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Enhancing patient participation among older and migrant cancer patients through eHealth

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CHAPTER 7

The Health Communicator: Systematic development of a digital oncology tool for bridging language barriers between older migrant cancer patients and healthcare professionals

An adapted version of this chapter is in press as: Sungur, H., Yilmaz, N. G., Chan, B. M. C., van den Muijsenbergh, M. E. T. C., van Weert, J. C. M., Schouten, B. C. (forthcoming). Fulfilling Older Migrant Cancer Patients' Needs: Systematic Development of a Digital Oncology Tool for Bridging Language Barriers with Healthcare Professionals. *J Med Internet Res* (forthcoming). doi:10.2196/21238

ABSTRACT

- Background** Older migrant cancer patients face many language- and culture-related barriers to patient participation during medical consultations. To bridge these barriers, the *Health Communicator*, an eHealth tool with a multilingual history and video patient education system, was developed which includes specific illness-related modules, such as a diabetes module. However, it did not include an oncological module yet, despite the fact that the prevalence of Dutch migrant cancer patients will triple in the coming years.
- Objective** The aim of this study was to systematically develop, implement and conduct a pilot-evaluation of an oncological module for the *Health Communicator* in order to stimulate patient participation in the medical encounter among older Turkish-Dutch and Moroccan-Dutch cancer patients.
- Methods** The Spiral Technology Action Research model was used as framework in developing the oncological module, which incorporates five cycles that engage all relevant stakeholders in intervention development. The listen phase consisted of a needs assessment. The plan phase consisted of developing Question Prompt Lists (QPLs) and scripts for patient education videos. Based on pre-test results, the oncological module was created in the do phase, containing six audiovisual QPLs on patient rights, treatment information, psychosocial support, lifestyle and access to healthcare services, patients' preferences, and clinical trials. Five patient education videos were created about patient rights, psychosocial support, clinical trials, and patient-professional communication. In the study phase, the oncological module was pilot-evaluated among 27 older Turkish-Dutch and Moroccan-Dutch cancer patients visiting their healthcare professional, who received training prior to the pilot-evaluation. In the act phase, the oncological model was disseminated to practice.
- Results** The QPL about patient rights was chosen most often. Patients and healthcare professionals perceived the QPLs as somewhat easy to understand and useful. There was a negative correlation between ease of using the tool and patients' age. Patients reported that using the module impacted the consultation positively and thought they were more active compared to previous consultations. Professionals also found patients to be more active than usual. Healthcare professionals asked significantly more questions than patients though during consultations. After their consultation, patients requested to see the patients' rights video most often. Patients rated the videos as easy to understand, useful and informative. The majority of patients reported that they like to use the tool in the future.
- Conclusions** Older migrant cancer patients and survivors and healthcare professionals found the oncological module to be a useful tool and have shown intentions to incorporate this tool into future consultation sessions. Both QPLs and videos were evaluated positively, the latter indicating that the use of narratives to inform older low literate migrant cancer patients about health-related topics in their mother tongue is a viable approach to increase effectiveness of healthcare communication with this target group.

INTRODUCTION

Migrant patients across the globe are facing numerous adversities within the healthcare system. For instance, healthcare professionals communicate less adequately with migrant patients compared to non-migrant patients (Butow et al., 2011), and their affective and instrumental needs are often not fully met (Ahmed et al., 2017). Healthcare professionals particularly tend to overlook the importance of ensuring that migrant patients in language-discordant consultations comprehend all information presented. This can induce dissatisfaction amongst migrant patients and their family members, ineffective consultation sessions, and ultimately, worse patient health outcomes compared to language-concordant consultations (Jacobs & Diamond, 2017). In addition to language barriers, unresolved cultural barriers might also provoke migrant patients' perceptions of lack of healthcare professionals' respect, inability to participate in the decision-making process, perceived inequalities in care quality, and even discrimination (Akhavan & Karlsen, 2013; Jangland et al., 2009; Suurmond & Seeleman, 2006).

As the number of Dutch migrant cancer patients is expected to triple within the next 20 years, mainly due to ageing of the first generation Turkish-Dutch and Moroccan-Dutch population (Dutch Cancer Society, 2006), it is becoming increasingly important to address language and cultural barriers to adequate healthcare professional-patient communication and enhance older migrant patients' participation during medical consultations in oncological care. In general, patient-targeted intervention strategies that have been found to significantly enhance patient participation, which can be defined as *“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 healthcare professional's beliefs and behaviours”* (Street & Millay, 2001, p. 62), include coaching, providing educational materials and having patients offer their opinions to their healthcare professionals (Castro et al., 2016; Haywood et al., 2006). An example of a successful intervention which employed the above-mentioned strategies comes from Epstein and colleagues (Epstein et al., 2017), in which patients received question prompt lists (QPLs) and individualized communication coaching which assisted them in identifying issues that needed to be addressed during consultation sessions. In addition, previous research indicated that a written QPL is beneficial to the communication, and to psychological and cognitive outcomes of cancer patients (Brandes et al., 2015).

However, Fukui and colleagues concluded that interventions need to be remodelled to be aligned with the cultural characteristics of their participants to yield satisfactory results (Fukui et al., 2000). In an intervention tailored to Americans, cancer patients were provided with statistical information such as the rate of recurrence and survival rates. However, information related to the truth of illnesses in Japan was frowned upon

amongst the Japanese participants. In the modified version, cancer patients were given the liberty to ask for medical information in their own terms. Upon modification, more than 80% of Japanese cancer patients expressed high satisfaction with the intervention, and no participants dropped out of the intervention compared to a 30% drop-out rate in the American version of the intervention. Hence, the results of this study show that interventions have to be culturally tailored to be effective.

Given the lack of interventions tailored specifically to older Turkish-Dutch and Moroccan-Dutch migrant cancer patients to combat the barriers they experience in communicating with their healthcare professionals (Ferguson & Candib, 2002; Paternotte et al., 2015), the current study set out to systematically develop and implement an intervention to improve their participation and satisfaction with care. As the Turkish and Moroccan community is ever-growing as a result of migration and recent figures have shown that they not only make up approximately 5% of the Dutch population, but have also accounted for being two of the fastest-growing populations in the last five years (Central Intelligence Agency, 2020; Statistics Netherlands, 2017), we focused on older Turkish-Dutch and Moroccan-Dutch cancer patients (>55 years). We developed the intervention to be implemented in the *Health Communicator*, a Dutch eHealth tool that has a multilingual history and video patient education system, and has been developed to resolve the language barrier between non-Western patients with low Dutch language proficiency and their healthcare professionals. The inclusion of an online oncological module is further supported by evidence pointing towards the fact that older adults and Turkish-Dutch patients are more inclined to use media over interpersonal sources to gather health information, ranging from television to the internet (Schinkel et al., 2015). In addition, healthcare professionals have expressed positive attitudes and intentions to use the *Health Communicator* in order to increase patient participation in a recent study (Yilmaz, Sungur, et al., 2020, submitted manuscript). Furthermore, presenting information in audiovisual format yields positive effects on information processing, such as lower perceived cognitive load, higher satisfaction with the information, and less decisional conflict in terms of perceiving the decision as more effective (Yilmaz, Timmermans, et al., 2020, submitted manuscript; Yilmaz, van Weert, et al., 2020, submitted manuscript). In particular older adults display more competence in recalling health information in an audiovisual format as compared to just a text-only format (Bol et al., 2015). Hence, the overall aim of this study is to systematically develop, implement and conduct a pilot-evaluation of an online oncological module to integrate with the *Health Communicator* in order to stimulate patient participation among older Turkish-Dutch and Moroccan-Dutch cancer patients.

METHODS

The Spiral Technology Action Research (STAR) (Skinner et al., 2006) model was used as the guiding framework in developing the oncological module. This model encourages several evaluation cycles amongst stakeholders, enabling continuous improvement of the intervention until it is finalized. In order to establish a high degree of relevance for target users, the model incorporates five guiding cycles that engage relevant community members in the development of the intervention. These five cycles; “listen”, “plan”, “do”, “study”, “act” continuously weave technological and community development together (Skinner et al., 2006). In the following sections we describe the steps taken in each phase with a special emphasis on the *study* phase and its results. *Table 12* provides an overview of the aims and the actions during each phase.

Table 12. Overview of the phases, their aims, action, and outputs.

Phase	Aim	Action(s)	Output
Listen	Target group analysis	<ol style="list-style-type: none"> 1. Conducting a literature review to identify (older) ethnic minority cancer patients’ information and participation preferences and needs. 2. Conducting a qualitative study to identify unfulfilled instrumental and affective needs of older Turkish-Dutch and Moroccan-Dutch cancer patients, and the barriers perceived by healthcare professionals (i.e. general practitioners and oncology nurses) to fulfil patients’ needs. 	Review (Yılmaz et al., 2019) Submitted; paper under review (Yılmaz, Sungur, et al., 2020)
Plan	Methodology development	<ol style="list-style-type: none"> 1. Developing question prompt lists and pilot-testing these among patients. 2. Developing narrative patient education videos and pilot-testing these among both patients and healthcare professionals. 	Results shortly described in method section current paper
Do	Development of the oncological module prototype	Finalizing the 6 question prompt lists and 5 narrative patient education videos by revising them based on feedback from patients and healthcare professionals from the <i>listen</i> and <i>plan</i> phase.	Prototype oncological module
Study	Pilot-evaluation of the oncological module	Conducting a quantitative study to pilot-evaluate the oncological module prototype among patients and healthcare professionals.	Findings described in results-section of current paper
Act	Creating a dissemination plan	Creating and disseminating the oncological module, integrated in the <i>Health Communicator</i> and as a stand-alone module: <i>The Conversation Starter</i>	Dissemination of module into health practice

Listen: Target Group Analysis

In order to identify existing findings about the needs of older ethnic minority cancer patients, a systematic literature review was conducted. The results of the literature review revealed that a majority of non-Western ethnic minority cancer patients and survivors

have a high preference and need for information, and shared or active participation. No information was available, however, regarding the preferences and needs of our target population, Moroccan-Dutch and Turkish-Dutch older cancer patients (see for more results (Yilmaz, et al., 2019, **Chapter 5** of this dissertation)).

Given the lack of findings in the literature regarding the needs of older Turkish-Dutch and Moroccan-Dutch patients with cancer, further in-depth interviews were conducted to determine the topics that need to be addressed within the oncological module. Nineteen interviews were carried out with Turkish-Dutch and Moroccan-Dutch (ex)patients with cancer. Results revealed unmet instrumental needs concerning (treatment of) cancer and the healthcare system, and unmet affective needs concerning psychosocial support and affective doctor-patient communication. Acceptance of the *Health Communicator*, which was studied based on concepts of the Technology Acceptance Model (TAM), revealed that patients thought that the *Health Communicator* would be useful to fulfil their unfulfilled needs, but ultimately did not intend to use the tool (Yilmaz, Sungur, et al., 2020, submitted manuscript, **Chapter 6** of this dissertation).

Following patient interviews, two focus groups with GPs and oncology nurses were conducted. Healthcare professionals were asked to reflect on the findings of the patient interviews, share their own experiences and indicate the type of information they would like to receive from their patients to better fulfil their unmet needs. Although professionals acknowledged most unmet instrumental and affective needs of patients that emerged from the interviews, they appeared not to be aware of patients' need for psychosocial support or misunderstandings surrounding clinical trial requests. Professionals also needed more information about patients' instrumental needs and the role of family members in the treatment process (Yilmaz, Sungur, et al., 2020, submitted manuscript, **Chapter 6** of this dissertation). Overall, the patient interviews and focus groups with GPs and oncology nurses provided valuable insights for the following content creation phases.

Plan: Methodology Development

Based on the results of the target group analysis, two types of content, namely Question Prompt Lists (QPLs) and narrative patient education videos were created for the oncological module. In the methodological development phase, several pilot-tests with patients and professionals were conducted for the QPLs and videos before moving on to the third phase where the prototype was built.

Developing QPLs

Based on the emergent instrumental and affective needs of patients, five QPLs were developed addressing the topics of (1) patient rights, (2) lifestyle and access to healthcare services, (3) treatment, (4) psychosocial support, and (5) clinical trials. Each QPL

consisted of four or five simple yes/no questions which aimed at stimulating patients to ask more questions to their healthcare professionals and have a more active role during consultations (e.g. “*Can I discuss my problems in my mother tongue with someone sharing my culture?*”, and “*Can I ask for a second opinion?*”). Additionally, in order to address healthcare professionals’ instrumental needs, a sixth QPL was developed which enabled them to learn more about patients’ instrumental and decision-making preferences and health behaviours (e.g. “*Are you using any medication bought from another country?*”, “*Who do you want, next to your doctor, to help you make healthcare decisions for you?*”). To assist patients with low literacy, additional illustrations that represent each question were developed.

All QPLs and accompanying illustrations were pilot-tested during in-depth interviews conducted with 11 older migrant cancer patients and survivors (8 Moroccan, 3 Turkish, $M_{\text{age}}=61.50$, $SD_{\text{age}}=9.36$). Patients evaluated each question and illustration for ease of understanding of the content and language (e.g. “*Do you understand this question?*”, “*Do you think this picture is a clear illustration of the question?*”). Results showed that patients found the QPL questions easy to understand while some illustrations were found too abstract. Patients had specific recommendations for word choices and requested increasing concreteness and familiarity of illustrations, such as adding headscarves to some of the female figures and removing abstract symbols. Based on their recommendations, revisions were made that were incorporated in the *do* phase of our intervention development.

Developing videos

Five scripts for the videos were created addressing: (1) patient rights and access to healthcare services, (2) doctor-patient communication, (3a and 3b) psychosocial support and (4) clinical trials. Two separate scripts featuring a male and a female patient as main characters were created for the psychosocial support video. This was done to enhance identification with characters for both male and female patients. Each script related to the experiences of an older migrant patient who survived cancer from the patients’ point of view. The scripts incorporated actual experiences and specific language used by patients during interviews in the target group analysis phase as much as possible.

The scripts were pilot-tested with eight older migrant patients with cancer ($n=3$ Turkish, $n=5$ Moroccan, $M_{\text{age}}=63.75$, $SD_{\text{age}}=6.39$) during individual in-depth interviews. Patients evaluated each script on ease of understanding (“*Can you understand everything said in the video/happening in the video easily?*”), familiarity (“*Does this story sound familiar to you?*”), usefulness (“*Do you find the information provided in the story useful?*”), believability (“*Do you find the information believable?*”), emotions induced (“*Does this story induce any emotion for you and if yes what type of emotions?*”) and level of identification with the main characters (“*Can you put yourself in the shoes of the character in the story?*”). Patients

found the scripts easy to understand and reported very high familiarity, believability and identification with the characters. They stated that they could see themselves in these stories and understand the emotions shared by the characters, and they also found them to be very useful for other patients.

We also tested the scripts in two separate focus group meetings with GPs ($n=6$, $M_{\text{age}}=45.17$, $SD_{\text{age}}=11.89$, 2 women, 4 men) and oncology nurses ($n=5$, all women, $M_{\text{age}}=49.60$, $SD_{\text{age}}=12.16$). The healthcare professionals evaluated the scripts on accuracy (“*Is all the information provided in the script correct?*”) and usefulness of the provided information (“*How useful do you find the information in the script?*”), as well as their willingness to share the videos once they are available (“*Would you share these videos with your patients in the future?*”). Results showed that healthcare professionals overall found them to be accurate and useful and they expressed their intentions to use them in the future.

Do: Developing the Oncological Module Prototype

Based on the results of the pilot-tests with patients and the healthcare professionals, we created the prototype for the oncological module. The prototype included the six QPLs tested in the previous phase. We made use of voice actors and added audio support to the QPLs in Turkish, Moroccan Arabic and Berber (Taraft dialect), enabling (illiterate) patients to listen to the QPLs in their mother tongue.

Similarly, feedback on the scripts was incorporated and five short videos (1.5 - 3.5 minutes long) featuring Turkish-Dutch and Moroccan-Dutch actors were filmed. Once again, voice actors were used to narrate these stories in Turkish, Moroccan Arabic and Berber (Taraft). The first video addressed patients’ instrumental needs about patient rights (e.g. right to informed consent) and access to healthcare services (e.g. dietician, home care, psychological support). The second video included suggestions to improve GP-patient communication, by encouraging patients to prepare before consultations, ask more questions, make use of interpreters and inform the doctor about their affective needs. The third and fourth videos aimed to provide psychosocial support to patients. The videos acknowledged the negative emotions experienced by cancer patients and tried to counter them by giving a positive but also realistic message of hope. Topics about self-care such as importance of good diet, social contacts, psychological and spiritual support were incorporated in these videos as well. The final video aimed at clarifying the misunderstandings surrounding clinical trial requests. The video emphasized that a request to join a clinical trial does not mean that patient has no hope of treatment and that patients can take time to decide on joining these trials, can refuse to join without risking their relationship with their doctors, and can quit if they accept to join. Furthermore, information with regard to the general aim of these trials was given.

Study: Pilot-evaluation of the Oncological Module

Sample

The oncological module was pilot-evaluated in practice among 27 Turkish-Dutch and Moroccan-Dutch older (ex)patients with cancer aged 50 years and older (Turkish: $n=15$, 9 females, $M_{age}=63.47$, $SD_{age}=2.59$, Moroccan: $n=12$, $M_{age}=63.33$, $SD_{age}=2.70$) and their healthcare professionals (GPs and oncology nurses) ($N=12$, $M_{age}=53.50$, $SD_{age}=13.34$) (see *Table 13* and *Table 14* for sample characteristics). Dutch language proficiency was self-reported by patients on a 4-point scale ($1=poor$, $2=mediocre$, $3=reasonable$, $4=good$). Patients were recruited by firstly targeting their healthcare professionals. Based on snowball sampling with the help of the healthcare professionals that participated in the earlier phases of the study, we reached other healthcare professionals, who then invited their patients to participate in the study.

Table 13. Background characteristics of patients.

	Turkish ($n=15$)	Moroccan ($n=12$)	Total ($N=27$)
Age ($M \pm SD$)	63.47 \pm 2.59	63.33 \pm 2.70	63.41 \pm 9.55
Gender			
Female	9	9	18
Male	6	3	9
Level of education			
No schooling	26.7%	50.0%	36.0%
Primary school in Turkey/Morocco	46.7%	40.0%	44.0%
Secondary school in Turkey/Morocco	6.7%	-	4.0%
Primary school in the Netherlands	-	10%	4.0%
Secondary school in the Netherlands	13.3%	-	8.0%
Higher education in the Netherlands	6.7%	-	4.0%
Years residing in the Netherlands ($M \pm SD$)	39.40 \pm 3.21	34.09 \pm 3.54	37.15 \pm 12.19
Dutch language proficiency ($M \pm SD$)	1.89 \pm .30	2.21 \pm .29	2.02 \pm 1.08

Table 14. Background characteristics of healthcare professionals.

	General practitioners (n=10)	Oncology nurses (n=2)	Total (N=12)
Age (<i>M</i> ± <i>SD</i>)	57.50 ± 10.50	33.50 ± 2.12	53.50 ± 13.34
Gender			
Female	5	2	7
Male	5	0	5
Work experience in years (<i>M</i> ± <i>SD</i>)	23.44 ± 10.37	6.00 ± 2.82	20.27 ± 11.67
Number of 50+ years old cancer patients with a Turkish or Moroccan background treated in previous two years			
1-2	1	0	1
2-4	4	0	4
5-10	5	1	6
10+	0	1	1

Procedure

Prior to the pilot-evaluation, all participating healthcare professionals received an hour long individual training on how to use the oncological module. Patients evaluated the QPL content and use before their consultations in GP practices or hospitals by means of surveys which were verbally administered to the patients in their mother tongue by bilingual trained interviewers. Interviewers presented patients the QPL themes in the oncological module and asked them to choose one or more QPLs that they would like to fill out. After choosing a theme (e.g. patient rights), patients saw all available questions within that QPL (e.g. “*Can I record consultations?*”) and selected the ones they wanted to discuss with their professionals during the consultation (see *Figure 9*). Before the consultation started, patients evaluated their experience with the QPLs that they chose. Healthcare professionals rated the usefulness and ease of use of QPLs at the end of the pilot-study.

Following the QPL selection, patients and professionals had a consultation in the same GP practice or hospital. Eighteen patients gave consent to have their consultation being audio-taped. Patients who did not consent felt the topics were too private and did not want anyone else to hear them even though their anonymity and confidentiality were guaranteed. After the consultations, patients filled out a survey again measuring their evaluation of the consultation. After filling out the post-consultation survey, the topic of all available narrative videos was shortly described to the patients. Patients selected the videos they wanted to watch. Most patients preferred to receive the videos on their smartphones. When this was not possible, patients requested that the videos were sent to patients’ family members’ phones. After patients watched the videos, phone interviews were conducted with them on average within a week’s time to assess how they perceived the videos. During the same phone interviews, patients were asked to rate the overall usefulness of the oncological module for improving their communication with their

healthcare providers (i.e. *“Overall, this tool is useful to improve my communication with my healthcare provider”*). Healthcare professionals also responded to a similar question during the survey that they filled in at the end of their participation (i.e. *“The oncological module is useful in bridging communication barriers between migrant patients and their providers”*).

Measures

All survey items were measured with 5-point Likert scales (e.g. *1 = completely disagree, 5 = completely agree; 1 = very difficult, 5 = very easy; 1 = very unsatisfied, 5 = very satisfied*).

Patients’ evaluation of QPLs

After making their selection, patients assessed the ease of using the tool (both with and without assistance), ease of understanding of QPL content and accompanying graphic images, and finally how convenient it was to choose QPLs before a consultation.

Patients’ evaluations after consultation

Patients’ general satisfaction about the consultation was measured with one item (i.e. *“Overall, how satisfied are you with your consultation?”*). Patients’ perception of the informativeness and supportiveness of the healthcare professional was measured by three and four items respectively, based on Street et al. (2007) (informativeness Cronbach’s $\alpha=.84$, supportiveness Cronbach’s $\alpha=.95$). Patients’ attitudes towards the oncological module was measured with two items (Using this tool: *“...made communicating with my doctor/nurse easier than usual”*, *“...had a positive influence on my consultation with my doctor/nurse”*, Cronbach’s $\alpha=.87$) and intention to use it again was measured with one item (*“I would like to use this tool again in the future”*) (Street et al., 2007).

Patients’ perceived participation during the consultation was measured by using five items from Street et al.’s (2007) adaptation of the Lerman et al.’s (1990) perceived involvement in care scale (PICS) (e.g. *“I asked my healthcare professional to explain the discussed topics in detail”*, Cronbach’s $\alpha=.82$) (Lerman et al., 1990). An additional question was used to measure the level of participation in comparison to previous consultations (i.e. *“I felt I could participate more than usual in this consultation”*).

Patient participation

Patient participation was assessed with a self-developed codebook, containing two measures: (a) relative talk for each person (i.e. patient, healthcare professional, interpreter/companion), (b) number and type of questions asked by patients, professionals and interpreter/companion. In 11 of 18 consultations, an informal interpreter and/or companion was present. Eight consultations were held by nurses, ten by GPs. Type of questions were divided according to the QPLs, except for clinical trials because this QPL could not be

chosen, because it was deemed irrelevant for GPs (i.e. patient rights, treatment-related information, psychosocial support, lifestyle and access to healthcare services, and patient information). In addition, a category ‘miscellaneous’ was added for questions that were unrelated to these categories (e.g. social questions, checking understanding, etc.). Number of questions was counted per speech turn. If more than one question per turn was asked addressing the same topic, this was counted as one question. Rhetorical questions were not counted. Interpreters/companions’ questions that were a translation of a patient’s or professional’s question were not counted.

Patients’ evaluation of the narrative videos

During the phone interviews, patients rated how easy it was for them to access the videos (“*How easy was it for you to access the videos*”), and ease of understanding (“*The video was easy to understand*”), usefulness (“*The video was useful to improve my understanding of the topic about...*”) and informativeness (“*The video was very informative concerning the topic about...*”) of each video that they had seen. The level of identification with the main characters in the narrative videos was measured with four items (Cronbach’s $\alpha=.81$). Two items were based on Murphy et al. (2013) and measured similarity and liking of the main characters (Murphy et al., 2013), the other two items were based on Cohen’s (2001) identification scale and measured empathy for emotions experienced by main characters (Cohen, 2001). Finally, patient’s intention to watch similar videos in the future (i.e. “*In the future, would you like to watch videos that are similar to the ones that you watched?*”) and whether they have mentioned the videos to others (e.g. friends, family members) was measured.

Healthcare professionals’ evaluation

After each consultation, healthcare professionals evaluated the participation of the patients during the consultation. To measure this, the same questions that patients responded to when reporting their own participation were used. Specifically, these were the 5 items from the PICS (e.g. *The patient asked me to explain the discussed topics in detail*, Cronbach’s $\alpha=.74$) and the additional question about comparison of the participation level (i.e. “*The patient participated more than usual in this consultation*”). During the final survey study, healthcare professionals also evaluated the QPLs and narrative videos on perceived usefulness, ease of sharing with patients and their intentions to use in the future during the final survey.

Analysis

Correlations between variables are calculated by running bivariate correlations using Pearson’s r as correlation coefficient. Relative talk was measured by counting all words per person and calculating the word ratio, question-asking was analysed by means of descriptive analyses (Means and standard deviations). Differences in amount of question-

asking were assessed by means of paired samples t-tests. Relationship between the first QPL topic choice by the patients and number of asked questions by patients and healthcare professionals about that topic during consultations were assessed by simple linear regression analyses. Interrater reliability was calculated for 5 of 18 transcripts (27.7%; two-way mixed effects model) and was 0.99 for professionals' questions, 1.0 for patients' questions, and 0.99 for interpreter/companions' questions.

Act

After the *study* phase was completed, a dissemination plan was devised in collaboration with the Dutch expertise centre on migrant healthcare, Pharos, to distribute the oncological module to target audiences. Firstly, in order to clearly communicate the goal of the oncological module it was named *The Conversation Starter*. Next, the key organizations and actors that could help us reach healthcare professionals and older migrant patients with cancer were identified. Different newsletters highlighting the relevant parts of *The Conversation Starter* were prepared for these different audiences. Finally, a web version of *The Conversation Starter* that can be freely accessed without the *Health Communicator* application was created (to see this version: <https://www.healthcommunication.nl/blog/category/gesprekstarter/>)

RESULTS

Evaluation QPL Content and Use

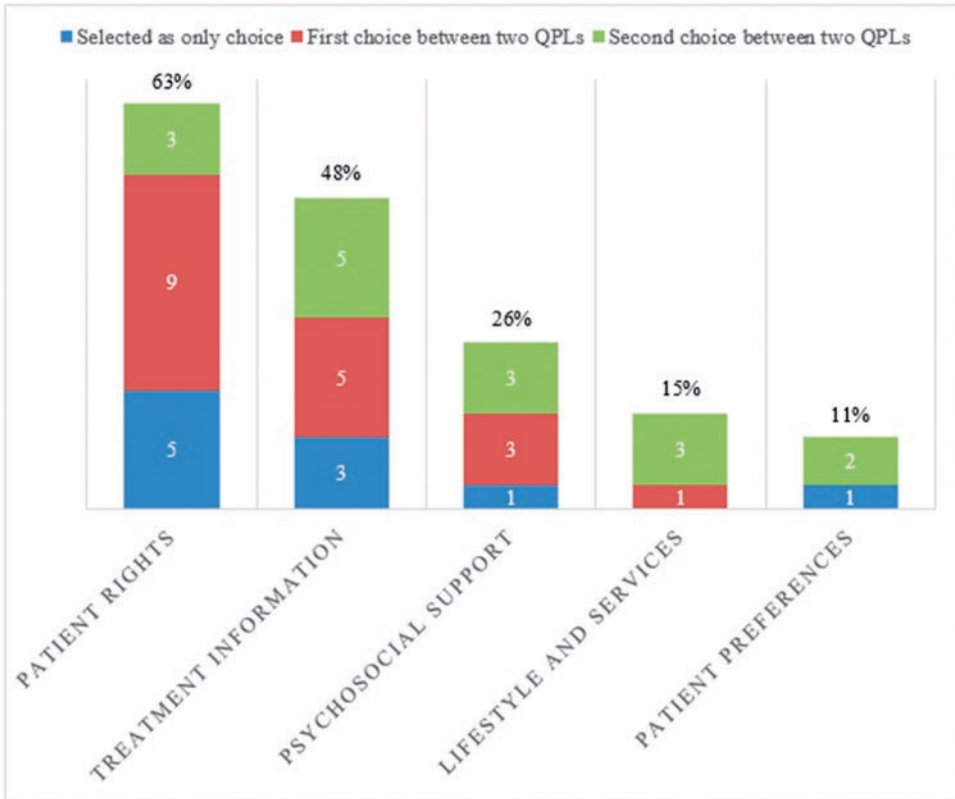
Patients

Overall, patients perceived the questions in the QPLs as easy to understand ($M=4.30$, $SD=.65$) and useful ($M=3.96$, $SD=.72$). Graphic images accompanying the QPLs were perceived as rather easy to understand ($M=3.75$, $SD=1.14$). Patients found the usefulness of the images in aiding the understanding of the questions as neutral ($M=3.23$, $SD=1.27$). Overall, participants found it relatively easy to use the QPL function in the oncological module ($M=3.54$, $SD=1.07$). They were less confident, although still neutral, about their ability to use the tool easily without any assistance ($M=3.19$, $SD=1.44$). There was a strong negative correlation between how easy it was to use the tool and patients' age. It was harder for older patients to use the QPLs ($r= -.48$, $p=.012$) and they were also less confident in their ability to use the tool without any assistance ($r= -.67$, $p < .001$). Around 70% of the patients reported that it was convenient for them to select the QPLs before their consultations ($M=3.85$, $SD=1.35$). Similarly, a younger age was related to reporting more convenience to use the QPL function before the start of consultations ($r= -.56$, $p=.003$).

Professionals

Healthcare professionals rated the QPLs as rather useful ($M=3.67$, $SD=1.07$) and overall somewhat easy to use ($M=3.44$, $SD=.96$).

Figure 9. Breakdown of QPLs selected by the patients in the evaluation study.



Note. Percentages reflect percentage of participants that selected that QPL. Among 27 participants, 10 selected one and 17 selected two QPLs.

Patient participation

Mean consultation length was 14.09 minutes ($SD=7.60$, range 3.37-35.06). Professionals spoke on average most words (48.15%, range 166-2,481), followed by patients (33.5%, range 130-2,544), and interpreters/companions (18.35%, range 38-1,672). Mean number of total questions asked per consultation was 24.55 ($SD=17.21$, range 11-89). Professionals asked significantly more questions per consultation ($M=15.72$, $SD=9.36$; range 3-43) than both patients ($M=4.56$, $SD=5.45$; range 0-23; $t(17)=6.61$, $p < .001$) and interpreters/companions ($M=4.28$, $SD=6.44$; range 0-23; $t(17)=4.81$, $p < .001$). Most questions were asked about treatment-related information ($M=9.89$, $SD=15.87$), followed by questions on

miscellaneous topics ($M=9.28$, $SD=4.34$), patient rights ($M=2.17$, $SD=2.04$), psychosocial support ($M=1.67$, $SD=2.97$), and lifestyle and access to healthcare services ($M=1.50$, $SD=2.75$). Least questions were asked about patient preferences ($M=.06$, $SD=.24$).

Relationship between QPL Choice and Participation during Consultations

Patients

Overall, no significant relationship was found between the first QPL choice and amount of questions asked by patients during the consultation about that topic (Patient rights: $R^2=.17$, $b^*=.12$, $t=.68$, $p=.509$, 95% CI [-.27 ; .52], Treatment: $R^2=.05$, $b^*=-.01$, $t=-.20$, $p=.844$, 95% CI [-.06 ; .05] and Psychosocial Support: $R^2=.15$, $b^*=-.11$, $t=-.60$, $p=.555$, 95% CI [-.50 ; .28]). Since there were not enough patients that selected the QPLs about life style and access to healthcare services and patient preferences as their first choice, it was not possible to run the analyses to test these relationship.

Professionals

Similarly, we tested the relationship between patients' first QPL choice and the number of questions posed by the healthcare professionals about that topic. Number of questions asked by the healthcare professionals in a given topic were marginally significantly predicted by the first QPL topic selected by the patients for Patient rights ($R^2=.42$, $b^*=.14$, $t=1.85$, $p=.083$, 95% CI [-.02 ; .31], but not for Treatment: $R^2=.09$, $b^*=-.01$, $t=-.37$, $p=.720$, 95% CI [-.04 ; .03] and Psychosocial Support: $R^2=.15$, $b^*=.02$, $t=.61$, $p=.553$, 95% CI [-.06 ; .11]).

Evaluation of Consultations

Patients

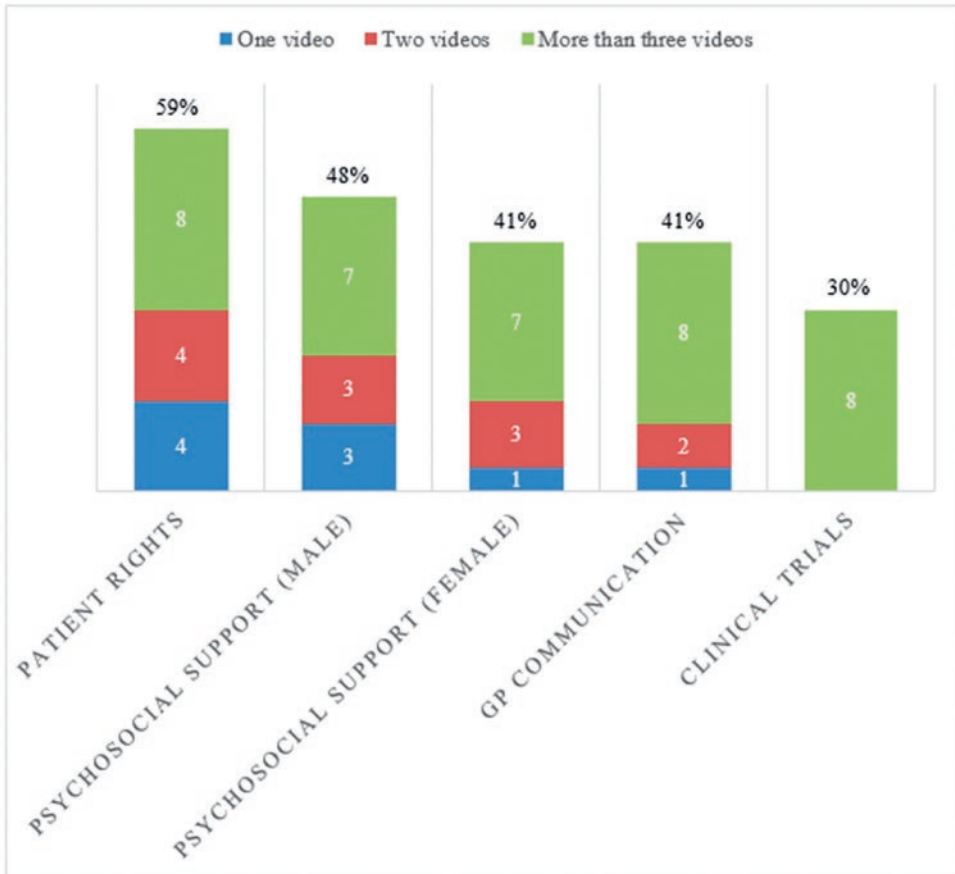
Overall patients reported being highly satisfied with their consultations ($M=4.31$, $SD=.55$). They perceived their providers to be informative ($M=4.17$, $SD=.57$) and supportive ($M=4.34$, $SD=.59$). They also reported that using the module impacted the consultations positively ($M=3.90$, $SD=.55$). Patients perceived themselves to be rather active during the consultations ($M=3.75$, $SD=.84$) and thought they were somewhat more active in comparison to previous consultations ($M=3.75$, $SD=.79$). The majority (70%) of the participants reported that they would like to use the tool in the future ($M=3.85$, $SD=1.25$). Age of the participants had a strong negative correlation with their wish to use the tool in the future ($r= -.45$, $p=.021$).

Professionals

Professionals' evaluation of the patients' participation revealed similar albeit slightly lower scores. Professionals found patients to be slightly active in asking questions and

expressing themselves ($M=3.42$, $SD=.70$) and somewhat more active than their usual levels of participation ($M=3.61$, $SD=1.06$). Both patients' and providers' evaluations were positively correlated for each of these measures ($r=.58$, $p < .001$, and $r=.64$, $p < .001$). Figure 10 shows a breakdown of the videos selected by patients.

Figure 10. Videos selected by the patients.



Note. Percentages reflect percentage of participants that selected that video. 33% of patients selected one, 22% two, 4% 3, 19% 4 and 11% 5 videos, amounting to an average of 2.3 videos requested per patient.

Evaluation of Narrative Videos

Patients

Patients rated the videos as easy to understand ($M=4.30$, $SD=.47$), useful ($M=4.00$, $SD=.62$) and informative ($M=4.20$, $SD=.57$). Identification with the characters in the videos was high ($M=3.93$, $SD=.54$). Patients were somewhat motivated to watch similar videos in the future ($M=3.55$, $SD=.85$). Around 30% of the patients talked about the videos with others (i.e. told their friends and family members that they watched these videos).

Professionals

Professionals rated the videos to be useful ($M=3.92$, $SD=1.08$). They were neutral about the ease of sharing the video with their patients ($M=3.25$, $SD=1.06$) and showed some intentions to share the videos ($M=3.42$, $SD=1.08$).

Overall evaluation of the oncological module

Overall, patients found the tool to be useful in improving their communication with their healthcare professionals ($M=4.27$, $SD=.88$). Healthcare professionals rated the usefulness of the oncological module less favourable than the patients ($M=3.42$, $SD=1.16$).

DISCUSSION

This paper elaborates on the development of an oncological module aimed at increasing patient participation between older migrant cancer patients and their healthcare professionals. Using the STAR model as our framework, the module was developed with continuous input from relevant community members, namely older migrant cancer patients, oncology nurses, GPs, and researchers. This multi-facet contribution allowed us to develop a multilingual intervention which received positive evaluations from both migrant cancer patients and professionals overall. Patients most often chose the QPL about patient rights. Both patients and healthcare professionals perceived the QPLs as somewhat easy to understand and useful. The correlation between ease of using the tool and patients' age was negative. Healthcare professionals asked significantly more questions than patients, while patients reported that using the module impacted the consultations positively and thought they were more active compared to previous consultations. Professionals echoed that patients were more active than usual. However, there were no significant relations between patients' first choice of QPLs and amount of questions asked about that topic during consultations. Patients requested to see the patients' rights video most often, and overall rated the videos as easy to understand, useful and informative. The majority of patients reported that they like to use the tool in the future.

Aligned with Walczak and colleagues' study, migrant cancer patients in this study evaluated the QPLs as easy to understand and quite useful (Walczak et al., 2013). This is likely to be the result of the fact that the QPLs served the function of breaking down all cancer-related information that existed into small segments. By doing so, large chunks of information are labelled, and this helped migrant patients to identify their concerns and needs more easily, thus preventing the possibility of experiencing cognitive overload (Walczak et al., 2013). Nonetheless, the evaluation became less positive with an increase in patients' age. The older the patient, the less easy they found using the tool, which might partly be explained by a decrease in one's cognitive competence over time (Bolle et al.,

2016; Nikou et al., 2019). To be readily able to adopt eHealth tools, older patients first have to be in a physically good condition and, second, also to be cognitively competent enough to develop internet literacy (Nguyen et al., 2018). Based on the results of a systematic review, a suggested solution to help (older) migrant patients to better understand how QPLs work would be through incorporating a training component for patients (Brandes et al., 2014). In our intervention, only health professionals were trained though. Such a training component for patients would not only ensure that the consultation sessions would be effectively guided by the QPLs, but also offer guidance for older migrant patients who might need help using the tool as a result of old age (Rodenbach et al., 2017).

Results collected for the examination of patient participation during the consultation sessions revealed that overall, professionals were more active than patients, in terms of leading the conversation and asking questions. A recent study revealed that patients' passive participation could be due to the knowledge and language barriers they face (Landmark et al., 2017), also indicated by the lack of relation between choice of QPLs and type of questions asked. Despite the fact that an interpreter or a companion was present during the majority of consultation sessions, it is still possible that the patients suffered from a lack of understanding about the subject matters raised by the professionals and/or did not have the ability to ask questions about the topics they indicated to want to discuss by their QPL choice due to an unresolved language barrier during the consultations. As a result of these barriers, there is a possibility that patients possessed insufficient competence to formulate the exact question or response they would like to make, especially when it comes to disagreeing with a statement proposed by the professional, as this requires more effortful processing, compared to simply agreeing with a statement (Hawkins et al., 2008; Landmark et al., 2017). As such, they may experience a lack of confidence and choose to refrain from making their point, thus generating less questions and talk leading to a relatively passive outcome in terms of patient participation. As indicated by Cegala and Post (2009), a lack of response from patients' end hinders the active adoption of a more patient-centered communication from the professionals' end. This shows that there is a need for patients to be more empowered first in order to secure a consultation session with active patient participation (Cegala & Post, 2009).

Given that the results indicated most questions raised were about treatment-related information, a possible solution to tackle patients' passiveness would be through distributing information related to their cancer diagnosis in their native languages along with the QPLs before each consultation session, if they have a preference for this information. This approach can enhance patients' knowledge towards the subject, which, in turn, allows them to become more confident in expressing their views and opinions about the professionals' suggestions and thus facilitate a patient-centered communication and result in an active patient participation. In addition, working with

professional interpreters instead of non-professional interpreters during consultations is recommended, as most patient rights topics discussed during the consultations were related to patients' need for a professional interpreter. This will lead to better translations and enhance patients' understanding of the conversation (Butow et al., 2011; Karliner et al., 2007), enabling more active participation during consultations.

Migrant cancer patients' assessment of their QPL incorporated consultation sessions was fairly positive, with patients expressing high satisfaction and concluding that the QPLs helped to impact their consultation sessions positively. Professionals' overall evaluation of patients' participation was less satisfactory though, possibly because patients did ask less questions and contributed less to the conversation than they might have expected as a result of the intervention. On the other hand, for patients the QPLs were able to help them to identify topics of interests in a more direct manner, and in turn, this helped professionals to formulate a clearer picture of their unmet instrumental and/or affective needs and prepare the consultation sessions based on this feedback accordingly. Although only marginally significant, the positive relation between patients' choice of the patient rights QPL and healthcare professionals' questions about patient rights seems to lend some substantiation for this positive effect of QPLs, helping both parties to bring up the topic of patient rights more immediately during their consultation, thus increasing patients' satisfaction with the consultation sessions (Brandes et al., 2014). Corresponding with previous research, this indicates that using QPLs allowed for a more effective communication between patients and professionals as indicated by higher perceived patient participation than usual, and helped to improve the consultation sessions and encourage active patient participation (Brandes et al., 2014; Noordman et al., 2017).

Last, both patients and professionals evaluated the educational videos positively. Patients reported fairly high levels of identification with the characters in the narrative videos and expressed moderate intentions to watch similar videos in the future. It is likely that high levels of identification with the character in the videos might have helped migrant patients with the ease of processing information presented in the videos due to sharing a common background with the characters in the video (Moyer-Gusé, 2008). Ultimately, this leads to more informed and empowered patients and, in turn, results in positive attitudes towards the videos and better quality of health communication and care. What was especially interesting here was that the results reflected the patients to show more interest towards narrative videos which covered the theme of patient rights in comparison to the other themes. This preference was also reflected in the selection of themes in the QPLs. Corresponding to previous research, this shows that there is a possibility that migrant patients often feel that they are not taken seriously, and to a certain extent, even discriminated against by their doctors (Jangland et al., 2009; Schinkel et al., 2019). Nonetheless, the precise concerns migrant patients might have with regard to their rights

is still scarcely researched and, thus pointing to the fact that more empirical evidence is needed to understand inadequacies in the healthcare system for older migrant patients. All in all, this warrants that more future research is needed to determine the underlying motivations and reasons behind choosing this theme.

Study limitations and suggestions for future research

Despite the fact that older migrant cancer patients showed some intentions to use the oncological module in the future, results indicated that older patients had concerns and expressed little ease and confidence towards their ability to use the tools on their own, especially regarding using the QPLs. Again, this shows that training patients remains a crucial component of such intervention to be effective, as the current study did not sufficiently target the issue of adopting and adherence of the eHealth tool which is especially important among older adults as a result of their low internet self-efficacy (Chung et al., 2010). Previous research has indicated that just a short-term training can lead to successful ICT adoption and outcomes for ethnically diverse older people (Czaja et al., 2018). In addition, future studies could incorporate the extended Technology Acceptance Model (TAM) and Senior Technology Acceptance Model (STAM) into the developmental process (Chen & Chan, 2014; Chung et al., 2010) instead of using the original TAM that was used in this study. The extended TAM sheds light on several spearheads, such as the amount of text used, page organization, and the incorporation of offline support to increase the perceived ease of use of an eHealth tool among older adults (Chung et al., 2010), while the STAM also includes age-related health and ability characteristics, such as gerotechnology self-efficacy (Chen & Chan, 2014). By taking these additional factors suggested by the extended TAM and STAM into consideration, this might increase the tool's overall user-friendliness further and lead to higher levels of perceived ease of use, usefulness and intentions to use. Furthermore, as there is a dearth of research assessing digital literacy skills amongst older migrant patients, future studies are needed to gain more insights into their (lack of) competence to use new technologies in everyday life (Schaffer, 2007) and what is needed to enhance their skills. Results of such studies will help future intervention developers to gain a deeper insight into understanding what features are indeed appropriate and easy to use for them. The combination of incorporating the extended TAM and measuring elderly patients' digital literacy might help to produce higher levels of adoption and adherence to QPLs, which ultimately increases patient participation during the consultation sessions.

Another limitation of this study is related to the developmental process of the prototype. The STAR model was designed fundamentally to promote healthy behaviours among young adolescents by encouraging them to actively take part in the e-tool developmental process (Buccieri & Molleson, 2015). This involves all stakeholders being present in the discussions and decisions taken during all developmental phases. Although we did include patients in as many phases as possible, this approach was deemed unfeasible in the

do phase when the prototype is developed, given the fact that our target group is rather vulnerable due to their sickness and old age. As the inclusion of people who represent different areas of expertise could increase the effectiveness of brainstorming sessions largely (Markman, 2016), future studies should explore the possibility and feasibility to invite migrant patients who are not ill yet, or the migrant patients' close relatives to take part directly in this phase of the intervention development. This could help eHealth developers to get a fuller picture of the attributes that can be added to the module, and also help maximize the customization of the tool for the target user.

Conclusions

Overall, migrant patients and professionals found the oncological module to be a useful tool and have shown intentions to incorporate this tool into future consultation sessions. The findings of this study show that QPLs make a beneficial tool for stimulating healthcare professionals' question-asking in the consultation sessions. Based on this, we conclude that the use of QPLs is an effective tool to assist their consultation preparation in order to better fulfil older migrant cancer patients' instrumental and affective needs. The educational videos were evaluated positively by the patients as well, indicating that the use of narratives to inform older low literate migrant cancer patients about health-related topics in their mother tongue is a viable approach to take to increase the effectiveness of healthcare communication with this target group. However, given that older migrant patients are less able to use the QPLs on their own, healthcare professionals should also look into the feasibility of adding a training component to offer offline guidance in navigating the QPLs. This component can perhaps be added after each consultation session and also shared with family members of the patient, so that older migrant patients and their relatives are exposed to the tool more frequently, which in turn helps increase their familiarity with the tool and enable relatives to help their older family members in using this tool.