots of the oncological module (QPLs from the Turkish version).

patient as well as possible solutions to the family barrier perceived by healthcare professionals.

Practice implications

Our study yielded some interesting results and discussion points that could be addressed in practice and in future research. First, there seems to be a mismatch between what information patients/survivors report to receive, and what information professionals report to provide. In order to tackle this mismatch, patients/survivors could be explicitly reminded of the option to make voice recordings of their medical encounters. Professionals, on the other hand, can actively inquire patients'/survivors' instrumental and affective needs, and monitor whether mutual understanding has been reached through teach-back during the conversation.

Second, family involvement was often mentioned by professionals as the main reason for perceived barriers in fulfilling patients'/survivors' instrumental needs. Western healthcare professionals frequently apply a patient-centered approach. In this approach, patients'/survivors' needs and preferences are central to the health-related choices to be made. However, as mentioned by professionals as a barrier, family members are involved in medical encounters, while older Turkish-Dutch and Moroccan-Dutch patients/survivors heavily rely on their family members. Hence, a family-centered approach could be more appropriate in care for older Turkish-Dutch and Moroccan-Dutch cancer patients/survivors. In order to train (future) healthcare professionals in communicating with and involving both the patient/survivor and their family members, a more family-centered approach could be a part of the curriculum of future medical doctors.

Third, in order to tailor the *Health Communicator* to both patients'/survivors' and professionals' needs, we have developed a new oncological module which can be integrated in the *Health Communicator*. In this module, a lot of attention has been paid to user-friendliness, and the points of improvement mentioned by patients/survivors and professionals have been taken into account (see Figure 1). Performing a similar study to ours among a younger and higher educated sample of Turkish-Dutch and Moroccan-Dutch cancer patients/survivors could also yield insightful results into the perceived ease of use of the *Health Communicator*.

Conclusion

To the best of our knowledge, this study is one of the first to explore the potential of an eHealth tool to (1) meet unfulfilled instrumental and affective needs among an ethnic minority population in the Netherlands, and (2) bridge barriers perceived by healthcare professionals in meeting these unfulfilled needs. The results contribute to an enhanced understanding of the unfulfilled needs of Turkish-Dutch and Moroccan-Dutch cancer patients/survivors, the specific barriers encountered by professionals dealing with these patients/survivors, the readiness to accept an eHealth technology among both groups, and the perceived potential to fulfill needs and bridge barriers by introducing the eHealth intervention. Altogether, it can be concluded that to enhance the doctor-patient relationship between older ethnic minority cancer patients'/survivors and their

healthcare professional, the *Health Communicator* is, under certain conditions, a promising tool to implement in the oncological setting for fulfilling patients'/survivors' unfulfilled instrumental and affective needs and for bridging barriers perceived by professionals. In turn, fulfilling patients'/survivors' needs could stimulate more active patient participation, leading to positive outcomes for both Turkish-Dutch and Moroccan-Dutch patients'/survivors' health and the Dutch healthcare system in terms of efficiency and quality.

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