



The perception of people with cancer of starting a conversation about palliative care: A qualitative interview study

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Abstract

Objective: Communication and patient-centred care are important determinants for timely initiation of palliative care. Therefore, we aimed to understand and explain the behaviour “starting a conversation about palliative care with a professional carer” from the perspective of people with incurable cancer.

Methods: A qualitative study using semi-structured face-to-face interviews with 25 people with incurable cancer: 13 not (yet) receiving palliative care and 12 receiving palliative care; 4 started the conversation themselves. Determinants related to the defined behaviour were matched with concepts in existing behavioural theories.

Results: Both positive and negative stances towards starting a conversation about palliative care with a professional carer were found. Influencing behavioural factors were identified, such as knowledge (e.g. about palliative care), attitude (e.g. association of palliative care with quality of life) and social influence (e.g. relationship with the professional carer). We modelled the determinants into a behavioural model.

Conclusion: The behavioural model developed helps to explain why people with incurable cancer do or do not start a conversation about palliative care with their professional carer. By targeting the modifiable determinants of the model, promising interventions can be developed to help patients taken the initiative in communication about palliative care with a professional carer.

KEYWORDS

behaviour, behavioural theory, health communication, health promotion, neoplasms, palliative care, Qualitative research, terminal care

1 | INTRODUCTION

People with cancer may need palliative care early in the disease trajectory (Beernaert et al., 2014; Dulaney et al., 2017). It can improve their quality of life (Bakitas et al., 2009; Temel et al., 2010), but it is often initiated late or not at all (Reville, Axelrod, & Maury, 2009; Temel et al., 2010). No palliative care or late initiation can lead to suboptimal care in the final months of life (Higginson et al., 2014). Studies focusing on palliative care initiation frequently do so from

a health service or professional carer perspective. Late recognition of palliative care needs (Beernaert et al., 2016) or late referral (Temel et al., 2010) by the professional carer (Bakitas et al., 2009; Dionne-Odom et al., 2015) are examples of factors hindering timely initiation of palliative care. These studies also showed that adequate and timely communication about palliative care is important for initiation (Horlait, Chambaere, Pardon, Deliens, & Belle, 2016), but there is room for improvement (Bauman & Temel, 2014). Initial palliative care discussions often seem to be postponed or avoided

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by the professional carer (Beernaert et al., 2014). Physicians wait until the person with cancer brings palliative care up because they fear that doing so themselves would be intrusive or discomforting (Beernaert et al., 2014; Beernaert, Haverbeke, Van Belle, Deliens, & Cohen, 2018). Inadequate communication about palliative care leads to unmet information needs in people with cancer (Beernaert et al., 2018), whose perspective seems to be entirely absent in the study approaches mentioned above.

Besides barriers among health services or professional carers, it is clear from previous literature that significant barriers, and hence opportunities for initiating palliative care, also exist among patients (Beernaert et al., 2018; Braithwaite et al., 2011). Patients' communicative behaviours greatly influence the quality of palliative care (Beernaert et al., 2014; Higginson et al., 2014). Qualitative research has indicated that patients often do not start a conversation about palliative care because they associate it with death and because they do not want to burden the professional carer with their psychosocial or existential needs but turn to them purely for physical and disease-related (as opposed to illness-related) problems (Higginson et al., 2014). Nevertheless, patients prefer an active role in decision-making at the end of life (Bélanger, Rodríguez, & Groleau, 2011). Many want to be informed about palliative care before the terminal phase of their illness (Beernaert et al., 2014, 2018) and attach value to their treating physician knowing their palliative care wishes (De Vleminck, Batteauw, Demeyere, & Pype, 2018).

Higher quality of palliative care can be achieved through greater patient-centred care and patient empowerment in communication (Epstein et al., 2005) about palliative care (Pardon et al., 2009). Therefore, insight into the determinants of patients' communicative behaviours related to palliative care initiation is important. This study focuses on the behaviour "starting a conversation about palliative care with a professional carer," implying the patient starts a conversation by using the words palliative care himself. Using the term palliative care enabled to identify hindering factors (including misconceptions) as well as certain facilitating factors. Evidence from research domains other than palliative care research (Fishbein & Yzer, 2003; Painter, Borba, Hynes, Mays, & Glanz, 2008) shows that the identification of behavioural determinants can be best supported by the use of behavioural theories such as the Theory of Planned Behaviour (Ajzen, 1991). Using a behavioural theory helps to explain why people with cancer do or do not display certain communicative behaviours (Glanz, Rimer, & Viswanath, 2015). This knowledge is needed to develop promising theory-based interventions (Eldredge et al., 2016). Achieving change in the behaviour "starting a conversation about palliative care with a professional carer" among people with cancer could improve communication with the professional carer and increase timely initiation of palliative care.

The aims are (a) to better understand the communicative behaviour "starting a conversation about palliative care with a professional carer (e.g. (family) physician)" from the perspective of people with incurable cancer by identifying related determinants with the

help of behavioural theories (e.g. the Theory of Planned Behaviour) and (b) to develop a theoretical behavioural model for the defined behaviour.

2 | METHODS

2.1 | Study design

We conducted a qualitative study, using semi-structured, face-to-face interviews with people with incurable cancer. This study design was deemed most suitable for this explorative study aimed at developing a palliative care behavioural model. In choosing this design, we also considered the vulnerability of these people and the sensitivity of the subject. We used the criteria for reporting qualitative research from the SRQR guidelines (see Appendix 1) (Tong, Sainsbury, & Craig, 2007).

2.2 | Participants

We took the following inclusion criteria into account: 18 years or older; any type of incurable cancer; aware of the diagnosis; decision-making capacity; ability to participate in a Dutch interview; incurable cancer was diagnosed at least one month ago. We assumed that perceptions of starting a conversation about palliative care with a professional carer him or herself and related determinants might differ depending on whether or not people have had the experience of palliative care. We included people with incurable cancer who were receiving specialised palliative care and people who were not (yet). The physician or nurse, specialised in oncology or palliative nursing, was asked whether the participant already had contact with a specialised palliative care team member (palliative home care, support team or day care centre). We opted for specialised palliative care for pragmatic reasons. Generalist palliative care—at least in Belgium—is not always defined well and not easy to measure. Focusing on specialised palliative care made it possible to identify the people who have had experience with palliative care easily. We formulated the following exclusion criteria: cognitively incapable of participating in an interview or too tired to do so, estimated life expectancy of more than five years, in follow-up or remission.

2.3 | Recruitment

Physicians or specialist nurses were the intermediaries for reaching people with incurable cancer. The intermediaries were selected by purposeful sampling through hospitals, a regional Palliative Care Network and the Flemish Palliative Day Care Centres. The physicians/nurses informed eligible people about the study and asked them to participate. If the person with cancer was willing, the physician/nurse gave the contact details of the participant to researcher

AS. AS contacted the participant by phone and provided additional information about the study objectives, interview themes and some ethical considerations. Upon oral confirmation of participation, AS made an appointment for an interview.

2.4 | Data collection

Two female researchers (AS, a nurse, and AM; both have an MSc in Health Education and Health Promotion) conducted individual interviews at the participants' home, hospital unit or palliative day centre between February and June 2018.

A topic guide (Table 1) was developed by a multi-disciplinary team including experienced researchers in the fields of end-of-life care and health promotion. We paid special attention to the structure of the topic guide to prevent palliative care from being perceived as threatening. Before the questions related to palliative care, we gave

a definition of palliative care (see Table 1, based on the World Health Organization's definition of palliative care (WHO | WHO Definition of Palliative Care, 2018). Both the definition and the questions focused on communication about generalist and specialised palliative care. The questions covered three major themes: (a) perception of starting a conversation about palliative care with a professional carer, (b) facilitating factors and (c) hindering factors. For identifying behavioural factors, we based some prompts on determinants of the Theory of Planned Behaviour ("attitude," "social norm and influence" and "behavioural control") with an opportunity to identify other determinants not included in this theory (multi-theory approach). The Theory of Planned Behaviour includes the behavioural intention, which was relevant to the group who had not yet started a conversation about palliative care and had to answer hypothetical questions. We used "if...then" questions to stimulate hypothetical thinking. For example, the participant indicated that palliative care might be discussed after hearing that the cancer had metastasised; the interviewer asked "if

TABLE 1 Topic guide

Question type	Question*	Prompts
Transition	<ul style="list-style-type: none"> - What does palliative care^a mean to you/what might palliative care mean to you? - When should palliative care be initiated? - Who should initiate palliative care? 	
Key	<ul style="list-style-type: none"> - <i>No palliative care (yet)</i>: have you already thought of talking to someone about palliative care? - <i>Already palliative care</i>: before receiving palliative care, did you think of talking to someone about palliative care? - <i>If yes</i>: with which professional carer? What did you discuss? Did you start the conversation yourself? What was facilitating and what was hindering to start a conversation about palliative care with a professional carer? - <i>If no</i>: how come? What would be facilitating and what would be hindering to start a conversation about palliative care with a professional carer? 	Prompts related to the concepts of the Theory of Planned Behaviour (depending on the content of the interview): <ul style="list-style-type: none"> - What were/would be the advantages/disadvantages of starting a conversation about palliative care with a professional carer? (attitude) - What did/would people in your environment think about palliative care initiation? (social norm) - What did/would people in your environment expect if you were about to start a conversation about palliative care with your professional carer? (social norm) - How confident were you/would you be about starting a conversation about palliative care with your professional carer (perceived behavioural control)Etc...

^aThe interviewer introduced palliative care as care that can be provided in addition to oncology care. Oncology care focuses on physical complaints related to the cancer/tumour. The interviewer gave a definition of palliative care prior to the first questions related to palliative care. Palliative care was defined as physical, psychological, social and spiritual care for people with a life-threatening illness; which can be introduced early in the disease trajectory; which is not only for people who are about to die in the short term; which is depending on the wishes and needs of a patient; and it was explicitly stated that it was not necessarily applicable to the participant.

you heard that the cancer had metastasised, would you start a conversation about palliative care?" All interviews were audio-recorded and lasted approximately one hour.

At the end of each interview, a brief questionnaire was administered to collect some socio-demographic data. We collected medical/clinical data (estimated life expectancy, specialised palliative care, etc.) from the treating physician.

2.5 | Data analysis

We transcribed the interview recordings verbatim, using Nvivo 11 for data structuring and thematic content analysis for data analysis (Reyniers, Houttekier, Cohen, Pasman, & Deliens, 2014). AS and AM independently and openly coded the transcripts. The data analysis was both inductive and deductive. First, we searched for influencing factors in the answers to the questions "what helped or would help you/what made or would make it difficult for you to start a conversation about palliative care?". Second, these factors were deductively matched with concepts in behavioural theories (e.g. "attitude" defined by the Theory of Planned Behaviour; "perceived health threat" defined by the Health Belief Model). The coders compared and debated their code nodes and trees. Where coding discrepancies occurred, consensus was sought. During data collection, we filled in a preliminary model for the identified factors related to the defined behaviour. We collected data until no new factors emerged from the interviews and data saturation was achieved. This resulted in a final behavioural model, which all authors agreed upon.

3 | RESULTS

Twenty-five interviews with people with 11 different types of cancer were conducted. Thirteen participants were not yet receiving specialised palliative care; twelve were. Their ages ranged from 39 to 77 years (see Table 2).

3.1 | Perception of the defined behaviour

Both positive and negative stances towards 'starting a conversation about palliative care with a professional carer' were found. Nine of the twelve participants who were receiving specialised palliative care had a positive stance towards the defined behaviour, as did eleven of the thirteen participants who were not. These twenty participants had already started a conversation about palliative care ($N = 4$; three receiving specialised palliative care and one not) or could imagine doing so ($N = 16$). The four participants who started a conversation did so with a family physician, oncologist, another specialist and an acquaintance specialised in palliative care. The others would choose to start a conversation with a family physician, oncologist, nurse or psychologist. Half the respondents were initially negative towards the defined behaviour, but the majority reported

that their perception might change with time and depending on their health. For example, they would not start the conversation when feeling good, but they would if they felt worse.

TABLE 2 Characteristics of the participants

Characteristics of participants with incurable cancer	Total (N =)
Number of people with incurable cancer interviewed	25
Sex	
Male	11
Female	14
Age	
<30	0
30–39	1
40–49	1
50–59	6
60–69	11
70–79	6
≥80	0
Mean age (SD)	63 (9)
Date of cancer diagnosis	
≤1 y ago	11
>1 y - ≤5 y ago	11
>5 y ago - <10 y ago	2
≥10 y ago	1
Cancer type	
Respiratory	7
Gastrointestinal	4
Soft tissue sarcoma	3
Breast	2
Urological	2
Gynaecological	1
Bone	1
Head and neck	1
Other ^a	4
Estimated life expectancy	
Few weeks	2
<6 months	2
<1 y	4
<2 y	5
<3 y	3
<4 y	0
<5 y	2
Unknown	3
Contact with specialized palliative care member (yes or no)	
Yes	12
No	13

^aOther: this group contains all other cancer types that were identified as adenocarcinoma ($n = 2$), non-Hodgkin's lymphoma ($n = 1$) and malignant peripheral nerve sheath tumour ($n = 1$).

TABLE 3 Overview of the determinants related to "starting a conversation about palliative care with a professional carer" by people with incurable cancer

Determinant	Facilitating factors	Hindering factors
Individual level		
Awareness Perceived health threat	Awareness of the poor health condition (e.g. sudden paralysis, incurable cancer, spectacular rise in tumour marker; feeling physically unwell, believing the end is near) Awareness that that curative treatments no longer make sense or/and that additional care support (e.g. pain relief, palliative care) is needed	Feeling too good - To feel too good (e.g. to think about palliative care yet, to be eligible for palliative care) - To feel the end is not near (e.g. to be convinced one will live 10 more years, to feel no death threat yet) Palliative care is too early and is not necessary yet - There are still treatment options, the treatment is still effective - To be convinced one will beat the cancer - To not need palliative care yet; to not need physical or psychological help
Past experience with palliative care	Having experience with palliative care among family, friends, acquaintances etc. Having experience with palliative care through work activities (e.g. voluntary work in a nursing home)	Having no experience with palliative care among family, friends, acquaintances etc.
Knowledge	Knowledge about palliative care (possibilities) Knowledge about the option of talking or starting a conversation about palliative care Knowledge about one's own health condition (e.g. a known prognosis of maximum 1 year) Basic medical knowledge	Enough knowledge about palliative care (possibilities) - To know enough about palliative care to make a conversation no longer relevant Lack of knowledge about palliative care (possibilities) - Palliative care and palliative care services are something unknown - Not knowing when one can receive palliative care - Not knowing who is qualified to have a conversation about palliative care Inaccurate knowledge about palliative care (possibilities) - To believe that palliative care is only for bedridden patients - Associating palliative care with financial costs Limited knowledge about one's own health condition (e.g. disease, prognosis) and care situation (e.g. the need of palliative care, the possible treatment options)
Attitude	Attitude towards palliative care - Being convinced palliative care is important (e.g. for a comfortable life, to improve the quality of life, to prevent deterioration or asphyxiation) Attitude towards starting a conversation about palliative care with a professional carer (e.g. not being afraid) Other facilitators (e.g. fearing physical complaints may cause shame to the patient's family, if it all gets too much, if the words 'palliative care' have already been used by another professional carer)	Attitude towards palliative care - Connotation of palliative care: association of palliative care with terminal care, with the last step, with death; with deterioration - To prefer other options than palliative care (e.g. euthanasia) - To be afraid (e.g. of the words 'palliative care', of the palliative care phase) - To not want to think about palliative care yet (too early, too soon after diagnosis), not to be interested in palliative care yet - To be convinced that palliative care is not relevant at the moment - To be convinced that palliative care takes away all hope of getting better

(Continues)

TABLE 3 (Continued)

Determinant	Facilitating factors	Hindering factors
		<p>Attitude towards starting a conversation about palliative care with a professional carer (negative attitude)</p> <ul style="list-style-type: none"> - To be convinced that palliative care conversations are not necessary or relevant yet - To expect the professional carer to take the initiative in starting a conversation about palliative care <ul style="list-style-type: none"> o To accept that the professional carer starts a conversation about palliative care o To be convinced the professional carers know better what is medically feasible o To be convinced that the professional carer will start a conversation about palliative care sooner o To be convinced that starting a conversation about palliative care is part of the job of professional carers, that they will help if necessary <p>Other barriers (e.g. cannot yet accept the disease/diagnosis)</p>
Outcome expectations	<p>Advantages related to the defined behaviour</p> <ul style="list-style-type: none"> - Getting information e.g. about diagnosis, palliative care possibilities... - Getting the chance to arrange things (e.g. activities that one would like to do while one's health permits) and to make decisions - Experiencing reassurance and/or relief - Relieving family carers from burden becoming too great - Informing the professional carer about how one feels and about one's wishes - Expecting the professional carer to take over the conversation, to elaborate on palliative care - The professional carer immediately follows up the conversation (e.g. by referring to palliative care services) - The professional carer cannot start the conversation about palliative care unexpectedly (e.g. if palliative care is not perceived as relevant yet) 	<p>Disadvantages related to the defined behaviour</p> <ul style="list-style-type: none"> - Not knowing what to expect of such conversation - Being convinced that such conversations are difficult and emotionally charged - Getting depressed when thinking about palliative care
Perceived behavioural control	<p>To feel able/to be confident about a conversation about palliative care (e.g. tomorrow, if one perceives health threat, if the words 'palliative care' have already been used by another professional carer etc.)</p>	<p>Not being able to start a conversation about palliative care (difficult and emotionally charged, lacking the courage)</p> <p>Not being able to assess the perceived threat</p> <p>Not being able to determine whether palliative care is needed</p>
Character traits	<p>Conviction that they know themselves best</p> <ul style="list-style-type: none"> - E.g. nobody knows me better than I do, I know myself better than my professional carers do, I know better how I feel than my professional carers do <p>Conviction that they have to make their own choices in life</p> <ul style="list-style-type: none"> - E.g. I have to choose to talk about palliative care, because it is my life; I have to be able to decide for myself what I want and do not want <p>Other character traits</p> <ul style="list-style-type: none"> - E.g. being a down-to-earth person, someone who arranges everything in advance, someone who is quick to turn to someone else, an extravert (who finds it easy to talk) 	<p>Character traits</p> <ul style="list-style-type: none"> - E.g. someone who manages on their own, optimistic, hopeful etc.

(Continues)

TABLE 3 (Continued)

Determinant	Facilitating factors	Hindering factors
Perceived environmental level Social norm and social influence		
Related to professional carers (E.g. oncologist, family physician, nurse etc.)	<p>Perceived professional carers' positive attitude towards palliative care (conversations) (<social norm)</p> <p>Wanting to know the professional carers' opinion (< social norm)</p> <p>Perceived professional carers' characteristics</p> <ul style="list-style-type: none"> - Someone who is reliable, empathetic, straightforward, neutral (e.g. less emotionally involved), correct, fantastic, honest, competent, does not place themselves above the patient (e.g. no macho behaviour) - Someone who makes time, who will clearly explain - Someone who knows about one's background, about one's health condition and treatment, about one's attitude and how one deals with health problems - Someone who works in the medical sector - Someone who has experience with palliative care <p>Connection with professionals carers</p> <ul style="list-style-type: none"> - Good, strong, trustful, long-term connection <p>Social support from the professional carers</p> <ul style="list-style-type: none"> - If professional carers take initiative to come by (e.g. shortly after diagnosis) <p>If professional carers offer sufficient guidance</p>	<p>Perceived professional carers' negative attitude towards palliative care (conversations) (<social norm)</p> <p>Perceived professional carers' factors</p> <ul style="list-style-type: none"> - Limited competence (e.g. the perception that family physicians only prescribe drugs addressing acute needs, do not offer added value to the care, always have to check with another physician etc.) - Limited time (e.g. the perception that professional carers have a lot of work to do and have limited time, which one does not want to waste) - Someone in whom one has no trust <p>No connection with professionals carers</p> <ul style="list-style-type: none"> - The professional carer is a stranger, not knowing the professional carer well enough (e.g. because they have not been acquainted for long) - Limited contact with the professional carer (e.g. limited contact with the family physician due to a long hospital stay)
Related to family and friends	<p>Perceived attitude of family and friends towards palliative care (conversations) (<social norm)</p> <ul style="list-style-type: none"> - E.g. holding a positive attitude towards palliative care, believing it is important to start the conversation about palliative care with a professional carer <p>Social support from family and friends</p> <ul style="list-style-type: none"> - E.g. they easily accept the disease and the treatment options, having had a conversation about palliative care with family and friends first, they accompany the patient to the conversation, they understand that the patient wants to start a conversation about palliative care, they stimulate the patient to start the conversation about palliative care <p>Suddenly being alone and losing family care (e.g. death of the partner)</p>	<p>Perceived attitude of family and friends towards palliative care (conversations) (<social norm)</p> <ul style="list-style-type: none"> - E.g. holding a negative attitude towards palliative care, not knowing how to react to the words 'palliative' and 'incurable', avoiding such conversations <p>No social support from family and friends</p> <ul style="list-style-type: none"> - Family is no support because they are upset - To have enough care support from family or friends
Physical environment	<p>Availability of contact details to know who one can contact</p> <p>Long-term hospital stay</p>	<p>No private room (e.g. a shared hospital room)</p>

I do not know how I am going to react (...). When you approach death, you see life differently.

(Woman, 65 y., not yet receiving specialised palliative care)

Five participants (three receiving specialised palliative care and two not) held an absolutely negative stance towards the defined behaviour.

3.2 | Determinants related to the defined behaviour

The interviews revealed various factors both facilitating and hindering the behaviour. The following individual and perceived

environmental determinants can be related to the behaviour: awareness (and perceived health threat), knowledge (and past experience), attitude, perceived behavioural control, character traits, social norm and social influence, and physical environment. These determinants interact with each other, and most are easy to change in behavioural interventions. Table 3 shows all identified determinants.

3.2.1 | Awareness (individual level)

The participants mentioned *awareness* of palliative care needs and *perceived health threat* as a facilitating factor. The participants mentioned that if they became aware of the incurability of their cancer

(e.g. if the tumour marker rose spectacularly or if metastases occurred), if they felt physically unwell, felt that life was no longer worth living or that the end was near, they might start a conversation about palliative care.

I think if I felt really physically bad, then +++ the threshold would be overcome to start talking about it [refers to palliative care]

(Woman, 39 y., already receiving specialised palliative care)

Lack of awareness and perceived health threat were identified as hindering factors. The respondents indicated it was too early to start palliative care conversations and they were not necessary yet (e.g. treatment options left, convinced that they would “beat” the cancer); they felt too good and believed the end was not near.

For the moment I do not feel ready at all to start a conversation about palliative care with anyone. Because I do not feel threatened by death at all. Maybe it is near, but I do not feel it. I do not know. I am more concerned with life than with death.

(Woman, 65 y., not yet receiving specialised palliative care)

3.2.2 | Knowledge (individual level)

Participants mentioned that knowledge of palliative care and its possibilities was a facilitating factor. *Past experiences* such as experience with family/friends who received palliative care led to increased knowledge of palliative care.

I think that having a little bit more information about palliative care would be facilitating for starting a conversation about palliative care, because you know what you are talking about.

(Man, 66 y., not yet receiving specialised palliative care)

Participants identified lack of knowledge about palliative care timing, providers and possibilities as hindering factors. Few participants indicated that the high costs of palliative care were hindering. Some respondents indicated that they did not want to ask about palliative care, because if they did not know more about it they could stay in the dark. They also reported a lack of knowledge of their own health condition, care needs and treatment as hindering, which may be related to the aforementioned *limited perceived health threat*.

I would not have started a conversation myself because I did not know anything about palliative care.

I could hardly pronounce “palliative.” I had not heard that word before.

(Woman, 72y., already receiving specialised palliative care)

Palliative care costs a lot of money. I would not like to lie somewhere and pay a lot of money to the government.

(Woman, 51 y., not yet receiving specialised palliative care)

3.2.3 | Attitude (individual level)

Participants reported that they were generally not afraid of starting a conversation about palliative care with a professional carer. They indicated *positive outcome expectations* (advantages) as facilitating. The following outcome expectations of starting a conversation about palliative care were cited as follows: a comfortable end of life; emotional support; information about their health condition, their care and palliative care (possibilities); and preventing the care burden on family carers from becoming too high.

I have asked the physicians about palliative care, because I do not want to waste away.

(Woman, 65 y., not yet receiving specialised palliative care)

I want to start a conversation about palliative care as soon as possible. I think it is important to know what my health condition is so I can make decisions.

(Man, 65 y., not yet receiving specialised palliative care)

The respondents, especially the group who were not receiving specialised palliative care yet, identified a negative attitude towards palliative care and the defined behaviour as hindering factors. These participants had not yet accepted the diagnosis and were not yet interested in palliative care. They associated palliative care with terminal care and death. They were afraid of the words “palliative care” and avoided them during the interview by using reference words such as “that” and “there.” The participants also indicated some *negative outcome expectations*. They did not know what to expect from such a conversation. They wondered why they would start a discussion about palliative care now, why anticipate. They were afraid of being confronted with information they would rather not know. They expected to experience the feeling of giving up afterwards.

Palliative care is something I do not think about or think about as little as possible. It makes me feel depressed.

(Man, 77 y., not yet receiving specialised palliative care)

Palliative care means the end for me.

(Woman, 66 y., not yet receiving specialised palliative care)

Some expected professional carers to take initiative in starting a conversation about palliative care.

I think that the physician plays the most important role in discussions about palliative care. I can say that I have a lot of pain, but it is the physician's job to start the conversation and ask if it is time to consider palliative care. It is difficult for me to determine whether discussions about palliative care are necessary.

(Woman, 39 y., already receiving specialised palliative care)

3.2.4 | Perceived behavioural control (individual level)

The participants who were positive towards the defined behaviour mentioned that they would feel confident about starting the conversation. They reported their confidence would increase in specific situations. For example, if they felt their health was threatened or if their professional carers already used the term "palliative care."

If I no longer feel good I might be ready to ask if it would be better to start palliative care. Unless my children were faster, because they have been thinking about palliative care for a long time.

(Woman, 71 y., not yet receiving specialised palliative care)

Some respondents reported that starting a conversation about palliative care was difficult and emotional. They found it difficult to assess their perceived threat and to determine whether palliative care was needed. They felt that physicians knew better what was medically feasible.

Even though I would consider it, I would never dare to start the conversation myself. I would try to postpone it.

(Woman, 46 y., not yet receiving specialised palliative care)

3.2.5 | Character traits (individual level)

The participants reported character traits both facilitating and hindering. Participants reported the following traits as facilitating: extroversion, arranging everything in advance, quickly trusting

someone and knowing themselves best. They often repeated that it was their choice ("my life, my choice").

I know myself better than the physician knows me. I know better how I feel.

(Man, 58y., not yet receiving specialised palliative care)

Others were reluctant to start a conversation about palliative care due to optimism or wanting to retain their independence.

I am a very independent person. I will try to do everything myself.

(Woman, 62y., not yet receiving specialised palliative care)

3.2.6 | Social norm and influence (perceived environmental level)

Participants reported that their family and professional carers' opinions about palliative care and the defined behaviour were influencing factors. Family wishes in favour of the defined behaviour (e.g. the family really wants the conversation to happen) and positive social support (e.g. the family has a positive attitude towards palliative care, the family attends the conversation) were considered as facilitating. The participants stated that suddenly being alone and losing family care was facilitating (e.g. death of their partner). Social capital (e.g. knowing a palliative nurse) was also considered a facilitator. Moreover, the participants reported professional carers' characteristics (e.g. reliability, openness to communication about palliative) and the relationship with the professional carer (e.g. strong and trustful) as facilitating factors.

I think I would start a conversation with a physician first. My physician is my confidant.

(Woman, 66 y., not yet receiving specialised palliative care)

The respondents also considered social influence as a hindering factor. Family reluctance to consider palliative care or participants' experiencing sufficient family care were hindering factors. The respondents indicated that negative characteristics of professional carers (e.g. perceived time constraints, limited knowledge about palliative care, negative attitude towards palliative care, etc.) and a weak connection with the professional carers (e.g. limited contact) were hindering.

I can do everything. I know I have a very aggressive and difficult cancer to treat. The only thing they [professional carers] can do is to control the cancer. (...) I can take care of myself with the support of my family and friends. I have enough with that support for the time being.

(Man, 54 y., not yet receiving specialised palliative care)

3.2.7 | Physical environment (perceived environmental level)

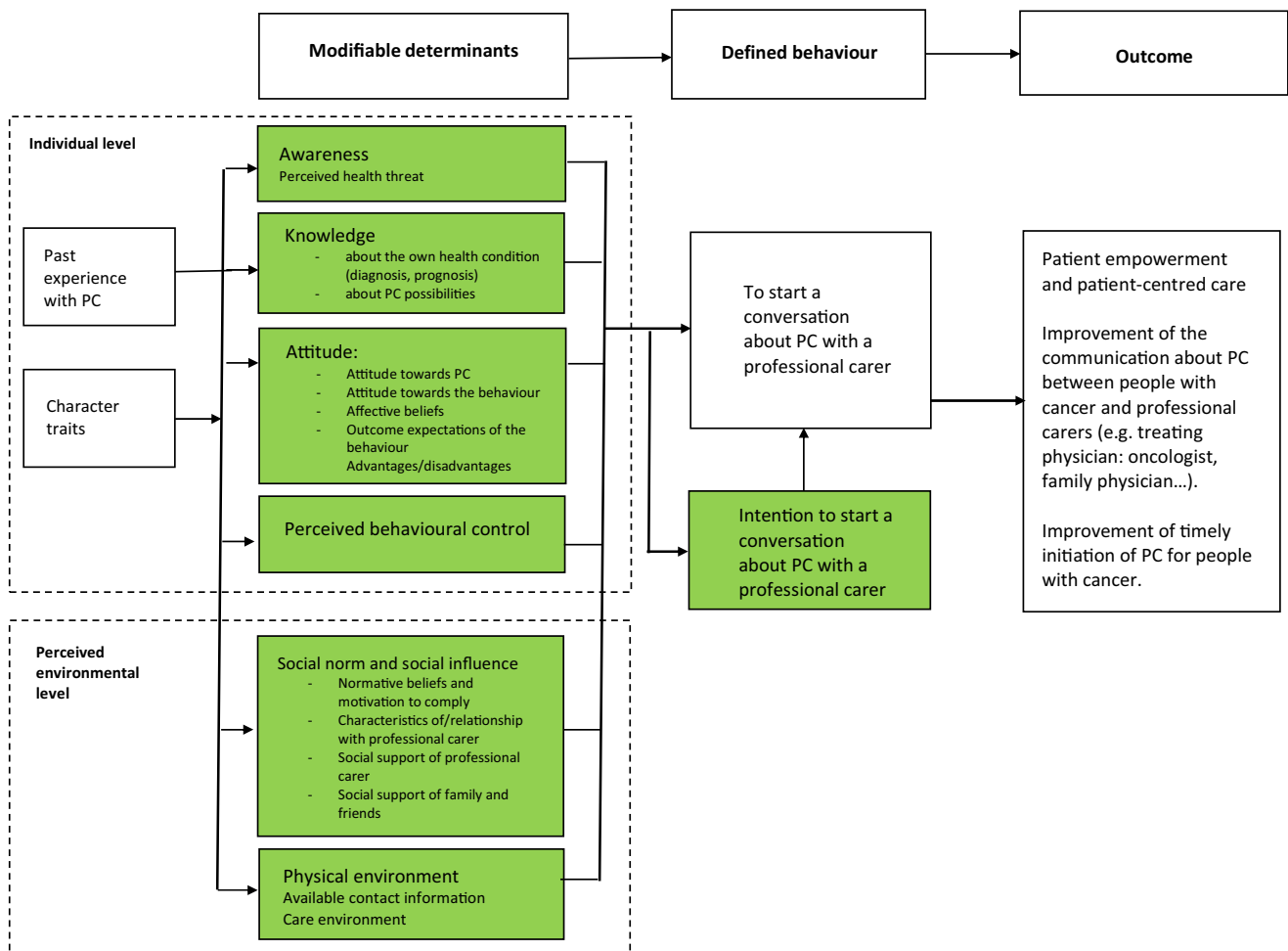
A physical environment that easily enables the participant to make an appointment (e.g. available contact information or regular consultation during a long-term hospital stay) was reported as facilitating. A lack of privacy (e.g. shared hospital room) was perceived as hindering.

3.3 | Determinants reported by specific groups of participants

Whether particular determinants were reported depended on (intentional) behaviour performance and whether or not palliative care was received. Respondents who had started conversations about palliative care in the past (N = 4) had experience with palliative care in their social network and claimed this was facilitating (*past experience*). They also said they were afraid of the term palliative care and associated

it with death (*attitude*) prior to the conversation, but did not experience these factors as hindering. They did not identify any *awareness* and *perceived behavioural control* factors as hindering either. The group who had a convincingly negative stance towards the behaviour (in any health situation and with any professional carer) and who were receiving specialised palliative care (N = 3) reported that they expected professional carers to take the initiative for palliative care conversations (*attitude*). They also reported experiencing a *lack of knowledge* about palliative care. The group with a convincingly negative stance towards the behaviour who were not receiving specialised palliative care yet (N = 2) mentioned the determinants *lack of knowledge* about diagnosis and palliative care possibilities, *negative attitude* towards palliative care, *limited perceived health threat* and *lack of social support* as hindering. They were not interested in palliative care and did not want to communicate about it at all. These last two groups did not identify any facilitating factor. Factors within *perceived health threat* mainly came up in the group who were not yet receiving specialised palliative care.

The identified determinants were combined in one behavioural model (see Figure 1).



PC = Palliative Care
Green boxes = modifiable determinants

FIGURE 1 Illustration of the identified determinants related to the defined behaviour

4 | DISCUSSION AND CONCLUSION

4.1 | Discussion

4.1.1 | Summary of main results

This qualitative study contributed to understanding and explaining why people with incurable cancer do or do not start a conversation about palliative care with a professional carer. A behavioural model was developed consisting of individual (*awareness, knowledge, attitude, perceived behavioural control*) and environmental determinants (*social norm and social influence, physical environment*).

4.1.2 | Discussion of main findings

Despite palliative care conversations with regular professional carers being difficult and emotional, the stance towards them was predominantly positive, irrespective of whether study participants already received palliative care. Many participants indicated that they could imagine starting a conversation about palliative care with a professional carer. This finding somewhat contradicts a systematic review of patient–physician discussions in palliative care suggesting that professional carers usually guide such conversations (Fine, Reid, Shengelia, & Adelman, 2010). During our interviews, participants were challenged to think about starting such conversations themselves, whereas participants in other interview studies might not consider it an option. However, we have to take the possible gap between imagined and effective behaviour into account (Eldredge et al., 2016).

Factors positively and negatively determining the behaviour ‘starting a conversation about palliative care with a professional carer’ were identified, resulting in a theoretical behavioural model that may help to improve communication about palliative care between people with cancer and professional carers.

Awareness of the need for palliative care and poor health are important determinants for initiating these conversations. As was found in a review study (Howie & Peppercorn, 2013) and clinical trial (Walczak et al., 2014) in cancer research, most participants overestimated their prognosis or minimised their disease. Participants stated that a perceived change in disease status (e.g. cancer metastases) would be facilitating. Literature from both the perspective of people with cancer and professional carers shows that understanding the poor prognosis is an important factor influencing initiation of palliative care conversations (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011; Jackson et al., 2013). Low prognostic awareness might be related to participants’ lack of knowledge about their disease and prognosis. However, it is better to initiate palliative care conversations early in the disease trajectory (Horlait et al., 2016), independent of the prognosis, to prevent people with cancer from being unable to make care decisions due to cognitive delay or too severe weakness (Gawande, 2016).

Participants’ knowledge of palliative care possibilities is another important determinant. A previous review study on unmet

supportive care needs showed that 39% of the people with advanced cancer lacked information about treatment, etc. (Harrison, Young, Price, Butow, & Solomon, 2009). Another study showed that only 7% of people with cancer with a life expectancy of >1 y and 33% with a life expectancy of <6 m received palliative care information. Up to 27% of these people wanted more information (Beernaert et al., 2018). The participants with a convincingly negative attitude towards starting a conversation about palliative care found it difficult to imagine themselves doing so. Possibly, they first need to know more about their health situation, what palliative care is and how it can be relevant to their situation (Grossman & Keastner, 1997). It remains a challenge for the healthcare system and for professional carers to provide timely palliative care information.

Participants’ attitude towards palliative care (conversations) is an important determinant too. Some participants associated palliative care with terminal care and/or death and believed that starting a conversation about palliative was not necessary yet, even though research shows the benefits of timely palliative care conversations (Bakitas et al., 2009; Temel et al., 2010). This belief that palliative care is only for people dying within a few days or weeks corresponds to the attitude towards palliative care among the general public (Higginson et al., 2014; Temel et al., 2010; Walczak et al., 2014). These restricted connotations may be explained by the current practice of late initiation of palliative care (Reville et al., 2009; Temel et al., 2010). In the present study, some participants were afraid to use the term palliative care and avoided it during the interview. This demonstrates that a strong stigma is still attached to the term, which confirms previous findings (Zimmermann et al., 2016). Behavioural interventions that inform and educate people about palliative care—including patient-centred care and a planned approach—might change preconceptions and might result in destigmatisation of the term palliative care in both patients and professional carers. However, it is an ongoing discussion whether to use the term palliative care or to use other terms such as supportive and anticipatory care to avoid the stigma attached to palliative care and to refer to total care with attention to physical, psychological and social care needs (Fadul et al., 2009; Hui et al., 2012; Tapsfield et al., 2016; Zambrano, Centeno, Larkin, & Eychmüller, 2019). Future research should examine to what extent patients receive the care they need and wished for when using the term palliative care compared to an alternative term. Furthermore, advance care planning (i.e. reflecting on goals and preferences for future medical treatment and care) may enable patients to start a conversation about palliative care with the physician (Rietjens et al., 2017). A small group was convinced that the physician would initiate the conversation, which was also found in people with advanced cancer participating in another qualitative study about advance care planning discussions (Barnes et al., 2011). These participants believed that physicians usually know better what is medically feasible and what care is needed (perceived behavioural control). These results illustrate that patient empowerment is not yet established and that the currently existing culture of physicians having higher medical authority in clinical decision-making needs to be

changed (Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010). Previous research showed that professional carers wait until the patient brings palliative care up, because they fear that bringing it up themselves would be discomforting (Beernaert et al., 2014, 2018). The combination of patients waiting for physicians and physicians for patients might result in patients not receiving timely palliative care. These findings emphasise the importance of stimulating people with cancer to start a conversation about palliative care with a professional carer (Beernaert et al., 2014).

We also found that social influence (e.g. professional carers' factors) was an important environmental determinant. The participants frequently emphasised the importance of the relationship with the professional carer and professional carers' characteristics such as reliability and empathy. This contrasts with findings from a recent study where professional carers perceived their own characteristics as less important in care discussions than patients' and family members' factors (Piggott et al., 2019). It seems that a combination of professional carers', family carers' and patients' factors and the relationships are important for people with cancer to start a conversation about palliative care.

The physical environment was mentioned as an influencing determinant as well. A shared hospital room was perceived as hindering; it was in a previous qualitative study also identified by professional carers as a barrier to end-of-life care conversations (Anselm et al., 2005). Professional carers should always be aware of privacy and creating a patient-friendly environment to stimulate patients to start such conversations.

The intention to start a conversation about palliative care with a professional carer and the other determinants identified are not stable over time. The perception of the participants of the behaviour was partly determined by feelings and thoughts at the time of the interview and differed depending on their health status. However, we were able to cover all the influencing factors by interviewing a wide variety of patients with different characteristics and health conditions as well as posing hypothetical questions and asking participants to think about "what-if" situations. The modifiability of these factors shows that it is easy to change them with the help of an intervention.

4.1.3 | Strengths and weaknesses

This study is innovative because it uses behavioural theories to identify and model determinants related to the behaviour "starting a conversation about palliative care with a professional carer." The model developed can serve as basis for developing effective and successful interventions (Michie & Prestwich, 2010). Another strength compared to previous studies is the focus on patients' perspectives rather than only those of professional carers. A detailed exploration of how people with cancer perceive starting a conversation about palliative care themselves does not exist so far. Certain limitations need to be acknowledged. Selection bias may result from the deliberate selection of people with cancer by

the professional carers (Collier & Mahoney, 1996). We asked the professional carers to select both participants interested and not interested in palliative care and to inform the participants that the study is about communication in care. We deliberately only started talking about palliative care in the interviews. Some professional carers may have presented the study to their own selection of patients (e.g. articulate patients) and informed them that the study was about palliative care. Few people dropped out when they heard it was about palliative care. The participants interviewed were possibly more willing to consider the subject. People with cancer without any interest in participating in palliative care studies could possibly have identified other determinants. However, the interviewed group was sufficiently varied and included five people who had a convincingly negative stance towards the behaviour. We found comparable determinants in different types of participants.

5 | CONCLUSION AND PRACTICAL IMPLICATIONS

This study identified determinants related to the behaviour "starting a conversation about palliative care with a professional carer" from patients' perspective through behavioural theories. The developed model contributes to understanding why people with cancer would or would not start such conversations. Based on our findings, we argue that interventions should focus on providing positive and correct information about palliative care to close the awareness and knowledge gap (*awareness, knowledge*) and on educating people with cancer about the relevance and benefits of palliative care conversations early in the disease trajectory (*attitude*). It helps them to be prepared. The findings suggest involving family members and professional carers. For example, professional carers should know how to communicate early in the disease trajectory that they are open to palliative care discussions. The model needs confirmation in a quantitative study evaluating which determinants are strongly, moderately or weakly related to the behaviour. The importance of the different determinants might inform behavioural interventions, suggesting the most important factors to focus on to stimulate people with cancer to start a conversation about palliative care. The more related factors are considered, the greater the chance of behavioural change. These interventions can improve patient empowerment in communication about palliative care and the communication between patients and professional carers. This may lead to more patient-centred care, more timely initiation of palliative care and improvement of quality of life in people with cancer.

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CONFLICTS OF INTEREST

The authors have no conflict of interest in the authoring of this manuscript.

ETHICAL APPROVAL

The study was approved by the ethics committee of Ghent University Hospital (registration number B670201734263) and AZ Sint-Lucas Ghent (2017/1465). Participants gave signed informed consent.

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