

Using behavioral theories to study health-promoting behaviors in palliative care research

Drs. Anne-Lore Scherrens, Prof. dr. Benedicte Deforche, Prof. dr. Luc Deliens, Prof. dr. Joachim Cohen*, Prof. dr. Kim Beernaert*

*shared last authorship

Anne-Lore Scherrens

Vrije Universiteit Brussel (VUB) & Ghent University, End-of-life Care Research Group, Brussels, Belgium; Ghent University, Unit Health Promotion, Belgium.

Benedicte Deforche

Ghent University, Unit Health Promotion, Belgium; Vrije Universiteit Brussel (VUB), Unit of Movement and Nutrition for Health and Performance Research Group, Brussels, Belgium

Luc Deliens

Vrije Universiteit Brussel (VUB) & Ghent University, End-of-life Care Research Group, Brussels, Belgium

Joachim Cohen

Vrije Universiteit Brussel (VUB) & Ghent University, End-of-life Care Research Group, Brussels, Belgium

Kim Beernaert

Vrije Universiteit Brussel (VUB) & Ghent University, End-of-life Care Research Group, Brussels, Belgium

Corresponding author: Anne-Lore Scherrens, End-of-life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University; Corneel Heymanslaan 10, 9000, Ghent, Belgium.

Email: annelore.scherrens@ugent.be or anne-lore.scherrens@vub.be (+32 9 332 36 25)

Number of tables: 1

Number of figures: 2

References: 44

Word count for the submission: 3235 words

Abstract

Background. Behavioral theories are often used to better understand and change health-promoting behaviors and develop evidence-based interventions. However, researchers often lack of knowledge on how to use these theories in palliative care and people confronted with serious illness. Clear examples or guidelines are needed.

Aim. To describe how behavioral theories can be used to gain insight into critical factors of health-promoting behavior in seriously ill people, using a case example of ‘starting a conversation about palliative care with the physician’ for people with incurable cancer.

Methods. We used a health promotion approach. Step 1: We chose a theory. Step 2: We applied and adapted the selected theory by performing interviews with the target population which resulted in a new behavioral model. Step 3: We operationalized the factors of this model. An expert group checked content validity. We tested the questionnaire cognitively. Step 4: We conducted a survey study and performed logistic regression analyses to identify the most important factors.

Results. Step 1: We selected the Theory of Planned Behavior. Step 2: This theory was applicable to the target behavior, but needed extending. Step 3: The final survey included 131 items. Step 4: Attitudinal factors were the most important factors associated with the target behavior of starting a conversation about palliative care with the physician.

Conclusions. This paper describes a method applied to a specific example, offering guidance for researchers and practitioners interested in understanding and changing a target behavior and its factors in seriously ill people.

Key statements

What is already known about the topic?

- A health promotion approach and focusing on promoting health behaviors in people confronted with serious illness can potentially improve their quality of life
- Behavioral theories are useful to better understand and change behaviors of people
- Behavioral theories are scarcely applied to behaviors in those confronted with serious illness, for example palliative care behaviors, and their use is often not precisely described

What this paper adds

- This paper describes how an individual behavioral theory can be used to better understand healthy and preferred behaviors in seriously ill people

- This paper demonstrates how the theory of planned behavior was used to better understand the factors related to starting a conversation about palliative care with the physician in people with incurable cancer

Implications for practice, theory or policy

- Researchers in the field of palliative care might want to use behavioral theories more often and apply them more adequately in order to develop effective interventions to change behavior
- This paper provides guidance for researchers and practitioners interested in understanding and changing a target (palliative care) behavior and its behavioral factors in seriously ill people.

Key words

Health promotion; behavior; behavioral theory; critical illness; palliative care; health communication

Introduction

Worldwide, palliative care is frequently started late or not at all[1], which can lead to suboptimal care in the final months of life[2]. Palliative care research is mainly dominated by the paradigm of pathogenesis, i.e. focusing on assessing and improving the biopsychosocial factors causing problems and suffering[3]. Additionally, the focus is usually on the role of health services or professional carers in achieving this[4]. Only some of the empirical literature uses a health promotion approach that focuses on factors (e.g. empowerment) that stimulate health and on enabling people confronted with serious illness (e.g. patients, family carers) to have control of these factors and to make healthy choices[3]. An example of health promoting palliative care is promoting behaviors that contribute to the timely initiation of palliative care and helping them to adopt these. There is growing evidence showing that using a health promotion approach and focusing on promoting health behaviors in those confronted with serious illness can potentially improve their quality of life in their final days[5]. However, this approach is scarcely applied to behaviors in those confronted with serious illness, because of researchers' lack of knowledge about how to apply it and a lack of tools available to support them in such a relatively new domain in health promotion research.

A variety of behaviors is related to timely initiation of palliative care. One important behavior (among others) is communication about palliative care. Although well-timed communication is important for timely initiation of palliative care, it is often postponed or avoided[6]. It is clear from previous literature that significant barriers, and hence opportunities for initiating palliative care, also exist among patients[7, 8]. More patient empowerment can help people with cancer in starting a conversation about palliative care[9, 10]. An important prerequisite for developing effective interventions to support people with serious illness in starting that conversation is to understand why they do or do not and to identify factors that facilitate or hinder them[4, 11–15].

Behavioral theories can help researchers to better understand behaviors. In general, little is known about how behavioral theories can be used, i.e. selected, applied, adapted, operationalized and evaluated, in order to gain insight into factors related to palliative care behaviors in people who are seriously ill[11, 16]. This paper describes in detail the process – in four different steps- of how an individual behavioral theory can be used to promote preferred or healthy behaviors in seriously ill people (methods section). Next, this paper demonstrates how the Theory of Planned Behavior, as one amongst other individual behavioral theories, was used to better understand the factors related to the specific behavior of starting a conversation about palliative care in people with incurable cancer. Similar steps can be taken by applying other individual theories. Although the results section focuses

on one specific behavior, the methodology described could also be used for other (palliative care) behaviors in people confronted with serious illness.

Methods

The four steps described below are not prescriptive, but are based on evidence-based protocols[12] and experiences from previous studies by a multidisciplinary expert group. This expert group consists of the (co-)authors, who are experts in either health promotion (n=2) or end-of-life care research (n=3).

Step 1) Describing the health problem, identifying the most important risk behavior and choosing a theoretical framework

Describing the health problem and identifying and defining the most important risk behavior

First, the health problem of interest was clearly described[12]. Next, possible causes of the health problem were identified based on literature and experiences of the multidisciplinary expert group. As a variety of risk behaviors were related to the health problem, the multidisciplinary expert group selected one important behavior to target[12, 17]. In a next step, the risk behavior was translated into a health-promoting behavior that contributes to improvement of quality of life in the target population[12, 18].

Choosing an appropriate theoretical framework

There is a wide range of behavioral theories, which made it challenging to choose an appropriate one. Behavioral theories are by nature abstract and not content- or topic-specific[13]. They can be generalized over behaviors and populations, but the weight of each behavioral factor can vary[12]. We limited to using one individual behavioral theory that focuses on one individual's behavior and individual factors, seeing the barriers and opportunities that exist on the level of the seriously ill[7, 8, 19]. Evidence shows their usefulness to impact on health outcomes[20]. An individual behavioral theory does not consider the social and environmental factors, but is also open to the identification of perceived environmental factors. Our choice was not based on familiarity with a theory[13], but depended on the study purpose and population. We studied a comprehensive overview of existing behavioral theories[12]. Furthermore, we searched for evidence of which behavioral theories were already used in studying palliative care behaviors and which theories or behavioral factors were proven

to be relevant[11, 17]. Based on this information, our multidisciplinary expert group selected a theory that was expected to be relevant for the selected target behavior and target group[17].

Step 2) Applying and adapting the selected theory

A deductive and inductive method were used[21] respectively to apply and adapt the selected theory and (the relevance of) its factors. Qualitative, individual face-to-face interviews with the target group, i.e. people with incurable cancer (n=25), were performed. The deductive approach was used to apply the factors from the theory selected in step 1 to the specific target behavior of starting a conversation about palliative care with the physician. This theory formed the basis for the development of the semi-structured interview guide[12, 21]. Questions covered 1) the perception of the behavior, 2) facilitating and hindering factors derived from the selected theory and 3) other facilitating and hindering factors not part of the selected theory (see **Appendix A**)[9]. The latter questions created the opportunity to adapt and extend the selected theory. We then used an inductive approach to analyse the collected data and modify the theoretical model accordingly. This made the newly developed behavioral model more complete and applicable to our target behavior[21]. Details about the methodology of this qualitative interview study are published elsewhere[9].

Step 3) Operationalizing the factors of the newly developed behavioral model

For the development and validation of the survey, no standard approach was used. We conducted a literature search searching for studies focusing on behavioral factors, to decide on measurement and operationalization of the factors of the newly developed model. Our systematic review[11] showed that few surveys assessing factors related to specific behaviors in end-of-life and palliative care were available (e.g. practice of euthanasia, advance care planning[11, 22, 23]). So besides these survey studies, we searched for practical guidance[24–26] and survey studies assessing the specific behavioral factors related to more conventional health behaviors (e.g. physical activity[21]). The relevant information retrieved from existing survey instruments was then integrated into our survey and adapted where necessary. We translated it into Dutch, and adapted it according to the specific target behavior. We added more content to the behavioral factors based on the qualitative findings from step 2 and input from the multidisciplinary expert group. To avoid abstractness, special attention was paid to the wording of the items and the type of responses[21]. The multidisciplinary expert group reviewed all survey items one by one with constructive face-to-face meetings by evaluating their relevance, language and structure. Face and content validity were also checked by asking the opinion of other experts in end-of-life care (n=4) and health promotion research (n=10) through one-time

feedback on each survey item. As some questions might be perceived as complex and/or confrontational in seriously ill people, we checked the appropriateness of the various items by cognitively testing a preliminary survey during face-to-face interviews with eight people with incurable cancer[29]. During these cognitive interviews, a standardized template for the evaluation of the items (clear/unclear or confusing/difficult/confronting) was completed. At the end of this operationalization process, the expert group checked again whether the operationalized items matched the meaning of each determinant.

Step 4) Empirically examining the factors of the newly developed behavioral model

We performed a cross-sectional survey with computer-assisted, answer-based personal interviews using a structured questionnaire among the target population, i.e. people with incurable cancer (n=88), to quantitatively test and evaluate the strength of the association of each factor in our adapted theoretical model with our target behavior. The target population was recruited through selected oncologists and nurses. Purposive sampling of the target population, taking into account the theoretically important heterogeneity, was used with the aim of theoretical or scientific generalization about associated factors rather than statistical generalization[30]. We needed a sufficient number of people who had already started the conversation about palliative care with their physician or had the intention to do so. We used descriptive statistics to describe participants' characteristics and conducted logistic regression analyses to find out which factors were related to (the intention of) the behavior.

In total, steps one to four took about two years and four months.

Results

Step 1) Describing the health problem, identifying the most important relating risk behavior and choosing a theoretical framework

Health problem and behavior

The health problem was that palliative care for people with incurable cancer is frequently started late or not at all, which can result in suboptimal care in their final days of life. Avoidance of a conversation about palliative care with the physician by people with incurable cancer was found to be one of the most important risk behaviors for not (timely) starting palliative care. Starting a conversation about

palliative care with the physician by people with cancer was found to be the matching health-promoting behavior[13]. Promoting this behavior can potentially improve patient-centred care and quality of care and quality of life among people with incurable cancer.

Theory of planned behavior (TPB) as theoretical framework

After performing a systematic literature review, we concluded that the available evidence of useful theories to better understand health behaviors in people with incurable cancer was limited[11]. We found that the TPB is most frequently used and that its factors are relevant to understand palliative care behaviors[11]. The TPB incorporates three factors ('attitude', 'subjective norms' and 'perceived behavioral control') that influence a behavioral 'intention', which in turn is the most important determinant for actual behavior[31, 32] (see **Figure 1**[31]). Literature showed that this theory is widely used in multiple health domains, populations and settings[33]. Findings show that important shortcomings of the TPB are that it is highly cognitive and does not take into account unconscious or automatic processes or environmental factors[31]. However, as it would be difficult to operationalize and measure these unconscious processes related to communication about palliative care, this was not considered a reason not to use this theory as a framework for our project. In addition, step 2 creates the opportunity to add perceived environmental factors to the model if these appear important and relevant. Based on this analysis, our multidisciplinary expert group selected the TPB as a relevant theoretical framework.

Step 2) Applying and adapting the selected theory

The face-to-face interviews with people with incurable cancer confirmed that the TPB is applicable to the target behavior. The inductive analysis of the data led to extension of the model. Relevant factors from other behavioral theories were identified: awareness, knowledge and perceived social influence. The detailed findings of the qualitative interviews are published elsewhere[9]. Step 2 resulted in a newly developed palliative care behavioral model for starting a conversation about palliative care with the physician by people with incurable cancer (see **Figure 2**).

Step 3) Operationalization of the factors of the newly developed behavioral model

Operationalization of the factors

The literature search identified few guidelines on how to operationalize the TPB, but it offered many survey instruments assessing factors of more conventional health-promoting behaviors. Our systematic review also showed that most of the existing studies focusing on palliative care behaviors failed to precisely describe the behavioral theory used or how the factors were operationalized[18].

The number of items for the survey and their content are based on the results from the previous qualitative interviews and the model. The operationalization and formulation of the survey item were based on existing surveys, of which most were based on behavioral theories (step 2). To illustrate this, the operationalization of the factor “affective beliefs towards palliative care” is described below. Studies in cancer and end-of-life care research measured affective beliefs towards palliative care as ‘how good/bad do you feel about palliative care?’ (five-point Likert scale ranging from strongly positive to strongly negative)[12, 15]. Our previous qualitative findings revealed that people with incurable cancer associate the term palliative care with feelings such as stress, anxiety and depression. We operationalized affective attitude towards palliative care with the following two items: At this moment... ‘...the words palliative care give me stress or anxiety’ and ‘...thinking about palliative care makes me feel depressed’ (five-point Likert scale ranging from strongly disagree to strongly agree). All results of the literature study and how we operationalized the relevant factors (and specific behavioral beliefs) related to the specific target behavior into a questionnaire is described in **Table 1**.

Validity checking

Testing the preliminary survey by cognitively interviewing eight people with incurable cancer (5 men, mean age 65 years) revealed that the questionnaire was acceptable and suitable, only needing minor adjustments to the order of the items and word choice. The final survey includes 131 items [see **Appendix B & C**].

Step 4) Empirically examining the factors of the newly developed behavioral model

A total of 135 people with incurable cancer were contacted and invited to participate. Of these, 88 people effectively participated (response rate = 65.2%) with 80 surveys fully completed; ten had already started a conversation about palliative care themselves and 18 had the intention to do so. People holding a positive attitude towards this behavior (OR 4.74; 95%CI 2.35-9.54), perceiving more benefits of it (OR 2.60; 95%CI 1.37-4.96) and perceiving a positive attitude towards the behavior in family/friends (OR 2.07; 95%CI 1.26-3.41) and the physician (OR 2.19; 95%CI 1.39-3.45) were more likely; people perceiving more disadvantages (OR 0.53; 95%CI 0.32-0.87) and barriers (OR 0.31; 95% CI

0.15-0.63) were less likely to perform the behavior or have the intention to do so. These factors explained 64% of the variance.

Discussion

This paper uniquely describes the four steps that can be taken to use a behavioral theory to gain deeper insight into factors related to a health-promoting behavior in people confronted with serious illness: 1) choose a theory, 2) apply and adapt the selected theory, 3) operationalize the factors of the newly developed behavioral model, 4) empirically examine the factors of the newly developed behavioral model. Our case illustrates how the TPB is used to identify factors related to the specific target behavior of starting a conversation about palliative care with the physician in people with incurable cancer. This allowed us to identify the most important factors for impacting this specific patient behavior regarding palliative care.

One of the challenges we faced during the process was choosing a suitable behavioral theory as the starting point in step one. Literature revealed a wide range of different theories[35]. It was not clear which theories would be most relevant to better understand the factors of our specific target behavior. We opted for an individual behavioral theory[35] rather than a model taking into account environmental factors such as meta-models[35]. Considering the importance of the direct environment in better understanding the individual's behavior and the interest in obtaining highly effective and long-term behavioral change[20, 36], changes in the social and physical environment might be needed as well. Therefore, using environment-oriented theories might be another possible line to take here. However, individual behavioral theories can also be applied with a socio-ecological approach taking into account environmental factors[12]. Individual behavioral theories can also be used to identify factors related to behaviors of environmental agents who are responsible for environmental factors influencing people with serious illnesses (e.g. family carers, professional carers, etc.)[12]. There may be no literature available showing which theories could be relevant to better understanding the factors of a certain target behavior. If so, researchers could start theoretically and perform inductive qualitative research to build a theory.

Steps one to four, combining qualitative and quantitative approaches, resulted in a behavioral model that explained 63.8% of the variance in starting a conversation about palliative care with the physician (or the intention to do so). The explained variance of most behavioral models ranges from 20 to 30%[35]. By carefully selecting, applying and adapting the theory, we seem to have included important and domain-specific factors. This might have contributed to a higher predictive

value of our model. However, researchers using behavioral theories should bear in mind that a behavioral model will only ever explain a proportion of variance in (the intention to perform) a behavior, as other unmeasured and unknown factors may also play a role[35]. To be able to develop highly effective behavioral interventions in palliative care, future research should focus more empirically on operationalization and evaluation of behavioral theories.

The entire process showed that it might be more complex to use behavioral theories to gain insight into critical factors related to palliative care behaviors than more conventional health behaviors such as physical activity or stopping smoking. There might be a difference in qualitatively and quantitatively testing the factors related to more complex and less familiar behaviors compared to those related to well-known health behaviors. People can easily imagine being physically active, smoking, eating fruit, etc. [5] but it is more difficult to imagine talking about palliative care. It is not easy to say if one would do so or not, or why. The participants might need cognitive skills to answer questions related to (future or past) palliative care behaviors. Therefore, it might be important to use face-to-face interviews and to provide clear interviewer instructions to enable interviewers to help the participants imagine themselves displaying the behavior. The current study made use of 'if...then' questions to stimulate this thinking process. For example, if the participant indicated that palliative care might be discussed after hearing that the cancer had metastasized, the interviewer asked "if you heard that the cancer had metastasized, would a benefit of starting a conversation about palliative care be that you received more information about palliative care?"

The challenges of using behavioral theories to gain better understanding of factors related to health-promoting behavior in seriously ill people do not outweigh the added value. The adequate use of behavioral theories will lead to more in-depth insight into factors influencing health behaviors. This information is crucial to be able to develop health promotion interventions in palliative care [12]. These theory-based behavioral interventions can help to empower people confronted with serious illness to take the initiative in communication about palliative care[12], for example, and to improve their health and quality of life[5].

Conclusion

Individual behavioral theories are a relevant tool to better understand and explain individual behaviors in seriously ill people by identifying factors influencing the behavior. This paper describes in detail how such theories can be applied. It is important to choose a relevant theoretical framework and to test its applicability to the target behavior in the target population by using a mixed methods design, i.e. a

qualitative study followed by a quantitative study. Another option is to start atheoretically and perform inductive qualitative research to build a theory. Future (empirical) research and wide dissemination of study findings related to the use of behavioral theories in palliative care research is recommended to further integrate its use.

Declarations

Authorship

All authors substantially contributed to the outline of this methodological paper. A-LS and KB wrote the first draft of the manuscript and critically revised the manuscript after receiving comments from all authors. B.D., L.D, J.C & K.B. supervised the study. All authors approved the final manuscript to be published. All authors have participated sufficiently in the work to take public responsibility for appropriate portions of the content. A-LS was responsible for final submission and as guarantor of content.

Funding

This work was supported by the Research Foundation Flanders.

Conflicts of interest

The authors declare that there is no conflict of interest.

Ethics and consent

For the studies (step 2-4) that involved human subjects (i.e. people with incurable cancer), ethical approval was obtained from the Ethical Committee of Ghent university and AZ Sint-Lucas Ghent.

Data sharing

The data that support the findings of this study are available from the corresponding author, AS, upon reasonable request.

Acknowledgements

The authors wish to thank the expert group of both the health promotion and end-of-life care research groups for their contributions. The authors are very grateful to the physicians, nurses and patients for participating in the qualitative interviews, the cognitive testing of the survey and the quantitative interviews. We further thank Helen White for help with linguistic editing of the text.

References

- [1] Jordan RI, Allsop MJ, ElMokhallalati Y, et al. Duration of palliative care before death in international routine practice: a systematic review and meta-analysis. *BMC Med* 2020; 18: 368.
- [2] Temel JS, Greer JA, Muzikansky A, et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *N Engl J Med* 2010; 363: 733–742.
- [3] Pelikan JM. The Application of Salutogenesis in Healthcare Settings. In: Mittelmark MB, Sagy S, Eriksson M, et al. (eds) *The Handbook of Salutogenesis*. Cham (CH): Springer, <http://www.ncbi.nlm.nih.gov/books/NBK435858/> (2017, accessed 15 January 2021).
- [4] Pardon K, Deschepper R, Stichele RV, et al. Preferences of advanced lung cancer patients for patient-centred information and decision-making: a prospective multicentre study in 13 hospitals in Belgium. *Patient Educ Couns* 2009; 77: 421–429.
- [5] Painter JE, Borba CPC, Hynes M, et al. The Use of Theory in Health Behavior Research from 2000 to 2005: A Systematic Review. *Ann Behav Med* 2008; 35: 358–362.
- [6] Bauman JR, Temel JS. The Integration of Early Palliative Care With Oncology Care: The Time Has Come for a New Tradition. *J Natl Compr Canc Netw* 2014; 12: 1763–1771.
- [7] Beernaert K, Haverbeke C, Van Belle S, et al. Information needs about palliative care and euthanasia: A survey of patients in different phases of their cancer trajectory. *Patient Educ Couns* 2018; 101: 132–138.
- [8] Braithwaite M, Philip J, Tranberg H, et al. End of life care in CF: Patients, families and staff experiences and unmet needs. *J Cyst Fibros* 2011; 10: 253–257.
- [9] Scherrens A, Cohen J, Mahieu A, et al. The perception of people with cancer of starting a conversation about palliative care: A qualitative interview study. *Eur J Cancer Care (Engl)*. Epub ahead of print July 2020. DOI: 10.1111/ecc.13282.
- [10] Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in Patient-Physician consultations: Theoretical and practical issues. *Soc Sci Med* 2005; 61: 1516–1528.
- [11] Scherrens A-L, Beernaert K, Robijn L, et al. The use of behavioural theories in end-of-life care research: A systematic review. *Palliat Med* 2018; 32: 1055–1077.
- [12] Eldredge LKB, Markham CM, Ruiter RAC, et al. *Planning Health Promotion Programs: An Intervention Mapping Approach*. John Wiley & Sons, 2016.
- [13] Grol RPTM, Bosch MC, Hulscher MEJL, et al. Planning and studying improvement in patient care: the use of theoretical perspectives. *Milbank Q* 2007; 85: 93–138.
- [14] Glanz K, Rimer BK, Viswanath K. *Health Behavior: Theory, Research, and Practice*. John Wiley & Sons, 2015.
- [15] DiClemente RJ, Crosby RA, Kegler MC. *Emerging Theories in Health Promotion Practice and Research: Strategies for Improving Public Health*. John Wiley & Sons, 2002.
- [16] Baranowski T, Lin LS, Wetter DW, et al. Theory as mediating variables: Why aren't community interventions working as desired? *Ann Epidemiol* 1997; 7: S89–S95.
- [17] Ruiter RAC, Crutzen R. Core Processes: How to Use Evidence, Theories, and Research in Planning Behavior Change Interventions. *Front Public Health*; 8. Epub ahead of print 2020. DOI: 10.3389/fpubh.2020.00247.
- [18] Blalock SJ. The theoretical basis for practice-relevant medication use research: Patient-centered/behavioral theories. *Res Soc Adm Pharm* 2011; 7: 317–329.
- [19] Horlait M, Chambaere K, Pardon K, et al. What are the barriers faced by medical oncologists in initiating discussion of palliative care? A qualitative study in Flanders, Belgium. *Support Care Cancer* 2016; 24: 3873–3881.
- [20] Davis R, Campbell R, Hildon Z, et al. Theories of behaviour and behaviour change across the social and behavioural sciences: a scoping review. *Health Psychol Rev* 2015; 9: 323–344.
- [21] Boateng GO, Neilands TB, Frongillo EA, et al. Best Practices for Developing and Validating Scales for Health, Social, and Behavioral Research: A Primer. *Front Public Health*; 6. Epub ahead of print 2018. DOI: 10.3389/fpubh.2018.00149.
- [22] McIlpatrick S, Hasson F, McLaughlin D, et al. Public awareness and attitudes toward palliative care in Northern Ireland. *BMC Palliat Care* 2013; 12: 34.
- [23] Lavoie M, Godin G, Vézina-Im L-A, et al. Psychosocial determinants of nurses' intention to practise euthanasia in palliative care. *Nurs Ethics*. Epub ahead of print 8 December 2014. DOI: 10.1177/0969733014557117.

- [24] Ajzen I. The theory of planned behaviour: Reactions and reflections. *Psychol Health* 2011; 26: 1113–1127.
- [25] Brug J, van Assema P, Lechner L. *Gezondheidsvoorlichting en gedragsverandering: een planmatige aanpak*. 8ste ed. Assen: Van Gorcum, 2012.
- [26] Francis J, Eccles MP, Johnston M, et al. Constructing questionnaires based on the theory of planned behaviour: A manual for health services researchers, <http://openaccess.city.ac.uk/1735/> (2004, accessed 27 November 2018).
- [27] Lavoie M, Godin G, Vézina-Im L-A, et al. Psychosocial determinants of physicians' intention to practice euthanasia in palliative care. *BMC Med Ethics* 2015; 16: 6.
- [28] Giles-Corti B, Donovan RJ. The relative influence of individual, social and physical environment determinants of physical activity. *Soc Sci Med* 1982 2002; 54: 1793–1812.
- [29] Willis GB. *Cognitive Interviewing: A Tool for Improving Questionnaire Design*. SAGE Publications, 2004.
- [30] Rothman KJ, Gallacher JEJ, Hatch EE. Why representativeness should be avoided. *Int J Epidemiol* 2013; 42: 1012–1014.
- [31] Ajzen I. The theory of planned behavior. *Organ Behav Hum Decis Process* 1991; 50: 179–211.
- [32] Zhou D, Jill C, Parks M, et al. Knowledge, attitudes, and practice behaviors of oncology advanced practice nurses regarding advanced care planning for patients with cancer.
- [33] Fernandez ME, Ruiter RAC, Markham CM, et al. Intervention Mapping: Theory- and Evidence-Based Health Promotion Program Planning: Perspective and Examples. *Front Public Health*; 7. Epub ahead of print 2019. DOI: 10.3389/fpubh.2019.00209.
- [34] Section AGD of H and APC. Community Attitudes to Palliative Care Issues 2003, <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-comm-attitudes.htm> (accessed 30 November 2018).
- [35] Hekler EB, Klasnja P, Froehlich JE, et al. Mind the theoretical gap: Interpreting, using, and developing behavioral theory in HCI research. In: *Conference on Human Factors in Computing Systems - Proceedings*, pp. 3307–3316.
- [36] Sharma M. Multi-theory Model (MTM) For Health Behavior Change. *WebmedCentral BEHAVIOUR*; 6, <http://www.webmedcentral.com/> (2015, accessed 23 February 2022).
- [37] Sallis JF, Cervero RB, Ascher W, et al. An ecological approach to creating active living communities. *Annu Rev Public Health* 2006; 27: 297–322.
- [38] Enguidanos S, Kogan AC, Lorenz K, et al. Use of Role Model Stories to Overcome Barriers to Hospice among African Americans. *J Palliat Med* 2011; 14: 161–168.
- [39] Vandecreek L, Frankowski D. Barriers that predict resistance to completing a living will. *Death Stud* 1996; 20: 73–82.
- [40] Ko E, Lee J. Completion of Advance Directives Among Korean American and Non-Hispanic White Older Adults. *Res Aging* 2010; 32: 618–644.
- [41] Earp MA, Sinnarajah A, Kerba M, et al. Opportunity is the greatest barrier to providing palliative care to advanced colorectal cancer patients: a survey of oncology clinicians. *Curr Oncol* 2018; 25: e480–e485.
- [42] Bluethmann SM, Bartholomew LK, Murphy CC, et al. Use of Theory in Behavior Change Interventions: An Analysis of Programs to Increase Physical Activity in Posttreatment Breast Cancer Survivors. *Health Educ Behav* 2016; 1090198116647712.
- [43] Michie S, Atkins L, West R. *The Behaviour Change Wheel Book - A Guide To Designing Interventions*. 1st ed. Great-Britain: Silverback publishing, <http://www.behaviourchangewheel.com/> (2014, accessed 26 November 2018).
- [44] Fayers P, Bottomley A. Quality of life research within the EORTC—the EORTC QLQ-C30. *Eur J Cancer* 2002; 38: 125–133.

Figures

Figure 1

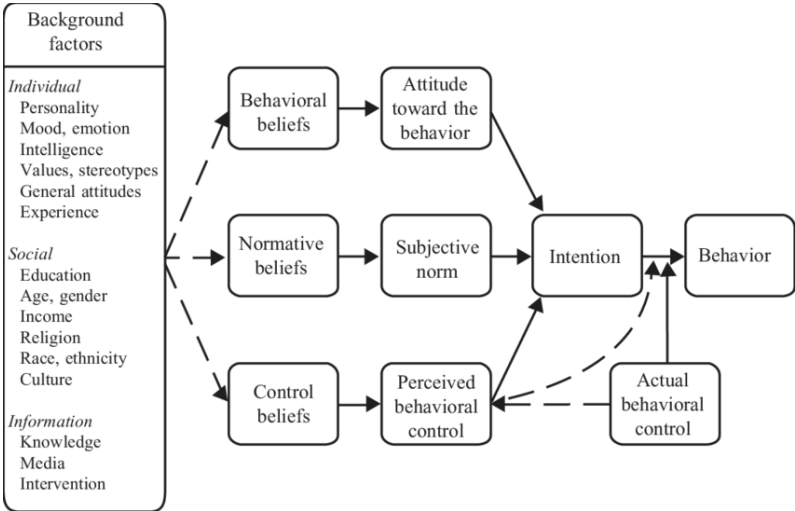


Figure 1. The Theory of Planned Behavior – factors and underlying beliefs

Figure 2

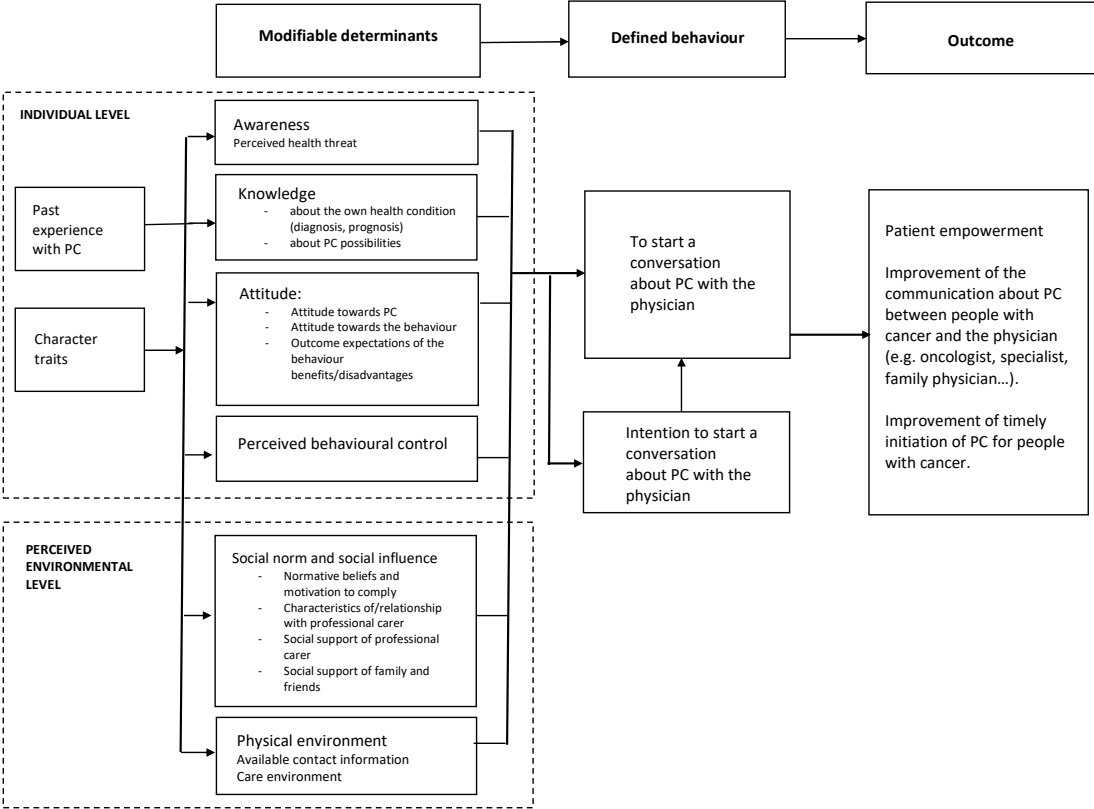


Figure 2. The palliative care (PC) behavioral model developed and tested

Foodnote: while developing and further testing our palliative care behavioral model, it was a methodological choice to combine the intention to start a conversation about palliative care with the physician with the defined behavior of starting a conversation about palliative care with the physician. Evidence shows that intention is strongly associated with the actual behavioral performance (refs Eldredge and ajzen). Furthermore, for having sufficient power in the quantitative testing of the model sufficient number of events in the positive group were needed.

Tables

Table 1. Operationalization of the behavioral factors related to starting a conversation about palliative care with the physician

Behavioral factor	Description	Main constructs (underlying beliefs)	Operationalization
Awareness	Need recognition or problem appraisal: the extent to which a person perceives his/her own behavior as unhealthy (e.g. health condition, care needs etc.).	/	<p>Awareness about palliative care (n=3 items)</p> <p>In literature, awareness of palliative care was operationalized as ‘Have you ever heard of palliative care? Do you know what palliative care is? Do you know when palliative care can be used? (yes/no)[34]. These items (n=3) were integrated and translated into the survey. Because of known misconceptions about palliative care, the response categories were adapted from yes/no to no, I don’t know/I think so/yes, I know for sure.</p>
Knowledge	The individual’s knowledge about health and disease; specific information about health risks of unhealthy behaviors; information about how to change. This knowledge is needed to obtain behavioral change[25].	/	<p>Knowledge about palliative care (n=12 items)</p> <p>In health promotion research, knowledge about a concept was operationalized by ‘I know that...’ and ‘I know how to...’ [25]. In the study by Eguidanos et al., knowledge about palliative care was operationalized by asking if palliative care statements based on the WHO definition, eg ‘palliative can alleviate the pain’, were false or true[38]. In the current survey, knowledge about palliative care was also operationalized based on eight statements in the WHO Definition, for example: ‘palliative care also addresses possible psychological problems’ (definitely false, probably false, probably true, definitely true). Four extra items were added based on incorrect knowledge or negative connotations found in the previous qualitative study such as ‘palliative care equals the end, death’.</p> <p>Knowledge about starting a conversation about palliative care with the physician (n=1 item)</p> <p>To operationalize knowledge about our specific target behavior, the following item was designed ‘Do you know you can start a conversation about palliative care with the physician yourselves?’(yes/no).</p>

Behavioral factor	Description	Main constructs (underlying beliefs)	Operationalization
Attitude	The individual's positive or negative evaluation of an object/a concept/ performing the particular behavior of interest. Behavioral outcome expectations (advantages/ disadvantages).[12, 31]	<p>Attitude is composed of three components: affective beliefs, cognitive beliefs and outcome beliefs[12].</p> <p>1) Affective beliefs: related to feelings (pleasant or unpleasant)</p> <p>2) Cognitive beliefs: related to knowledge (important or not important; relevant or irrelevant)</p>	<p>Attitude towards palliative care (n=6 items) General attitude towards starting a conversation about palliative care with the physician (n=5 items) Perceived reasons to start a conversation about palliative care with the physician myself (n=7 items) Perceived reasons not to start a conversation about palliative care with the physician myself (n=6 items) Perceived benefits to starting a conversation about palliative care with the physician myself (n=12 items) Perceived disadvantages to starting a conversation about palliative care with the physician myself (n=5 items)</p> <p>Guidelines for how to measure theory of planned behavior constructs as well as studies related to physical activity show that affective beliefs can be operationalized as 'displaying the behavior is e.g. good/bad, irrelevant/relevant, satisfying/dissatisfying' (seven-point semantic differential scale)[26, 28]. Studies in cancer and end-of-life care research measured affective attitude as 'How do you feel about palliative care? (Five-point Likert scale ranging from strongly positive to strongly negative)[12, 15]'. The previous qualitative interviews showed that stress, anxiety and depression were related to the term palliative care. In the current survey, affective attitude towards palliative care was operationalized by the following two items 'At this moment ... the words palliative care give me stress or anxiety' and '...thinking about palliative care makes me feel depressed'.</p> <p>Cognitive beliefs were measured in existing health behavior studies as 'I think it is important/relevant/necessary that...' (Five-point Likert scale ranging from strongly disagree to strongly agree)[31]. Studies focusing on attitude towards advance care planning measured the cognitive beliefs as 'ACP is important', 'ACP can improve satisfaction with care...' (Five-point Likert scale ranging from strongly disagree to strongly agree)[32]. In the current study, cognitive beliefs about palliative care (4 items) were operationalized as e.g. 'I am interested in palliative care', 'I think palliative care is necessary for me' (4 items). Cognitive beliefs about the specific target behavior (4 items) were operationalized as e.g. 'I think starting a conversation about palliative care with the physician myself is important'. Some studies also captured reasons to perform the behavior and reasons to not perform the behavior. For example, an end-of-life care survey measured 'I am/I am not interested in displaying the behavior, because ...' (Four-point Likert scale ranging from fully disagree to fully agree)[39]. In the current study, reasons to perform (6 items) and not to perform the behaviour (7 items) were based on reasons identified in the previous qualitative study. For example: 'A reason why I should start or started a conversation about palliative care with the physician myself is or was that my quality of life decreases', 'a reason for me to not start a conversation about palliative care with the physician myself is or was that I am feeling good'.</p>

Behavioral factor	Description	Main constructs (underlying beliefs)	Operationalization
		<p>3) Outcome beliefs: expected outcomes of the behavior (advantages/disadvantages) and evaluation beliefs: how important these outcomes are [12, 31].</p>	<p>In existing literature outcome beliefs (benefits/disadvantages) were measured with 'perceived benefits/disadvantages of the behavior for me are that...'[26, 28, 39–41]. The previous qualitative interviews identified benefits such as receiving information about palliative care. This led to the following items (11 items) in the survey, e.g. 'A perceived benefit of starting a conversation about palliative care with a treating physician myself was/would be that... I received information about palliative care', '...that I could express my care wishes'. The previous qualitative interviews also identified disadvantages such as feeling stress and anxiety afterwards. This led to the following statements (5 items) e.g. 'A perceived disadvantage of starting a conversation about palliative care with a treating physician myself was/would be that... I would feel/felt stress and anxious afterwards'. All attitude-items were scaled on a five-point Likert ranging from totally disagree to totally agree.</p>
Perceived social norm	The perceived social expectations[42].	<p>1) Normative beliefs (the estimated important others' opinion)</p>	<p>Perceived social norm in attitude towards palliative care – family/friends (n=4 items) Perceived social norm in attitude towards palliative care – physician (n=4 items) Perceived social norm in attitude towards the person with cancer starting a conversation about palliative care with the physician – family/friends (n=5 items) Perceived social norm in attitude towards the person with cancer starting a conversation about palliative care with the physician – physician (n=4 items) Perceived social norm in attitude towards the person with cancer starting a conversation about palliative care with the physician – fellow sufferers (n=1 item)</p> <p>In existing surveys normative beliefs were measured as follows: Important others think that...[31], important others approve/disapprove...[24], Important others expect of me that I... [25], Do you think that other people around you (e.g. other patients) perform the behavior?[43]. According to guidelines describing how to measure this determinant of the theory of planned behavior, it can be measured as 'Important others think I (should not -3 to +3 should or disapprove -3 to +3 approve) perform the behavior'[26]. Qualitative interviews showed that the perceived opinion of important others such as the partner/family/friends/the physician about palliative care and the behavior were influential.</p>

Behavioral factor	Description	Main constructs (underlying beliefs)	Operationalization
		2) The motivation to comply with this opinion (how important is it to comply with the social expectations)	<p>Operationalization of the social norm towards palliative care resulted in ‘My partner/family/friend think(s) that palliative care is important (Five-point or four-point Likert scale ranging from nobody to everybody)’ and the social norm in attitude towards the specific target behavior was operationalized as ‘My partner/family/friend think(s) that starting a conversation about palliative care with the physician myself is important (Five-point Likert scale ranging from nobody to everybody).</p> <p>In literature, the motivation to comply was measured as ‘I am willing to do what people around me expect of me’ (Five-point Likert scale ranging from strongly disagree to strongly agree)[25]. Guidelines suggest measuring it as ‘I think doing what my environment expects of me is...’(important/not important)[26]. Operationalization of the motivation to comply resulted in ‘the motivation to comply with the opinion of family/friends is important to me’ (Five-point Likert scale ranging from strongly disagree to strongly agree).</p>
Perceived behavioral control	The subjective probability that a person is capable of executing a certain course of action[42].	Control beliefs[31].	<p>Perceived behavioral control (n=1 item)</p> <p>Guidelines describing how to measure this determinant of the theory of planned behavior, describe measuring it with the following statement ‘I am confident that I can display the behavior’ (Seven-point semantic differential scale ranging from fully disagree to fully agree)[26]. In the current survey, we specified it for the defined behavior. This resulted in the statement ‘I would be / was confident that I can / could start a conversation about palliative care with the physician myself’ (Five-point Likert scale ranging from strongly disagree to strongly agree).</p>
Perceived social influence	Interpersonal processes that can change someone’s thoughts, feelings and/or behavior.[43]		<p>Social influence – partner/family/friends (n=4 items)</p> <p>Social influence – physician (n=10 items)</p> <p>Social influence – fellow sufferers (n=3 items)</p>

Behavioral factor	Description	Main constructs (underlying beliefs)	Operationalization
	The social support or pressure to perform or not to perform a given behavior[44].	Social support (emotional support, informative support) v. social pressure	Practical guidelines to operationalize the theory of planned behavior describe to measure social influence as follows: My partner/friends/family... support(s) me in..., ... encourage(s) me to..., ... stop(s) me from...[25]. Previous qualitative interviews showed that positive social support was related to family (e.g. attending the conversation), the physician (good relationship, being empathetic...) and fellow sufferers (supporting). The interviews showed that negative social support was mainly related to the physician (e.g. weak connection, perceived time constraints, perceived negative attitude towards palliative care...). Again a distinction was made between family/friends (n=4), the physician (n=10) and fellow sufferers (n=3). For example, my partner/friends/family... would encourage or encouraged me to start a conversation about palliative care with the physician myself. A social factor that would help me or helped me to start a conversation about palliative care with the physician myself is or was that I have a good relationship with my physician (Five-point Likert scale ranging from strongly disagree to strongly agree).
Behavioral intention	The extent to which someone intends to display a certain behavior, ie to start a conversation about palliative care with the treating physician themselves.		<p>Behavioral intention (n=4 items) Behavior (n=2 items)</p> <p>The main outcome (i.e. the intention to start a conversation about palliative care with the treating physician as well as the behavior itself) was operationalized on a dichotomous scale (yes/no). Participants could indicate whether they had already started a conversation about palliative care themselves. If the participants responded no, they were asked if they had the intention to do so in the next (six) month(s) in case of not (yet) receiving specialist palliative care (yes/no), or if they were receiving specialist palliative care, they were asked if they would do it with hindsight (yes/no).</p>

