



# A conversation approach based on shared goal-setting and shared decision-making for nurses in cancer aftercare: A developmental study

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## ABSTRACT

**Purpose:** This study aimed to develop and pretest a systematic conversation approach for nurses to tailor aftercare to oncology patient's goals, unmet needs and wishes.

**Methods:** We used an iterative developmental process for complex interventions: 1. Identifying problems 2. Identifying overall objectives 3. Designing the intervention 4. Pretesting and adapting the intervention.

**Results:** The main results of the problem identification were: non-systematic and incomplete screening of potential issues, caveats in providing information, and shared decision-making. The overall objective formulated was: To develop a model for aftercare conversations based on shared goal-setting and decision-making. The conversation approach consists of four phases: 1. Preparation of the consultation including a questionnaire, 2. Shared goal-setting by means of a tool visualizing domains of life, and 3. Shared care planning by means of an overview of possible choices in aftercare, a database with health care professionals and a cancer survivorship care plan. 4. Evaluation. The results of the pretest revealed that the conversation approach needs to be flexible and tailored to the patient and practice setting, and embedded in the care processes. The conversation approach was perceived as enhancing patient-centeredness and leading to more in-depth consultations.

**Conclusion:** The conversation approach was developed in co-creation with stakeholders. The results of the pretest revealed important implications and suggestions for implementation in routine care. The aftercare conversation approach can be used by nurses to provide tailored patient-centered evidence-based aftercare. Tailored aftercare should support oncology patient's goals, unmet needs and wishes. Further tailoring is needed.

## 1. Introduction

Cancer survival rates have improved due to advances in early detection and treatment (American Cancer Society, 2015; European Society for Medical Oncology (ESMO), 2014). In conjunction with rising global cancer incidence rates (Torre et al., 2016), this has led to a rapid increase in the number of individuals living with and beyond cancer. In 2012, the estimated global 5-year prevalence for all cancers combined was 15,296 per 100,000 persons, equivalent to 32.6 million people living with a cancer history (within 5 years of diagnosis) (Corsini et al., 2017; Ferlay et al., 2015).

Cancer and its treatment are often associated with long-term physical and psychosocial issues such as fatigue, pain, reduced muscle mass and strength, problems in daily functioning, fear, anxiety, sleep

disturbances, reduced self-esteem and problems with returning to work (Aaronson et al., 2014; ESMO, 2014; Integraal Kankercentrum Nederland (IKNL), 2011a; Simard et al., 2013). As such, cancer survivors often face the imposing task of rebuilding their physical and psychological health, which requires evidence-based aftercare (The Health Council of the Netherlands, 2007; Hewitt et al., 2005). Oncology nurses and advanced practice nurses may play a crucial role in the development and delivery of coordinated aftercare (Klemp, 2015).

Aftercare is often intertwined with clinical follow-up, as these terms are not always clearly distinguished. In this study, aftercare and follow-up are defined in accordance with the Dutch Health Council (The Health Council of the Netherlands, 2007) as follows: aftercare includes interventions such as education, physical training and psychosocial support that helps patients to deal with potential issues of cancer and its

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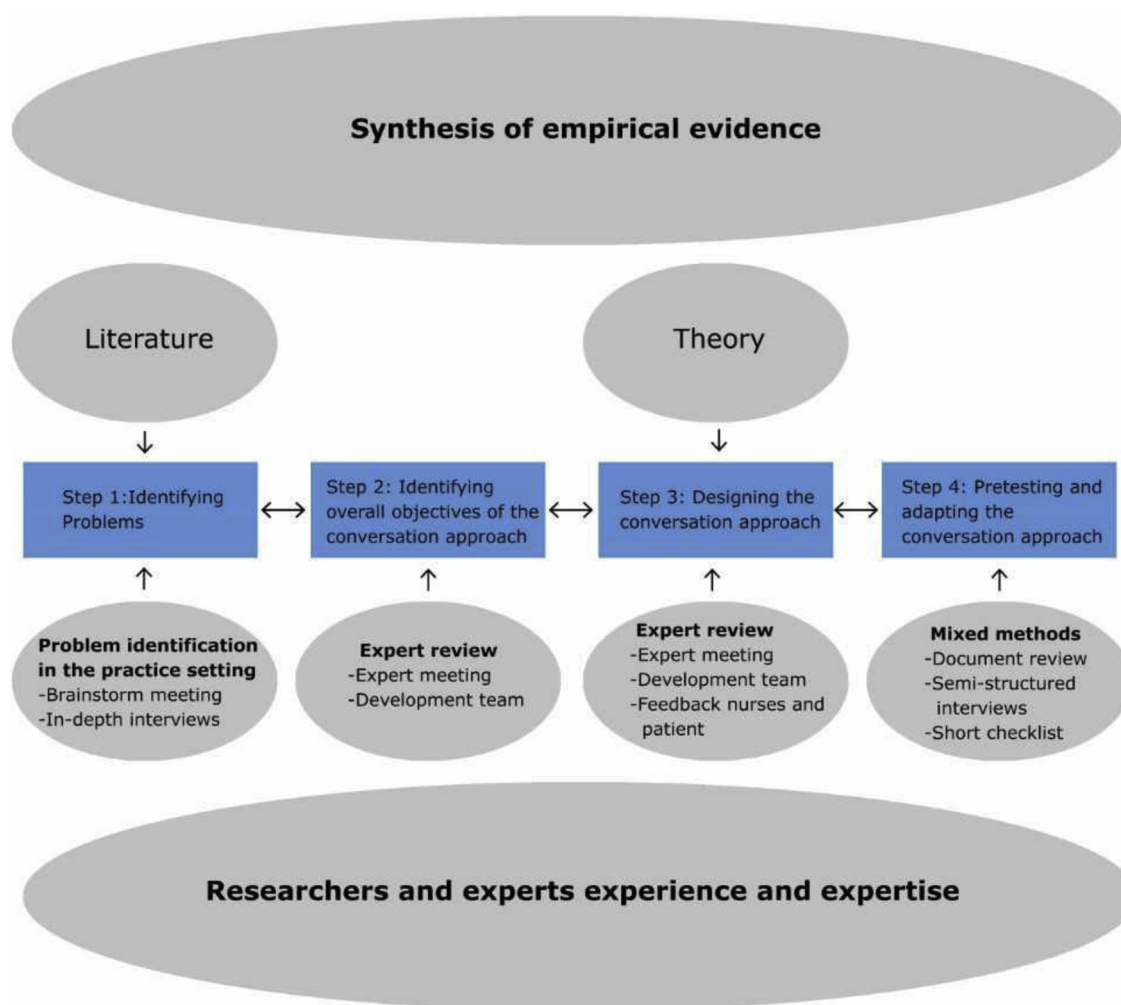


Fig. 1. Development process for a conversation approach in cancer aftercare in nursing (Corry et al., 2013).

treatment. Follow-up is the programmatic approach to prevent cancer recurrence.

According to Dutch's evidence-based clinical practice guidelines, aftercare should address the personal goals of the patient and stimulate his or her self-management (IKNL, 2011a; Visserman et al., 2014). Guidelines recommend a systematic approach for aftercare based on shared decision-making, in which problems, goals, and wishes are systematically screened, shared, and integrated in a cancer survivorship plan (IKNL, 2011a, b). Shared decision-making (SDM) actively involves patients in making health care choices based on the best available evidence, clinical expertise, and the values or goals of the informed patient (Charles et al., 1997; Friesen-Storms et al., 2015; Légaré et al., 2014; Weston, 2001). In chronic care, it is always important to include patients in making shared decisions about their health care management, which may, in turn, have positive effects on health and self-management (Coulter et al., 2015; Friesen-Storms et al., 2015).

Very few cancer survivors receive any comprehensive aftercare, although a number of potential issues and needs have been identified for which evidence-based guidelines exist. These evidence-based guidelines do not seem to be consistently implemented (Klemp, 2015) and a majority of survivors report having unmet information and support needs (Kotronoulas et al., 2017; Paterson et al., 2015; Rowlands et al., 2015; Willems et al., 2016). Patient advocacy groups, expert consensus panels, and governmental reports have recommended improvements in the quality of aftercare (ESMO, 2014; Hewitt et al., 2005; The Health Council of the Netherlands, 2007).

Registered oncology nurses and advanced practice nurses can

significantly contribute to the quality of aftercare (Corcoran et al., 2015). Nurses focus on teaching and control of potential issues, whereas physicians concentrate on medical diagnostics and therapy. Nurses also focus on personal goals and needs and are often more available than physicians to patients and families who call with problems associated with symptom management or home care support (Schulman, 2013).

Although the relevance of goal-setting and shared decision-making in aftercare is acknowledged, nurses do not always know how to implement them in daily practice (Bekelman et al., 2017; Friesen-Storms et al., 2015; Marsland and Bowman, 2010; Revello and Fields, 2015). In the literature, various models of how shared decision-making can be applied in daily practice have been developed (Elwyn et al., 2012; Makoul and Clayman, 2006; O'Connor et al., 2007). In addition, several authors describe models or guides for goal-setting (Bekelman et al., 2017; Lenzen et al., 2015; Scobbie et al., 2011). These models, however, have not been specifically adjusted for cancer aftercare. It is important to develop a specific model or systematic conversation approach to facilitate shared goal-setting and shared decision-making in daily practice for cancer aftercare (The Health Council of the Netherlands, 2007; IKNL, 2011a).

The aim of this study was to develop and pretest a systematic conversation approach for nurses to tailor aftercare to the oncology patients' goals, unmet needs, and wishes.

## 2. Methods

We applied an iterative development process for complex

interventions based on a model proposed in the literature to develop a systematic conversation approach (Corry et al., 2013). The rationale for using this model was, firstly, a conversation approach for aftercare is a complex intervention that contains several interacting components (Craig et al., 2008). Interventions are complex if they request changes in individual health care providers' treatment approaches, in operational systems, and in the organization of care (Lau et al., 2015). Secondly, this model is based on a systematic review identifying the most comprehensive approach to the development of complex interventions for nursing practice. The development process consisted of the following steps: 1. Identifying problems. 2. Identifying overall objectives of the intervention. 3. Designing the intervention based on theory and expert review. 4. Pretesting and adapting the intervention. Each step delivered input for the next step.

The development team consisted of four researchers and one oncologist. Two researchers are nurses (one PhD and one PhD student) and lecturers with expertise in EBP and SDM. One researcher is a medical doctor (PhD) and a professor in implementation of guidelines and an expert in SDM. One researcher is a physical therapist (PhD) and a professor in autonomy and participation for person's with a chronic illness and goal oriented measurement in patient care. The oncologist is also an associate professor in integrative patient centered health care.

The setting and the specific methods of the development process are described below (Fig. 1).

The setting of the study is a large urban 600 beds, teaching hospital in the South of the Netherlands. In the hospital there are several oncology care pathways, in which oncology nurses and nurse practitioners, provide a major contribution to the continuity of care during diagnosis, treatment, and aftercare. These care pathways include breast cancer, colorectal cancer, lung cancer, and malignant lymphoma.

### 2.1. Step 1: identifying problems

In addition to the identification of aftercare problems in the literature, we identified problems in daily practice to tailor the development process to the setting.

First, 16 health care professionals that are experts in oncology care were invited to a brainstorming meeting in February 2013. In subgroups, they brainstormed about current and desired aftercare situations. The outcomes were discussed in a plenary session and summarized by the researcher (JF) after the meeting.

Second, individual in-depth interviews were conducted with patients ( $n = 8$ ) and health care professionals ( $n = 9$ ) about aftercare. A topic list was used based on the literature and on the results of the brainstorm meeting. Health care professionals and patients from different pathways were selected by purposive sampling in October 2013 and May 2014, respectively. Patients with different types of cancer (breast, malignant lymphoma and colorectal), variations in educational level, age, treatment, and duration after medical cancer treatment (from 6 weeks to 1 year) were selected by their health care professionals. The interviews were audiotaped and transcribed. The transcripts were analyzed in QSR NVIVO 10 software by directed content analysis (Hsieh and Shannon, 2005). Two interviews were analyzed independently by two researchers. In cases of disagreement, the topics were discussed until consensus was reached. The other interviews were analyzed based on the topics agreed upon by the researchers.

### 2.2. Step 2: identifying overall objectives of the conversation approach

The development team discussed, summarized, and prioritized the results from the problem identification step. These results were presented in a two-hour expert meeting in September 2014. Twenty-one health care professionals, mainly including the same individuals as the brainstorming meeting in the problem identification phase, were invited. In addition, two patients interviewed during the problem identification phase who were found to have a critical helicopter view, were

invited. The findings of the problem identification phase were discussed within subgroups and finally, the development team summarized the results from the subgroups and formulated the objectives for improvement of the conversation approach.

### 2.3. Step 3: designing the conversation approach based on expert review and theory

After the expert meeting, the development team designed a first-draft of the conversation approach for an aftercare consultation based on evidence-based practice guidelines and the literature. The prototype conversation approach was discussed in winter 2014 with five health care professionals and with one patient from the expert meeting. The conversation approach was adapted to meet their wishes and needs.

### 2.4. Step 4: pretesting and adapting the conversation approach

The feasibility of the conversation approach was evaluated with patients ( $n = 11$ ), three oncology nurses, and one nurse practitioner within two care pathways: breast cancer and malignant lymphoma. Feasibility was evaluated based on two areas of focus: acceptability and implementation of the intervention (Bowen et al., 2009). Acceptability was determined by the satisfaction with the intervention. Implementation was measured by the levels of adherence to the principles of the approach and the reported barriers and facilitators (Bowen et al., 2009).

The nurses and the nurse practitioner first received instruction in the use of the conversation approach and practiced the approach in pairs. We did not expect nurses to use the phases and tools as a "cookbook", but rather as a flexible approach to support their consultations.

From April to June 2015, the nurses and nurse practitioner tested the conversation approach for aftercare consultation based on the principles of SDM during regular scheduled aftercare consultations. We used mixed methods.

To measure the levels of adherence we collected data by:

- Document review. We reviewed whether the patient and the nurse filled out the forms that were part of the conversation approach. In addition, the frequency of completed forms was counted.
- A short checklist. After each consultation, the nurse filled out a short checklist based on the conversation approach. The nurses could use three answer categories: yes, no, or partially.

To measure satisfaction and barriers and facilitators, we collected data by:

- A short checklist. On the same short checklist as for the level of adherence, the nurse assigned a score between 0 and 10 (0 being very unsatisfied and 10 being excellent satisfaction) for the aftercare consultation and registered how much time was needed to complete the consultation.
- Semi-structured interviews were conducted with all patients that gave informed consent ( $n = 9$ ) and the oncology nurses and nurse practitioner. The interviews were conducted with a topic list based on the conversation approach and the literature (Bowen et al., 2009; Kothe and Mullan, 2014; Stevens et al., 2013; Vandelandotte and De Bourdeaudhuij, 2003). Additionally, the review of the forms from each individual patient was used for the interviews with the patients and a review of all patient forms for the interviews with the nurses. The interviews were audiotaped and transcribed by directed content analysis (Hsieh and Shannon, 2005).

### 2.5. Ethical approval

All procedures performed in studies involving human participants

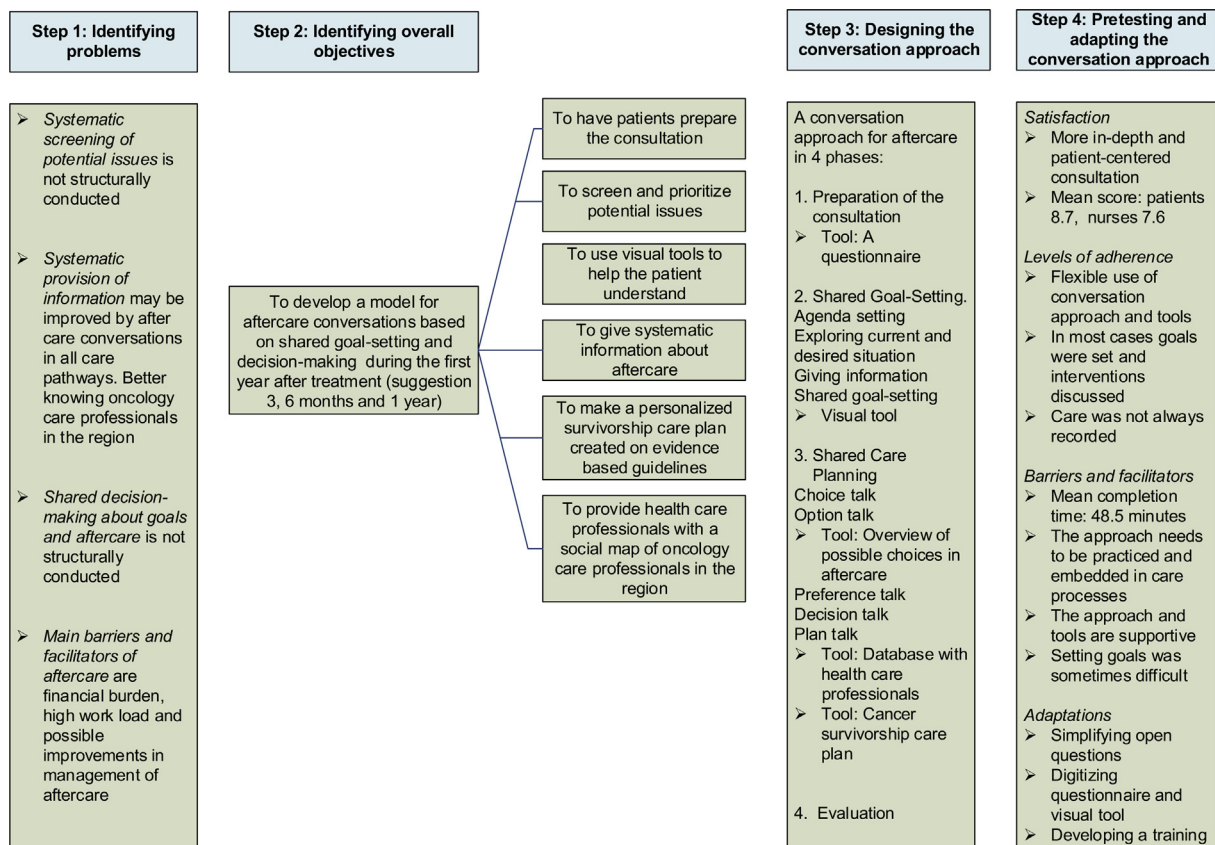


Fig. 2. Main results from the development process.

were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Ethical approval for this study was obtained from the Medical Ethics Committee Zuyderland-Zuyd (no. 13-N-150 and 15-N-70).

Informed consent was obtained from all individual participants included in this study.

### 3. Results

#### 3.1. Step 1: identifying problems

Eleven cancer care professionals and three researchers attended the brainstorming meeting. Individually, we interviewed nine health care professionals and eight patients after cancer treatment. We interviewed four patients with malignant lymphoma, three with breast cancer and one with colorectal cancer. Patients were aged between 18 and 79 years with an average of 56 years.

The main results arising from both the brainstorm and interviews (Fig. 2) were:

##### 3.1.1. Systematic screening of potential issues

Patients experienced many issues after cancer treatment. The main issue was fatigue. Patients were screened with the Screening Inventory Psychosocial Problems questionnaire (Braeken et al., 2009). However, screening was not conducted structurally in aftercare in all cancer pathways.

##### 3.1.2. Systematic provision of information

Patients reported not always being informed about aftercare by health care professionals.

Most health care professionals stated that it would be good to have aftercare conversations with patients in all care pathways. According to

some health care professionals, the timing is important. These conversations should not be planned too early, as patients receiving information about aftercare during the diagnostic and intake phase, may suffer from information overload. However, issues related to cancer and its treatment should receive attention throughout the cancer pathway.

Some health care professionals mentioned that they knew which health care professionals were available within the hospital, but they did not have an overview of the available cancer care professionals in the region.

Patient (male, age 54, diagnosed with malignant lymphoma): “I got the idea for rehabilitation from people around me, not so much from Oncology. They asked if I was up for rehabilitation. What rehabilitation? I discussed it with Doctor (name) during the September check up. “Oh, you want to join that, that’s fine”. It was not offered actively, it was not mentioned, so I said I would want to do that.”

At the intakes in October they found out that, in my case, physical condition was not really an issue. Which in itself is a major part of the rehabilitation program. My issue would be dealing with anxiety and depression.”

Nurse 1: “Yes that is what we do. But, no more, and why? Knowingly we don’t. Patients are already overburdened. When I look at the two patients this morning. One at 9 o’ clock, the other at 9:15. Who do not even manage to report at the proper ward. It’s obvious not to overload them with information. It is no use going on about aftercare.”

##### 3.1.3. Shared goal-setting and decision-making

Some health care professionals and patients mentioned the importance of tailoring aftercare to the patient’s needs and wishes. The decision-making process was diverse and dependent upon the health care professional.

The brainstorming meeting revealed that the values and wishes of the patient should be integrated in a survivorship care plan that is developed together with each patient. Health care professionals



mentioned the following as important for the care plan: medical history, diagnosis, treatment, screening outcome, and a holistic summary of the aspects of life, patient goals, aftercare interventions, and referral and evaluation dates.

Patient (female, age 58, diagnosed with breast cancer): *Yes, right, and everyone around me keeps telling me I should go for it (concerning rehabilitation), but I really hate fitness and swimming also. We also have a camper and regularly we take it out, we are thinking about going soon, we are going this weekend for a few days. If you sign up for rehabilitation, which you then have to do for three months, you are always dependent on the rehabilitation schedule"*

Nurse 2: *"I mean as health care professionals we sometimes want to shout it from the rooftops. Rehabilitation this that and the other and that is fine, it surely is, but a very large group are really not up for it."*

#### 3.1.4. Barriers and facilitators of aftercare

According to health care professionals and patients, the main barriers were: financial, if a treatment is not covered by health insurance it can be a problem for patients to undergo treatment, and the high workload and shortage of case managers. The management of aftercare could be improved: it would probably help to have oncology nurses as case managers on all cancer care pathways and to engage these nurses in aftercare. Health care professionals also mentioned that it would help to set up a network of primary and in hospital health care professionals within the region. Furthermore, there is a development that the responsibility for organizing aftercare is going to be transferred to the general practitioners. This, however, has not yet been organized and some major barriers, such as the possible lack of relevant oncological expertise among general practitioners, have not yet been resolved.

#### 3.2. Step 2: identifying overall objectives of the conversation approach

The expert meeting was attended by 11 cancer care professionals, two patients and three members of the development team. The two patients were treated for malignant lymphoma and had high levels of education.

Based on the data from step 1 (literature and practice analyses) the development team suggested developing an aftercare conversation approach based on the principles of SDM and presented the initial ideas. In three subgroups, the participants thought about the design of the conversation approach and the implementation in cancer care pathways. Based on the results of the expert meeting the development team formulated the following main objective (Fig. 2): To develop a model for aftercare conversations based on shared goal-setting and shared decision-making during the first year of treatment (suggestion: 3, 6 months and 1 year after treatment). The main objective was further divided in six sub-objectives: 1. To have patients prepare the consultation; 2. To screen and prioritize potential issues related to cancer and its treatment; 3. To use visual tools to help the patient understand relevant information; 4. To give systematic information about aftercare; 5. To make a personalized survivorship care plan, created on evidence-based clinical practice guidelines; 6. To provide health care professionals in the hospital with a social map of oncology care professionals in the region.

#### 3.3. Step 3: designing the conversation approach based on expert review and theory

The conversation approach consists of four phases as depicted in Fig. 2.

During the development we cooperated with researchers who developed a conversation approach for shared goal-setting and decision-making for chronic patients in primary care (Lenzen et al., 2015; National Health Care Institute, 2015). We incorporated visual practical tools within the different phases of the approach that were mainly derived from existing tools (Figs. 2 and 3).

The first three phases and tools are further explained in the text below. The fourth phase, Evaluation, is a basic phase in conversations.

##### 3.3.1. Preparation of the aftercare consultation

The questionnaire to prepare the consultation was based on two currently used screening tools. The Dutch version of the Problem List (PL) (Cronbach's alpha total: 0.9) and Distress Thermometer (DT) (Correlation between DT and total score on PL: 0.68) (Tuinman et al., 2008; IKNL, 2017) and the Screening Inventory Psychosocial Problems (Cronbach's alpha total: 0.91) (Braeken et al., 2009, 2011). In Dutch clinical practice guidelines, the Distress Thermometer is recommended as an overall screening instrument in aftercare (IKNL, 2011 a, b). The Screening Inventory for Psychosocial Problems was developed and validated in the Dutch cancer setting (Braeken et al., 2009, 2011) and is the standard screening tool in our hospital. We added open questions to enable the patient to give his or her own opinion. We subdivided the questions into four main domains of life, derived from the International Classification of Functioning Disability and Health (World Health Organization) (functions, activities, participation, personal and external factors) to focus on all aspects of a person's life and to acknowledge the interrelation between health and health-related domains of life. The domains are 1. 'My Health', representing the patient's experiences with his health and health care problems, subdivided into physical, emotional and cognitive problems. 2 'My activities' representing the patient's experiences with daily activities and related problems. 3 'My environment' representing the patient's experiences with social relations, the physical environment and possible problems. 4 'My own way' representing the patient's current coping strategies and associated problems in coping. The domains of life also incorporate the three dimensions of 'work' involved in living with a chronic condition (Corbin and Straus, 1985): My Health incorporates "illness work", My own Way incorporates "biographical work" and My Activities and My environment incorporate "everyday life work".

##### 3.3.2. Shared goal-setting

After setting the agenda for the consultation, the results of the questionnaire are used in the goal-setting phase (Fig. 2) to explore the current and desired situation together with the patient. If the current and desired situation deviate, goals are set with the patient. If not, no goals are set. To facilitate the dialogue between patient and health care professionals regarding problems and goals, a visual tool (Lenzen, 2015) based on the same four domains of life, was incorporated (Fig. 3).

##### 3.3.3. Shared care planning

The Shared Care Planning phase was divided into a choice talk, an option talk, a preference talk, a decision talk and a plan talk (Elwyn et al., 2012, 2014; National Health Care Institute, 2015) (Fig. 2). We used a shared decision-making model from Elwyn et al. (2012, 2014) as the basis for this phase. Although various SDM models have been developed (Makoul and Clayman, 2006), we chose this model because of its relative simplicity, which may make it applicable in clinical practice. The essential elements of the model include choice talk, option talk, preference talk and decision talk. In this model, choice talk involved clarifying that reasonable options are available to patients. Option talk refers to providing detailed information about the pros and cons of each option, preferences talk refers to eliciting patient's preferences and decision talk refers to supporting the process of considering the patient's preferences (including the patient's right to opt out of making a decision) and deciding on the best option; it is the deliberation.

In the choice talk of our model, the patient is informed about the choices that can be made to reach goals and the nurse explores the patient's knowledge regarding choices.

In the option talk, the nurse discusses the different options with the patient including attributes, like impact on life style and resources, of the intervention options (Friesen-Storms et al., 2015) (for example exercising or physiotherapy to cope with fatigue). To support the option

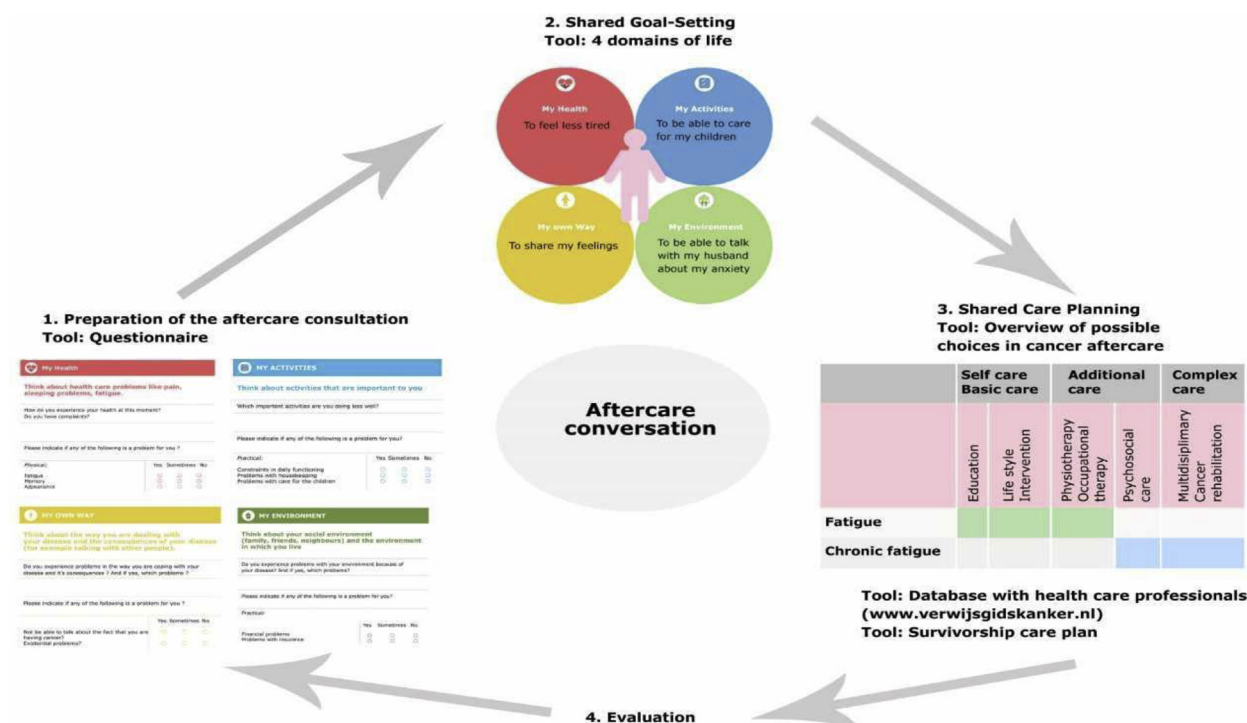


Fig. 3. The tools embedded in the conversation approach.

talk, an overview of possible aftercare choices was made based on an existing Stepped Care Model from the Netherlands Comprehensive Cancer Organization (IKNL, 2015) (Fig. 3).

In the preference talk, the nurse supports the patient in phrasing wishes and preferences. In the decision talk the nurse and patient decide about aftercare interventions together. We added a plan talk to the model, in which the decisions are noted and concrete appointments are made. To support the plan talk, we incorporated a database developed by the Netherlands Comprehensive Cancer Organization (IKNL), with an overview of available cancer care professionals ("<http://www.verwijsgidskanker.nl/>") (Fig. 3). In addition we developed the format of a care plan based on an aftercare plan example in an evidence-based guideline (IKNL, 2011a) and on the opinion of health care professionals.

### 3.4. Step 4: pretesting and adapting the conversation approach

The three oncology nurses and the nurse practitioner pretested the conversation approach with 11 patients. Nine patients were interviewed. We interviewed four patients with malignant lymphoma and five with breast cancer. The interviewed patients were between 44 and 88 years old, with an average age of 63 years. For one of these patients the short checklist was not completed by the nurse.

We structured the results of the pretest according to the elements of feasibility, satisfaction, and implementation operationalized in levels of adherence and reported barriers and facilitators. To obtain insights into the barriers and facilitators of all phases of the conversation approach, we described general barriers and facilitators, and barriers and facilitators at each phase of the approach. We described adaptations made based on the results of satisfaction, and barriers and facilitators (see Fig. 2).

#### 3.4.1. Satisfaction

All nurses liked the aftercare consultations based on the conversation approach, because it supported them in a patient-centered approach and allowed more in-depth consultations.

The patients rated the consultation with a mean score of: 8.7 (min

7.5, max 10) with 0 for very unsatisfied and 10 for excellent satisfaction. The nurses rated the consultations with a mean score of: 7.6 (min 7.0 and max 8.0).

Nurse 3: "What I like about this conversation model is that it creates an in-depth conversation. It doesn't become one of those conversations in which everything is just hunky dory."

Nurse 4: "Especially if you do that once a treatment has been completed. When you get them to figure out what to aim for, to set goals and a way of getting there and how we can support them. That, to me, appears to be the pinnacle of such a conversation."

Nurse 4: "What we mostly say is something along the lines of, what's important is how you feel now and what would you want to improve yourself, what's bothering you. Ahm.. that's also the first time a patient is really asked how they are doing. The central topic is always the treatment and we are the ones suggesting things and then all of a sudden it turns around. You get a completely different atmosphere."

Patient (female, age 55, diagnosed with breast cancer): "And then Uh.. right, then the conversation turns to, uhm, towards uhm, what's supposed to happen now and this and that and uhm.. It goes more like, uhm, what can we do for you and what's next."

#### 3.4.2. Levels of adherence

See Table 1 for the results of the document review and the short checklist.

The conversation approach and tools were used in a flexible manner. In most cases goals were set, intervention options were discussed, and care was planned; however, the format of the patient care plan was not filled out for all patients.

#### 3.4.3. General barriers and facilitators

The completion time for the questionnaire was on average 12 min (SD 2 min, minimum 10, maximum 15 min).

The mean time needed to complete the aftercare consultation based on the checklists was 48.5 min (SD 21 min, minimum 15, maximum 90 min), including the time needed to complete the questionnaire.

Two nurses stated that the conversation approach took more time then they regularly have planned for an aftercare consultation. One

**Table 1**  
Document review and short checklist results.

Phases of the conversation approach	Document review Frequency of yes N (total n = 11)	Checklist by nurses Frequency of yes N (total n = 10 <sup>a</sup> )
<b>1. Preparation of aftercare consultation</b>		
Patient filled out questionnaire	11	10
<b>2. Shared goal-setting</b>		
Explored current and desired situation		10
Set goals with patient		7 <sup>b</sup>
Used visual tool: “four domains of life”	4	
<b>3. Shared care planning</b>		
Discussed different intervention options		9
Used the tool with possible post-treatment choices		6
Planned care with patient		9
Recorded care within patient care plan	7	8

<sup>a</sup> One checklist missing.

<sup>b</sup> Two missing values.

nurse, however, said that if patients fill out the questionnaire at home and the nurses have more routine in the conversation approach, she thinks they might not need more than 30 min. Another nurse said she thinks they should structurally plan 45 min for an aftercare consultation to allow for a more in-depth consultation. All nurses said that the conversation approach needs to be practiced.

The timing of the aftercare consultation after the treatment differs between the malignant lymphoma and breast carcinoma pathways. In the breast carcinoma care pathway, aftercare consultations were regularly scheduled approximately three Months after treatment. The lymphoma care pathway recently reorganized aftercare and did not have a regularly scheduled time for aftercare consultations. During the pretest in the lymphoma care pathway, all aftercare consultations bar one were conducted approximately three-weeks after treatment. One aftercare consultation was conducted three months after treatment, because the consultation had to be rescheduled several times. The “optimal” timing after treatment is not obvious.

To further implement the conversation approach, it needs to be embedded in care processes.

### 3.4.4. Barriers and facilitators of different phases

**3.4.4.1. Preparation of the aftercare consultation.** All patients and nurses perceived the questionnaire as strengthening the consultation. None of the patients interviewed found the questionnaire too extensive. Most patients thought it was easy to read with clear questions. Some patients needed help from a nurse or spouse because of age or cognitive problems. Some patients felt that not all questions were relevant to their personal situation, but they realized that this was inherent to questionnaires.

The patients had various opinions on the additional value of the open questions. Some patients found it difficult to respond, which was also confirmed by one nurse. The nurses thought the open questions were of additional value.

Patient (male, age 70, diagnosed with malignant lymphoma): “*Well sometimes, but I don't mind, I can imagine uhm ... such forms are drawn uhm.. not drawn up exclusively for me but for loads of people. And obviously there are certain questions that don't apply to me personally.*”

**3.4.4.2. Shared goal-setting.** One nurse said that patients need help formulating goals. Some patients find it difficult to reflect on their situation and sometimes are very talkative, which makes exploring the current and desired situation a time-consuming process. Another nurse found it difficult to set goals. One nurse found it difficult to time the

interruption needed to support the patient in determining problems and goals.

The nurses liked using the visual tool “four domains of life” to facilitate the conversation, especially because the questionnaire is divided into the same domains. Two nurses mentioned that using the tool was not yet routine practice. Two patients explicitly stated that they found the visual tool supportive.

Patient (female, age 44, diagnosed with breast cancer): “*Yes that's exactly how it uhm ... well, it sure illustrates it rather nicely, my attitude towards it. It's spot on. The four main issues obviously, uhm.. Right, I quite like the look or rather the graphical illustration of the way that, well, what I think about all of this.*”

**3.4.4.3. Shared care planning.** All nurses said that they did not explicitly follow all steps of shared care planning. The nurses said that although they did not follow all steps of shared care planning, the separate steps were helpful in making the shared care planning more explicit. One nurse said that she maybe did not use the in-between steps because of her own preferences for aftercare.

Two nurses said that they found the aftercare plan on paper redundant, because they also have to report care in the electronic patient file.

Nurse 5: “*Yes, however that is mostly my personal preference, I'm mostly in favor of rehabilitation, when you see someone fits a in group ... is a team player. So when I come across someone more autonomous, working fulltime, than I think they should perhaps consider exercising with someone else at a local physical therapist. Find out if there is a program going on. So that's it, that's what I think, talking about physical rehabilitation specifically that is. Or for example when someone has a knee injury and they should be swimming, then I'm mostly looking at the patient, but most days it's between rehabilitation and the physical therapist.*”

### 3.4.5. Adaptations

The analysis of the interviews revealed several important adaptations. The conversation approach needs to be flexible and tailored to the patient and practice setting.

Suggested alternatives to fill out the questionnaire are to send a questionnaire home before the consultation or to digitize the questionnaire and send a link to the patient. In addition, information about the goal of the consultation may be added in the invitation to fill out the questionnaire. Open questions in the questionnaire are sometimes difficult to fill out and could be simplified.

To facilitate the use of the conversation approach and the tools, it seems important to digitize not only the questionnaire, but also other forms such as integrating the aftercare plan within the electronic patient files.

Conducting training sessions on the conversation approach and underlying theory seems necessary before further implementation.

We implemented the suggested adaptations accordingly: 1. We simplified the open questions by integrating two open questions and by relating one question more to the disease. 2. We digitized the questionnaire and the visual tool. We added information about the goal of the consultation and the background of the questionnaire. Patients can fill out the questionnaire at home via a link and get an overview of the results depicted in the “four domains of life”. Patients can print the results and send them via e-mail to the nurse. 3. We developed training on the conversation approach consisting of two meetings, with a month in-between where nurses can practice the approach in daily care. In addition, we made a short movie with an example of how to conduct the consultation based on the conversation approach.

## 4. Discussion

A conversation approach was created for aftercare in cancer survivorship. The approach developed is based on principles of shared goal-setting and shared decision-making and consists of four phases with

supporting tools: 1. Preparation of the aftercare consultation using a questionnaire. 2. Shared goal-setting by means of a tool visualizing domains of life. 3. Shared care planning with an overview of possible choices in aftercare treatment related to particular issues, a database with available health care professionals, and an aftercare plan. 4. Evaluation. The conversation approach was systematically developed, pretested and adapted.

The pretest revealed that the conversation approach needs to be flexible, tailored to the patient and practice setting, and embedded in care processes. The conversation approach was perceived as enhancing patient centeredness and leading to more in-depth consultations. However, an important challenge for the nurses was to elicit patient preferences and set goals. Another challenge was the time-consuming nature of the approach.

#### 4.1. Results in context

The developed conversation approach contains the main recommendations of evidence-based clinical practice guidelines regarding aftercare (IKNL2011a,b. 2017; Visserman et al., 2014). Personalized care planning based on goal-setting and shared decision-making are strong elements of our approach, which has been shown to have positive effects on certain indicators of health status and capability for self-management (Coulter et al., 2015).

We believe that our study, which is focused on care decisions, adds to the current shared decision-making models in cancer that usually concern medical cure decisions, for example the choice between breast-conserving surgery or mastectomy as breast cancer treatments when both options have competing benefits and harms (Stacey et al., 2014). Although other studies (Coulter et al., 2015; Lenzen et al., 2015; van de Pol et al., 2016a; b) also use shared goal-setting and SDM in chronic care, our conversation approach is, to the best of our knowledge, the first approach that integrates goal-setting and SDM in cancer survivor aftercare.

Another important element of our conversation approach is the strong integration of supporting tools derived from currently used and existing tools from evidence-based clinical practice guidelines and the Netherlands Comprehensive Cancer Organization (IKNL). The graphic tool “four domains of life” is based on the framework of the ICF. Other studies (Lenzen et al., 2015; Murphy and Boa, 2012) also used a graphic tool based on the framework of the ICF. The holistic conversation approach and the four domains of life emphasize the recently developed concept of “positive health”, in which health is not merely the absence of disease or disorders, but is defined as the ability to adapt to and to self-manage disorders or disease (Huber et al., 2011). Our four domains of life are rooted in this concept (Institute for Positive Health).

Although the nurses and patients were positive about the approach, the pretest revealed that eliciting patient preferences, applying patient-centered goal-setting and SDM is challenging. The difficulty and complexity of setting goals has been confirmed in other studies. The complexity of goal-setting is also recognized in primary care (Lenzen et al., 2016), in stroke rehabilitation (Rosewilliam et al., 2011), and in the work of allied health professions in general (Marsland and Bowman, 2010). In addition, studies confirm the complexity of eliciting patient preferences (Klaassen et al., 2017) and implementing SDM in daily practice (Blair and Legare, 2015; Elwyn et al., 2016; Légaré et al., 2014).

The pretest also revealed that the approach needs to be embedded within existing care processes. In a review of personalized care planning in chronic care, the effects seemed to be larger when the intervention was appropriately integrated within routine care (Coulter et al., 2015).

Another challenge revealed in our pretest is the time-consuming nature of our approach. Time is an important barrier known from implementation research (Grol and Grimshaw, 2003). In daily practice and in research, there is growing attention for solely web-based interventions in aftercare without face-to-face contact with a health care

professional (Duman-Lubberding et al., 2016; Kanera et al., 2016; Post and Flanagan, 2016; Willems et al., 2015). These interventions seem less time-consuming. However, the actual reach of web-based interventions is undiversified and predominantly reaches participants who are female, highly educated, white, and living in high-income countries (Kohl et al., 2013; Post and Flanagan, 2016). Although solely web-based interventions might provide valuable support in cancer aftercare, they will probably not reach all cancer survivors. In addition, web-based interventions might lack individualized care (Post and Flanagan, 2016) and our pretest showed that without the interpersonal support of a nurse or other health care professional, goal-setting and choosing aftercare might be complex tasks for patients.

From our study, the “optimal” timing of the approach in the cancer trajectory does not seem to be obvious. During the problem identification, health care professionals stated that these conversations should not be planned too early, as patients receiving information about aftercare during the diagnostic and intake phase tend to forget this information. However, care for cancer survivors should take place along the entire cancer care continuum, from diagnosis throughout the life span (Klemp, 2015; National Coalition for Cancer Survivorship). For example, attention to psychosocial problems is needed during the treatment phase.

#### 4.2. Strengths and limitations

The strength of this study is the use of the iterative developmental process for complex interventions in nursing, which involves intended users in the process. We started by identifying problems in current practice. Subsequently, we decided on the objectives for improvement and the conversation approach with oncology experts and two patient experts. We tailored the development of the conversation approach to the setting.

During the various phases of the study, we used purposive sampling to select health care professionals and patients. We strived for multi-stakeholder involvement and for data saturation. We may not have succeeded in all phases. For example, at the beginning of the problem identification, the nurses selected mostly highly educated patients; so we asked them to purposeful also include patients with less education levels. Highly educated patients might be more competent in obtaining access to aftercare than patients with low education levels. In addition, during the problem identification we may not have reached data saturation for all stakeholder groups. For example, we only interviewed eight patients from three different cancer care pathways.

During the development process, two patients were invited to the expert meeting. We purposefully chose patients we thought would have a helicopter view. Both of these patients were highly educated, male and treated for malignant lymphoma. We might have chosen more patients with different education levels, sex and diagnoses.

In order to incorporate sufficient perspectives, we applied triangulation by searching the literature (Kotronoulas et al., 2017; Paterson et al., 2015; Pratt-Chapman et al., 2011; Rowlands et al., 2015; Willems et al., 2016) and we used an iterative developmental process.

To improve trustworthiness, we also carried out peer debriefing of the main results of the problem identification and pretest within the development team. We conducted a member check for the results from the problem identification at an expert meeting (consisting of some of the interviewed health care professionals and two interviewed patients) and during individual conversations with health care professionals that did not attend the expert meeting, wherein the results were confirmed. The results of the pretest were discussed with the nurse practitioner and nurses that participated in the pretest.

A limitation of the pretest may be that it was conducted within two cancer pathways that already had embedded aftercare consultations as part of their care chain and not in the other cancer pathways. This may have positively influenced the results of the pretest, because implementation within these care pathways may be more feasible than in



other care pathways.

#### 4.3. Recommendations for practice and further research

One of our future challenges is to provide nurses and nurse practitioners sufficient support to elicit patient preferences, apply shared goal-setting and decision-making, and to further tailor the approach to make it more flexible and facilitate integration within routine care. Giving patients the opportunity to fill out the questionnaire at home, either digitally or on paper, might support the implementation of the approach, as it is less time-consuming for the nurse. Providing nurses with training and on-the-job coaching might support the nurses in implementing the approach.

Within the care organization, having oncology nurses as case managers engaged in aftercare and having a network of health care professionals occupied with cancer care within the region, would facilitate further implementation. In addition, developing models in which hospitals and general practitioners share aftercare seems important for further development of aftercare (Hall et al., 2011; Jefford et al., 2013). The developed aftercare conversation approach could also be tailored for use in primary care.

In the pretest, we evaluated the feasibility of the conversation approach. Patients seemed satisfied with the approach. However, further research is needed to obtain deeper insight into what is actually on the agenda during the conversation approach and investigate patient's experiences of the approach. These insights might help to further tailor and embed the approach. Furthermore, after additional tailoring and embedding of the approach within care processes, conducting a process evaluation and an effectiveness study is the next step to study the implementation and its' effects. Outcomes may be determined by measuring the degree of SDM using SDM-Q-9 (Kriston et al., 2010) and the CollaboRATE (Elwyn et al., 2013), for instance.

#### 4.4. Conclusion

In this study, we describe the development and pretest of a conversation approach based on shared goal-setting and shared decision-making for nurses in cancer aftercare. Our model was co-created with important aftercare stakeholders, incorporates evidence-based cancer care guidelines and supports patient-centered care. The results of the pretest revealed important implications and suggestions for implementation, such as tailoring and embedding the approach within care processes and providing nurses with training and on-the-job coaching. In future, further evaluation of the conversation approach in practice is needed.

#### 4.5. Implications for cancer care

The aftercare conversation approach can be used by nurses and other health care professionals to provide tailored patient-centered evidence-based aftercare. Tailored aftercare should support oncology patient's goals, unmet needs and wishes. Further tailoring aftercare in future is needed.

#### Potential conflict of interest

The authors declare that they have no conflict of interest.

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