Identification of the most important factors related to people with cancer starting a palliative care conversation: a survey study

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ABSTRACT

OBJECTIVE. A late conversation about palliative care needs can lead to suboptimal care in the final months/weeks of life. Insight into factors related to patients' communication about palliative care is needed. This study aims to identify the factors associated with starting/intending to start a conversation about palliative care with the physician.

METHODS. We performed a cross-sectional interviewer-administered survey among people with incurable cancer. Purposive sampling was used, taking into account theoretically relevant heterogeneity. The questionnaire was developed based on the theory of planned behavior. Uni- and multivariable logistic regression analyses were performed.

RESULTS. Out of 80 participants, ten (13%) started the palliative care conversation and 18 (23%) intended to do so. People holding a positive attitude towards starting/intending to start the conversation (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 to start/intend to start a palliative care conversation; 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 do so. These factors explained 64% of the variance.

CONCLUSIONS. Our findings show that psychological and perceived socio-environmental factors, particularly patients' attitudes, are associated with starting a conversation about palliative care. Theory-based interventions targeting these strong associations might have a high potential to empower people with cancer to take the initiative in communication about palliative care and tot improve timely initiation of palliative care.

KEYWORDS. Behavior; behavioral theory; health communication; health promotion; cancer; psycho-oncology; neoplasms; palliative care; quantitative research.

BACKGROUND

Although people with cancer experience palliative care needs before the terminal phase of the disease[1], palliative care is often initiated too late or not at all[2–4]. As a result, care for people with cancer is often suboptimal in the final months or weeks of life[5]. A variety of behaviors can play a role in timely initiation of palliative care. One of these is communication about palliative care[6], which seems to be frequently avoided or postponed[7, 8].

Surprisingly, most studies of communication about palliative needs focus on the role of professional carers in starting it[9–11]. Despite opportunities[12, 13], few studies focus on the role and perspective of people with cancer themselves[7, 13, 14]. In a previous interview study in people with incurable cancer we aimed to understand better how palliative care conversations with the physician started (target behavior) by identifying the reasons why some people do and others do not[15]. This study suggested a palliative care behavioral model (**Appendix A**) inspired by the Theory of Planned Behavior (TPB) in which starting such conversation is influenced by psychological and perceived socio-environmental factors. There is no evidence so far about the relative importance of the different factors in this palliative care behavioral model in determining the target behavior. This model needs to be quantitatively tested by studying the strength of the associations between the factors and the target behavior among a larger sample of people with cancer[16]. Such quantitative information is essential if we want to use this model as a theoretical framework to develop an effective intervention to help people with cancer start conversations about palliative care with their physician themselves[16–19]. Interventions targeting the most important behavioral factors could improve patient empowerment in communication about palliative care[16, 20, 21], the timely initiation of palliative care (according to patients' needs and wishes) and quality of life[2, 22].

The aim of this study is to assess factors that are associated with having started a conversation about palliative care with the physician or intending to do so in people with incurable cancer. The study focused on modifiable psychological and perceived socio-environmental factors determined in our behavioral model[15].

METHODS

This study is reported in line with the STROBE statement[23].

Study design and setting

We performed a quantitative cross-sectional survey with computer-assisted personal interviews (CAPI). Interviewer-administered questionnaires measuring the behavior of starting a conversation about palliative care with the physician were completed with people with incurable cancer. The choice of interviewer-administred questionnaires was due to better control of the correct interpretation of the rather complex and abstract questions and the answers than in self-administered questionnaires. The specific target behavior implies that

people with cancer start to use the words palliative care (either verbally or by showing palliative care documentation) or alternative words that cannot be interpreted very differently (e.g. comfort care) in a conversation with the treating physician. Palliative care refers to both generalist and specialist palliative care. The study was conducted in Flanders (Belgium). All data were collected at the hospital or the participants' home, between August 2019 and March 2020.

Participants

We took the following inclusion criteria into account: adults with any type of incurable cancer, awareness of the diagnosis, decision-making capacity, and ability to participate in a Dutch study. We excluded people with incurable cancer if they were cognitively incapable of participating in an interview-administered survey study or too tired to do so, had an estimated life expectancy of more than five years, or were in follow-up or remission.

Sources and methods of selection of participants

We used purposeful sampling to select oncologists and oncology nurses from Ghent University Hospital. They identified potential participants and helped us as researchers to contact them. We needed a sufficient number of people who already started the conversation about palliative care with their physician or intended to do so. As the chance of recruiting people who had started the conversation previously was higher among people already receiving palliative care, we also involved the Palliative Care Network and the hospital palliative care unit. Purposive sampling of the target population, taking into account the theoretically important heterogeneity, was used with the aim of theoretical generalization about associated factors rather than statistical generalization towards populations. An overview of the recruitment process is demonstrated in a flow chart (**Appendix B).**

Ethics

The study protocol was approved by the Ethical Review Board of Ghent University Hospital (Belgian registration number: B670201940338) and we obtained written informed consent from all study participants.

Measures and data collection

Patient questionnaire

The selection of items was mainly based on the modifiable factors of our previously described palliative care behavioral model[15]. Illness perception was added, as this factor was found in literature to be related to other end-of-life care behaviors and assumed to be relevant.

The questionnaire started with the health status and cancer diagnosis. The total questionnaire contained 131 items, of which 5 were related to behavior or intention and 98 to behavioral factors: firstly psychosocial and

perceived socio-environmental factors related to palliative care, and secondly psychosocial and perceived socio-environmental factors related to starting a conversation about palliative care with the physician or intending to do so (see **Appendix C** for a detailed description). After the participants answered the questions related to the awareness, knowledge and attitude towards palliative care, they received a clear definition of palliative care. At the end, a number of sociodemographic questions (see **Table 1**) were asked.

Computer-assisted personal interviewing

Computer-assisted personal interviewing was used for data collection on a portable device, via a web-based survey server (Survey Monkey). This technique was easy to use, resulting in fewer missing data and immediate availability of data. The researchers read the questions aloud and participants were asked to answer the questions orally. For the questions that had to be answered on a scale, answer cards presenting the answer options were provided. The researchers filled out the questionnaire, but the participant was encouraged to indicate a score themselves.

Sample size

A priori power analyses (power=0.80, alpha=0.05) for calculating sample size showed that at least 79 participants were needed to detect an odds ratio of 1.2 (alternative hypothesis) using logistic regression with a continuous predictor (e.g. attitude score), assuming a percentage of positive outcomes of 16% in the total group. This percentage was based on the number of participants in the previous qualitative study[15] who had started a palliative care conversation with the physician or intended to do so, as no similar studies focusing on this outcome were available. The patients questionned had a wide variety of characteristics and health conditions.

Statistical methods

Data processing

We coded the outcome as binary: having started the conversation about palliative care with the physician + not having started the conversation about palliative care with the physician yet, but intending to do so (1) versus not having started the conversation about palliative care with the physician themselves and receiving specialist palliative care + not having started the conversation about palliative care with the physician and not intending to do so (0). In addition to the theoretical assumptions concerning how several items formed a construct, Cronbach's Alpha (cut-off of 0.60) was used to check internal consistency of the constructs. To increase internal consistency of the scales, a few items were removed or kept as a single item (**Appendix C**). Intention and behavior were combined as evidence show that intention is strongly associated with the actual behavioral performance and sufficient number of events in the positive group were needed[16, 24]**.**

Data analyses

All analyses were conducted using IBM SPSS Statistics 26. We conducted univariable logistic regression analyses to find out which factors were associated with starting a conversation about palliative care with the physician or intending to do so. Univariable models were used because of the small number of events in the positive group. R square (Nagelkerke) values were used to find out which factors were most strongly associated with the outcome. A P-value cut-off of <0.05 was used to eamine and report on significant associations. Additionally, multivariable logistic regression analyses were performed to calculate the explained variance (**Appendix D**). To test the mutual relations between the (border-)significant factors, we performed Independent T-Tests with Levene's Test <0.05 and Pearson Correlation Tests.[24]**.** These results were put into a quantified palliative care behavioral model (see **Figure 1**). Data from incomplete questionnaires were removed from the dataset.

RESULTS

Physicians/nurses contacted 135 people with incurable cancer and invited them to participate. Eighty-eight patients participated (response rate=65.2%), with 80 questionnaires fully completed. Reasons for non-completion were emotional reactions to the theme of palliative care (n=6), too exhausting and completed incorrectly. **Table 1** provides a summary of the participants' characteristics.

Table 1. Characteristics of the participants with incurable cancer.

	Total (N=80)	
Socio-demographic characteristics	*n=*	*(%)*
Sex		
Male	42	52.5%
Female	38	47.5%
Age (years)		
Min.	29	
Max.	88	
Average ± SD	66.4	± 12.3
Native language		
Dutch	79	98.8%
Other	1	1.2%
Country of birth		
Belgium	74	92.5%
Other[a]	6	7.5%
Importance of faith/beliefs in care choices		
Min. (not important)	1	
Max. (very important)	5	
Average ± SD	2.3	± 1.3
Education		
Primary to postsecondary education	48	60%
Higher to university education	32	40%
Living situation		
Living alone	19	24.1%
Living with parents, partner, children etc.	58	73.4%
Living in a care institution	2	2.5%

	Total (N=80)	
Socio-demographic characteristics	*n=*	*(%)*
Work experience in healthcare		
No	73	91.3%
Yes	7	8.7%
Having children		
No	6	7.5%
Yes	74	92.5%
Illness and care characteristics	*n=*	*%*
Cancer type		
Respiratory	18	22.5%
Gastrointestinal	15	18.8%
Urological	15	18.8%
Blood	11	13.8%
Breast	8	10%
Head and neck	4	3.8%
Gynecological	3	5%
Thyroid	2	2.5%
Bone	1	1.3%
Other[b]	3	3.8%
Time since diagnosis		
< 1 year	18	22.5%
>= 1 years – ≤ 5 years	36	45%
> 5 years	26	32.5%
Received care from specialist palliative care service		
Yes	18	22.5%
No	62	77.5%
Metastasis		
Yes	58	72.5%
No	22	27.5%
Time since metastasis		
< 1 year	26	44.8%
>= 1 years – < 5 years	24	41.4%
>= 5 years	18	13.8%

Missing values –living situation (n=1)

[a]This group includes the Netherlands (n=5) and Denmark (n=1)

[b] This group includes sarcoma (n=2) and melanoma (n=1)

Out of 80 participants, 29 had already had a palliative care conversation. Of those 29, 10 had started it themselves. Seven did so with the family physician, two with the oncologist and one with another specialist. Participants who had not started a conversation and were not receiving specialized palliative care (n=56) were asked about their intention to do so in the near future. Eighteen had a positive intention and 38 did not. Twenty-eight would start the conversation with the family physician, 26 with the oncologist and 16 with another specialist. None of the socio-demographic, illness or care characteristics were significantly associated with our outcome.

Table 2 shows the results from the univariable logistic regression. Participants were more likely to have started the conversation or to have intended to do so when they held a more positive attitude towards starting a conversation about palliative care with the physician (OR 4.74; 95% CI 2.35-9.54); perceived more behavioral benefits (OR 2.61; 95% CI 1.37-4.96); perceived a more positive attitude in family/friends (OR 2.07; 95% CI1.26-

3.41) and in their physician (OR 2.19; 95% CI 1.39-3.45) towards starting a conversation about palliative care themselves. Starting a conversation about palliative care with the physician or intending to do so was less likely in participants who perceived more behavioral disadvantages (OR 0.53; 95% CI 0.32-0.87), and more barriers (OR 0.33; 95% CI 0.16-0.68). The attitude towards the target behavior had the highest explained variance (R^2=0.406).

Table 2. Associations between factors and having started a conversation about palliative care with the physician or intending to do so

	n= ; mean (± SD)	OR	95% CI for OR	p-value	Nagelkerke R Square
Psychological factors					
Illness perception: care to cure					
No (ref.)	n=45				
Yes	n=35	0.85	0.34-2.13	0.723	0.002
Illness perception: care to live longer					
No (ref.)	n=12				
Yes	n=68	0.92	0.25-3.36	0.896	0.000
Illness perception: care to feel better					
No (ref.)	n=38				
Yes	n=41	0.72	0.29-1.83	0.490	0.008
Illness perception: impact on daily activities	3.05 (0.87)	1.35	0.78-2.32	0.282	0.020
Awareness of palliative care	2.22 (0.74)	0.63	0.34-1.17	0.145	0.037
Knowledge about PC	5.50 (2.53)	0.91	0.76-1.10	0.330	0.017
Behavioral awareness					
No (ref.)	n=31	Ref			
Yes	n=49	0.39	0.14-1.07	0.068	0.060
Attitude towards PC	3.14 (1.01)	1.44	0.92-2.29	0.123	0.041
Attitude towards the behavior	2.88 (1.01)	4.74	2.35-9.54	**<0.001**	0.434
Perceived benefits	3.50 (0.98)	2.61	1.37-4.96	**0.004**	0.180
Perceived disadvantages	2.43 (1.07)	0.53	0.32-0.87	**0.012**	0.118
Perceived facilitators	3.36 (0.95)	1.32	0.79-2.22	0.287	0.020
Perceived barriers	2.54 (0.79)	0.33	0.16-0.68	**0.002**	0.177
Perceived behavioral control	4.40 (0.99)	1.97	1.00-3.89	0.050	0.087
Perceived socio-environmental factors					
Subjective norm PC (family/friend)	2.57 (0.90)	1.23	0.75-2.04	0.416	0.011
Subjective norm PC (physician)	2.97 (1.18)	1.30	0.87-1.94	0.209	0.029
Subjective norm behavior (family/friend): perceived attitude	2.76 (1.02)	2.07	1.26-3.41	**0.004**	0.151
Subjective norm behavior (family/friend): motivation to comply	2.79 (1.65)	1.04	0.79-1.38	0.781	0.001
Social influence, social support (family/friend)	3.01 (1.63)	0.91	0.68-1.22	0.525	0.007
Subjective norm behavior (physician): perceived attitude	2.90 (1.24)	2.19	1.39-3.45	**0.001**	0.221
Subjective norm behavior (physician): motivation to comply	3.93 (1.44)	0.98	0.71-1.34	0.883	0.000
Social influence: social support (physician)	3.38 (1.41)	0.88	0.56-1.22	0.437	0.010
Subjective norm behavior (fellow sufferers)	3.00 (0.90)	1.42	0.84-2.43	0.194	0.030
Social influence, facilitator (family/friend)	3.97 (1.32)	1.00	0.70-1.41	0.982	0.000
Social influence, facilitator (physician)	4.49 (0.80)	1.56	0.74-3.29	0.242	0.029
Social influence, facilitator (fellow sufferer)	3.53 (1.65)	0.95	0.71-1.28	0.742	0.002

PC = palliative care

OR = odds ratio

CI = confidence interval

Bold text indicates P-value <0.05

Missing values: knowledge about PC(n=1), illness perception: care to feel better(n=1), subjective norm PC (physician): perceived opinion(n=4), subjective norm behavior (family/friend): perceived attitude(n=1), subjective norm behavior (physician): perceived attitude(n=1), social influence support (family/friend)(n=1), subjective norm behavior (physician): perceived attitude(n=1), social influence support (physician)(n=1), social influence, facilitator (fellow sufferer)(n=8)

All items could potentially range from 1 to 5, except from awareness of palliative care (range from 1 to 3) and knowledge of palliative care (range from 1 to 12)

No multicollinearity was detected. The final multivariable analysis (**Appendix D**) showed attitude towards the behavior (OR 3.29;95% CI 1.38-7.84), perceived benefits of it (OR 5.48;95% CI 1.78-16.87), and perceived barriers (OR 0.18;95% CI 0.05-0.60) as significant factors related to starting a conversation about palliative care or intending to do so. The perceived attitude towards the behavior in the physician (OR 1.89;95% CI 0.10-3.57) turned border-significant. This model, retaining only these four factors, resulted in a Nagelkerke R square of 63.8%.
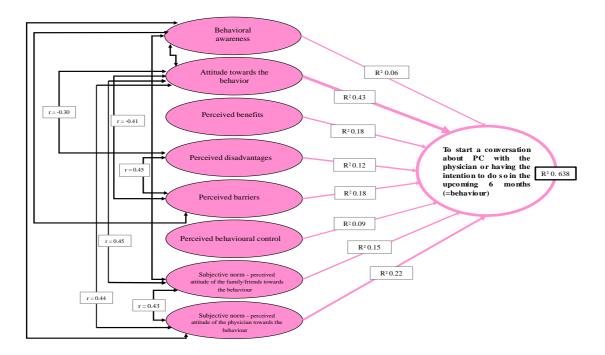

Figure 1. Quantified palliative care behavioral model illustrating on the left side the mutual relations (r ≥(-)0.30) among the (border-) significant (p<0.10) factors associated with the target behavior; and on the right side the Nagelkerke R square values of the (border-) significant (p<0.10) factors associated with the target behavior.

DISCUSSION

This quantitative study in people with incurable cancer shows significant associations between psychological and perceived socio-environmental factors and intending to start or starting a conversation about palliative care with the physician. Attitudes towards the target behavior, i.e. general attitude, perceived benefits, perceived disadvantages and perceived barriers, and the subjective norm towards the target behavior were found to be the most important factors related to this target behavior and should therefore be the focus of future interventions to change patients' behavior[16].

Study strengths and limitations

Study strengths

Using a palliative care behavioral model, inspired by the theory of planned behavior[24] that was applied and adapted by performing interviews around the topic[15], is quite unique and promising in palliative care research. By doing so, we ensured that the most relevant factors related to intending to start or starting a conversation about palliative care with the physician were assessed[16]. Performing interviewer-administered questionnaires were more time-consuming than sending postal surveys, for example, but it ensured the quality of the data collected.

Study limitations

A first limitation is that although the participants varied in terms of other socio-demographic, illness and care characteristics, only one non-native Dutch speaker participated and only six were not born in Belgium. Another limitation is that the cross-sectional design limits the possibility to make causal claims about what influences the behavior due to a large potential residual confounding. Additionally, it does not allow the study of temporality, such as whether a pre-existing attitude influenced intended behavior at a later time point (rather than attitudes being the result of post-hoc rationalization of an intention). Longitudinal studies might be needed to provide better evidence. Nevertheless, participants in different phases of their illness were included in this study and "illness characteristics" were not related to intending to start or starting a conversation about palliative care.

Interpretation of the most important findings

Our multivariable model showed an explained variance of 64%, which is quite high compared to other research using the TPB to explain health behavior, which showed an average explained variance of 41%[24, 25]. This high explained variance shows that our palliative care behavioral model[15] is useful to better understand why people with incurable cancer start a conversation about palliative care with the physician (or not). This is in accordance with a systematic review showing that behavioral theories (especially the TPB) are useful in better understanding palliative care behaviors[26]. Our results also suggest that interventions based on our model have a high potential to achieve preferred behavioral change and to improve patient empowerment, patient-physician

communication about palliative care, patient-centered care and the quality of life of both people with cancer and their families. However, a higher percentage may be slightly affected by the methodological choice to include the intention in the behavioral outcome. Other behavioral factors, i.e. independent variables, are often better predictors of intention than behavior[24]. We should bear in mind the possible gap between intention and behavior[16]. Furthermore, our behavioral model only explains a proportion of the variance in (the intention to) start the palliative care conversation and other unmeasured (e.g. health literacy) and unknown factors may also play a role[21].

We found that people with cancer who held a "more positive attitude towards the behavior" and "perceived more benefits of it" were more likely to perform the target behavior or intend do so. These participants believed that starting a conversation about palliative care with the physician was important, relevant and, for example, an opportunity to gain more control over their care. Previous advance care planning (ACP) studies also show that patients with a positive attitude are more likely to engage in ACP[27]. Bravo et al. identified a positive relation between attitude and patient empowerment[28]. In the present study participants' mean scores on the attitudinal factors (Table 2) are rather moderate. Our study results also show that a minority of participants started the conversation about palliative care themselves or had the intention to do so. In practice, physicians usually start the conversation about palliative care rather than the patient[29]. People with cancer might expect their physician to take the initiative at the appropriate time[30]. These findings illustrate that patients' positive attitudes towards starting a conversation about palliative care are not yet standard attitudes and that patient empowerment is not yet well established and embedded in palliative care research and policies. This contrasts with the increasing interest in patient empowerment in high-quality care[31, 32]. This emphasizes the need for the application and implementation of adequate theoretical strategies such as arguments and persuasive communication[16] to change patients' attitudes towards palliative care and increase patient empowerment.

We also found that people with cancer who "perceived more disadvantages and barriers" towards starting a conversation about palliative care were less likely to do so or intend to do so. These participants believed, for example, that starting a conversation about palliative care with the physician would cause stress and anxiety and would feel like getting ahead of themselves. They reported barriers such as feeling too good, associating palliative care with terminal care and not being interested in palliative care. Based on other study results, barriers such as the association of palliative care with terminal care might also be related to lack of understanding of the behavioral benefits[12]. As described above, attitudinal factors are the most important factors related to starting a conversation about palliative care. Therefore, we suggest that it would be interesting to invest in changing patients' attitudes rather than focusing on knowledge and prognosis[33], which seems to be the current prevailing research and practice focus. There is a need to inform patients about what timely communication about palliative care can offer them by highlighting its benefits and discussing the disadvantages and finding solutions for barriers[34].

The perception about the social environment also plays an important role in whether or not patients will start a conversation about palliative care. "The subjective norm towards the behavior" was significantly associated with the target behavior. Participants who perceived that their partner, family, friends and physician found it important, relevant or not too early to start the conversation were more likely to do so or intend to do so. The importance of the subjective norm corroborates previous studies of various health behaviors[35]. Previous studies also show that physicians recognize the importance of their own attitude towards palliative care in the communication with patients[10]. These physicians' attitudes might possibly determine whether they show patients that they are open to talk about palliative care or not, which in its turn affects the patients' perceptions of the physician's attitudes. The importance of the direct environment indicates the need for exploring dyadic processes (e.g. conflicting views) between the person with cancer and their caregivers in future research.

Clinical implications

This study looks for a way to empower the patient to take the initiative in conversations about palliative care. As the study results show, more attention should be paid to their role. Clinicians can encourage people with cancer to start the conversation about palliative care by highlighting its importance, relevance and benefits. They can inform patients that timely communication about palliative care can enhance patient-centered care and active involvement in decision making and inform them about the disadvantages of waiting until it is urgent[36]. Clinicians can also help people with cancer to identify their barriers and how to overcome them, for example, by providing prepared lists of simple questions such as how are you now or what do you want to do in the coming weeks/months?[37]. It can be facilitating if clinicians show their positive attitude towards palliative care and openness to talking about it. Furthermore, our findings emphasize the need for involvement of patients' family carers in encouraging people with cancer to start a palliative care conversation. Clinicians need to inform family carers better about palliative care and the benefits for themselves of timely communication as well (e.g. less care burden)[38]. It is suggested that a behavioral intervention aimed at behavioral change at patients' level involves the physician as environmental agent and aim at behavioral change at physicians' level as well (e.g. supporting them in reacting appropriately through training and a conversation card)[39].

CONCLUSION

Our findings suggest that several psychological and perceived socio-environmental factors – particularly patients' attitudes – are important determinants of starting a conversation about palliative care with the physician in people with incurable cancer. This is important information for developing a targeted behavioral intervention aimed at helping to empower people with cancer to take the initiative in starting the conversation about palliative care with the physician.

AUTHORSHIP

and KB wrote the first draft of the manuscript and critically revised the manuscript after receiving comments from all authors. K.B., L.D., BD, JC supervised the study All authors approved the final manuscript. A-LS was responsible for final submission and as guarantor of content.

ACKNOWLEDGMENTS

CONFLICT OF INTEREST STATEMENT

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

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

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