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Is Information Provision About Benefits and Risks of Treatment Options Associated with Receiving Person-Centered Care: A Survey among Incurably Ill Cancer Patients

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Abstract

Background: Cancer patients with advanced disease are confronted with increasingly complex life-prolonging/symptom-relieving treatment decisions. Being informed of treatment benefits and risks is important, but information provision might be suboptimal.

Objective: To assess the extent to which patients with incurable cancer feel informed about benefits and risks of possible treatments, and whether this relates to their self-perceived receipt of person-centered care.

Methods: Patients with incurable cancer ($N = 212$) reported the degree to which they felt informed about treatment benefits/risks. Person-centered care was operationalized as “feeling involved in care” and “feeling that preferences were taken into account”. (Logistic) regression analyses assessed the relationship between feeling informed and receiving person-centered care, exploring moderating influences of background characteristics.

Results: Two-thirds (66%) of patients felt incompletely informed about treatment benefits/risks. Two-thirds (65%) of patients felt that they were always involved in their care, and 60% felt their preferences were taken into account by all providers. If patients felt completely informed, they also felt they received more person-centered care ($p < 0.01$). Seventy six percent and 81% of completely informed versus 58% and 50% of incompletely informed patients felt that they were, respectively, always involved and that preferences were taken into account by all providers. Background characteristics did

not moderate these relationships, but influenced perceptions of received information and person-centered care.

Conclusions: Complete information provision about treatment benefits and risks is, according to patients, not commonplace. Yet such information is related to receiving person-centered care. More research into what specific information is preferred, provided, and remembered is warranted, to achieve optimal person-centered care.

Introduction

Cancer patients are confronted with increasingly complex treatment options and decisions, also in the extending phase of a life-limiting disease.^{1,2} Treatments may focus either on life prolongation, accepting the risk of adverse effects, or on symptom relief (palliation). Being informed of potential positive and detrimental treatment consequences is important in advanced illness, where treatment decisions are made in a context of limited time and prevalent symptom burden.^{3,4}

While there is evidence that incurably ill cancer patients are not always aware of and informed of treatment benefits and risks, patient's own perception of the extent to which they feel informed is still unexplored. For example, it is common for patients to hold unrealistic and sometimes inconsistent expectations of treatment benefit.⁵⁻⁷ In one study, 68% of patients believed that treatment could erase their cancer, but only 55% believed their disease was curable, indicating that even patients with accurate disease insight might hold inaccurate beliefs about treatment benefits.⁶ A lack of open communication from clinicians might contribute to these findings. Observational studies have found a lack of open communication about aims, options, and side effects of treatments in advanced illness.⁸⁻¹⁰ However, insight into the extent to which people with incurable cancers themselves feel informed about potential benefits and risks of treatment options is largely missing.

It is moreover unclear whether patients who feel better informed about treatment benefits and risks also experience their care as more person centered, that is, that care is respectful of and responsive to their preferences.¹¹ Person-centered care to optimize patients' quality of life lies at the heart of high-quality palliative care.^{12,13} Focusing on terminal care, there is evidence that early discussion of end-of-life care preferences can result in receipt of terminal care more aligned to patients' preferences.¹⁴ This is an important finding, as patients' often continue to receive anticancer treatment when their disease progresses¹⁵⁻¹⁸ increasing the risk of negative outcomes such as (emergency) hospital admissions,¹⁶ intensive medical interventions at the end of life,¹⁷ and impaired quality of death.^{17,19} Greater insight into whether information provision about potential benefits and risks of treatments is associated with patients' perception of receiving person-centered care preceding the terminal phase is vital.

Therefore this study had two aims: first, to determine the extent to which incurably ill cancer patients feel that they have been informed about the benefits and risks of treatment options. Second, to determine the relationship between feeling informed and patient perception of having received person-centered care.

Methods

Study design

Cross-sectional analysis of an existing set of questionnaire data, obtained in the evaluation study of the Dutch National Quality Improvement Program for Palliative Care (2012–2016).²⁰ The Evaluation Program was assessed and approved by the Ethics Committee of the University Medical Center in Leiden, the Netherlands (P13.03/NV/nv).

Participants

The patient inclusion criteria for the evaluation study were as follows: life expectancy <6 months (assessed by the surprise question²¹) and/or who underwent palliative treatment, understood Dutch,

were physically and mentally capable to respond to questionnaires, and had a >1 week care relationship. Health care professionals participating in the Evaluation Program collected contact details of patients meeting these criteria over a one month period. Patients received a questionnaire by post; data were collected from institutionalized patients through an interview. For this analysis only data from cancer patients were included ($N = 212$).

Measures

Several items of the validated questionnaire *Consumer Quality Index Palliative care (patient version)*²² were analyzed for this article.

Received information

The degree to which patients felt that they had received information about benefits and risks/side effects of different treatment options was assessed (answer categories “no, not at all”, “a bit”, “mostly”, “yes completely”).

Receipt of person-centered care

The degree to which patients felt that they had received person-centered care was assessed with two items, assessing the extent to which patients felt:

- (i) Involved in decisions about the care they received (answer categories: “never”, “sometimes”, “most of the time”, “always”)
- (ii) Care providers took their personal preferences/wishes into account (answer categories: “none”, “some”, “most”, “all”).

Background characteristics that may influence communication preferences or experiences in advanced illness were assessed; age,^{23,24} gender,²⁴⁻²⁶ and education.^{23,24}

Statistical analysis

Analysis was conducted in four stages. First, descriptive statistics was used to assess whether patients felt they had received information (dichotomizing answer options into “completely” [“yes completely”] and “incompletely” [“no, not at all”, “a bit”, and “mostly”]) and felt they had received person-centered care. Second, (logistic) regression analyses determined the influence of background characteristics (age, gender, and education) on whether patients felt completely informed and felt they had received person-centered care. Third, regression analyses assessed the relationship between feeling informed (completely/incompletely) and receiving person-centered care. A sensitivity analysis was performed, using logistic regression with alternative dichotomization of the responses into “completely” (“yes completely” and “mostly”) and “incompletely” (“no, not at all” and “a bit”) Fourth, the moderating effects of background characteristics found to be significant in step 2 on the relationship between feeling informed and receiving person-centered care were assessed. Interaction effects between background characteristics and feeling informed (completely/incompletely) were created, and regression analyses were performed. All analyses were conducted using Stata 14 with two-sided significance testing at $p \leq 0.05$. Missing data were not imputed.

Results

Background characteristics of patients are shown in [Table 1](#).

[table 1]

Feeling informed

One-third (33%) of patients felt completely informed about benefits and risks/side effects of available treatment options, 38% felt mostly informed, 14% felt a bit informed, and 14% felt not informed at all (Table 2).

Female ($p = 0.07$; OR = 0.57, 95% CI: 0.31–1.04, tendency) and higher educated ($p = 0.03$; OR = 0.70, 95% CI: 0.51–0.96) patients felt less completely informed (Fig. 1). Age did not influence the perception of feeling completely informed ($p = 0.14$; $\beta = -0.02$, 95% CI: -0.04 to 0.01).

[figure 1][figure 2]

Person-centered care

Two-thirds (65%) of patients felt that they were always involved in the care they received, 28% most of the time, 5% sometimes, and 1% felt that they were never involved (Table 2). Higher educated patients tended to feel less involved ($p = 0.08$; $\beta = -0.08$, 95% CI: -0.17 to 0.01). Neither gender ($p = 0.71$; $\beta = -0.04$, 95% CI: -0.22 to 0.15) nor age ($p = 0.15$; $\beta = -0.01$, 95% CI: -0.01 to 0.00) influenced perceived involvement in care received (gender and education displayed in Fig. 2).

Sixty percent of patients felt that their personal preferences were taken into account by all providers, 32% by most, 8% by some (Table 2). Older patients tended to feel that their preferences were taken less into account ($p = 0.08$; $\beta = -0.01$, 95% CI: -0.01 to 0.00, tendency). Neither gender ($p = 0.31$; $\beta = -0.09$, 95% CI: -0.27 to 0.09), nor education ($p = 0.17$; $\beta = -0.06$, 95% CI: -0.15 to 0.03) influenced the perception that personal preferences were taken into account (gender and education displayed in Fig. 3).

[figure 3][figure 4]

Association between feeling informed and receiving person-centered care

Patients who felt completely informed about treatment benefits and risks also felt more involved in their care ($p = 0.01$; $\beta = 0.29$, 95% CI: 0.08–0.49) and that their preferences were taken into account ($p < 0.01$; $\beta = 0.42$, 95% CI: 0.23–0.60). More specifically, as illustrated in Figure 4a and b, 76% of the patients who felt completely informed also felt that they were always involved in their care, compared to 58% of patients who felt incompletely informed. Moreover, 81% of patients who felt completely informed stated that their preferences were taken into account by all providers, compared to 50% of the patients who felt incompletely informed.

The sensitivity analysis found that the relationship between feeling informed and feeling involved in care ($p < 0.01$; $\beta = 0.36$, 95% CI: 0.15–0.57) and feeling that preferences were taken into account ($p < 0.01$; $\beta = 0.45$, 95% CI: 0.26–0.65) remained significant, when an alternative dichotomization of the variables was used.

Moderating effects of background characteristics

The moderating effect of education on the relationship between feeling informed and feeling involved was insignificant ($p = 0.34$; $\beta = 0.10$, 95% CI: -0.10 to 0.30). The moderating effect of age on the relationship between feeling informed and feeling that preferences were taken into account was also insignificant ($p = 0.24$; $\beta = -0.01$, 95% CI: -0.02 to 0.01).

Discussion

In this survey of Dutch cancer patients with advanced disease, two-thirds of patients felt incompletely informed about treatment benefits and risks. When patients did feel completely informed, they also felt more involved in their received care and that their preferences were better taken into account. Our study adds to the evidence that open communication in advanced cancer is not always achieved, even though it is increasingly recognized as important.²⁷ Most patients in our study felt incompletely informed about treatment benefits and risks. This corroborates observational studies which found that information about an illness being incurable is not mentioned or mentioned only briefly in 47% of consultations, while side effect information is omitted in 22–93% of consultations⁸ (depending on specific side effect). When treatment information is discussed, this is mostly done in general terms.⁹ Previous Dutch studies found that incurably ill (cancer) patients perceive the provision of information about treatment benefits and risks as important²⁸ and in need of improvement.²² Moreover, 95% of advanced cancer patients in a recent study opted to receive information about possible adverse effects of second-line chemotherapy.²⁹ Taken together, these findings highlight the fact that while most patients want to be extensively informed about benefits and risks of treatment, this seems not consistently done and is not being experienced as such.

This is problematic, given our finding that being well-informed is associated with perceived receipt of person-centered care. Our results provide further evidence for the link between improved communication and improved patient outcomes^{14,19} and support recent ASCO guidance stressing the importance of discussing treatment benefits and risks.²⁷ Being well-informed is a prerequisite for making well-informed treatment decisions.³⁰ Seriously ill patients who hold unrealistic beliefs about treatment benefit, for example, who are convinced chemotherapy will prolong life³¹ or face a 1% chance for cure,³² may be inclined to accept all side effects. It should be noted that in this study, we did not assess the specific decisions that were being made. However, in the advanced phase of a disease, care plans are appropriate if consistent with patient preferences.¹² To achieve care that takes preferences into account, appropriate information provision about treatment benefits and risks (if preferred by patients) seems crucial.

While the positive association between feeling informed and perceived receipt of person-centered care was evident for all patients, background characteristics did influence feelings of received information and care. Higher educated^{23,24} and female²⁴ patients tend to have high information needs, explaining our findings that they were less likely to feel completely informed. The communication barriers which older patients can experience due to functional and cognitive decline and multimorbidity³³ might contribute to the finding that fewer older people perceived that their preferences had been taken into account by all.

These results beg the question how can clinicians best inform patients about treatment benefits and risks, to achieve optimal person-centered care? Although we did not assess which information was conveyed or preferred—and information preferences vary between patients^{23,34,35}—the importance of lay language, discussing potential adverse effects, acknowledging uncertainty, and checking patients' understanding has been highlighted.^{27,36} Information should be tailored to patients' changing preferences,²³ and this can be achieved by asking patients about their preferences³⁷ instead of making potentially incorrect assumptions.^{29,38,39} While providing information is important, the risks of information provision should also be acknowledged. If patients are informed of⁴⁰ or expect side effects to arise,^{41,42} this increases their occurrence.⁴³ The optimal balance between full information disclosure without increasing the risk of side effects remains to be determined.

This study has strengths; we used data from a nationwide, relatively large sample of people with incurable cancer. It also has limitations. First, we did not know what specific information was provided to patients, as consultations were not recorded. Our findings might underestimate what was discussed, as patients' information recall is often impaired^{44–47}; only 40–50% of treatment related information was recalled in one (experimental) study of advanced cancer consultations.⁴⁴ We believe,

however, that what patients remember, opposed to what is provided, has ultimately most clinical relevance and that assessing patients' perceptions is a strength of the study. Second, we used a single question to determine whether patients felt informed about both benefits and risks. Previous studies found that 65–70% of incurable ill cancer patients felt informed about risks^{48,49} indicating a potential lack in discussing benefits. Third, due to the survey design we can infer relationships, but cannot establish causality. Last, it is difficult to establish whether our sample is representative of those with advanced cancer in the Netherlands. Participation in the Quality Improvement Program might have led to positive perceptions of receiving person-centered care.

Future studies should consider the relationship between preferred, discussed, and recalled information in more detail using both audio-recordings of consultations and patient-reported recall of information,⁴⁶ next to patients' stated preferences. This may provide more guidance for clinicians as to which information to provide and how best to do so to optimize patient recall. Further investigation of the relationship between the information provided about treatments and the treatment decisions that are made is also warranted. Observational studies of consultations can shed light on these questions. Moreover, the extent to which incurably ill patients are prone to experience side effects after being informed of them needs to be studied, to develop understanding of the balance between full information provision while not increasing the occurrence of side effects.

In conclusion, our results highlight that it is uncommon for patients with advanced cancer to feel that they have been fully informed about treatment benefits and risks. When patients feel fully informed, this is associated with perceived receipt of person-centered care. In our current era, the growing group of patients with advanced cancer is confronted with increasingly complex medical options. It is therefore essential that, tailored, information is provided, to support patients in planning for their future and making difficult treatment decisions affecting their quality and quantity of life.

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Author Disclosure Statement

No competing financial interests exist.

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Tables

	<i>M (range) N = 191</i>
Age	75 (20–98)
	<i>N (%)</i>
Gender	<i>N = 212</i>
Male	92 (43)
Female	120 (57)
Highest education	<i>N = 202</i>
Low (primary education or less)	49 (24)
Intermediate-1 (lower secondary)	83 (41)
Intermediate-2 (upper secondary)	34 (17)
High (tertiary)	36 (18)

From the 212 included participants, not all completed all measures. Hence, the number of participants per characteristic varies.

<i>Informed about benefits and risks/side effects of treatment options (N = 159)</i>		<i>Receiving person-centered care</i>			
		<i>Involved in care received (N = 205)</i>		<i>Personal preferences taken into account (N = 205)</i>	
<i>Answer option</i>	<i>N (%)</i>	<i>Answer option</i>	<i>N (%)</i>	<i>Answer option</i>	<i>N (%)</i>
Not at all (no)	28 (14)	Never	3 (1)	None	—
A bit (no)	27 (14)	Sometimes	11 (5)	Some	16 (8)
Mostly (no)	75 (38)	Most of the time	58 (28)	Most	65 (32)
Completely (yes)	65 (33)	Always	133 (65)	All	124 (60)

From the 212 included participants, not all completed all measures. Hence, the number of participants per item varies.

Due to rounding, not all percentages add up to 100.

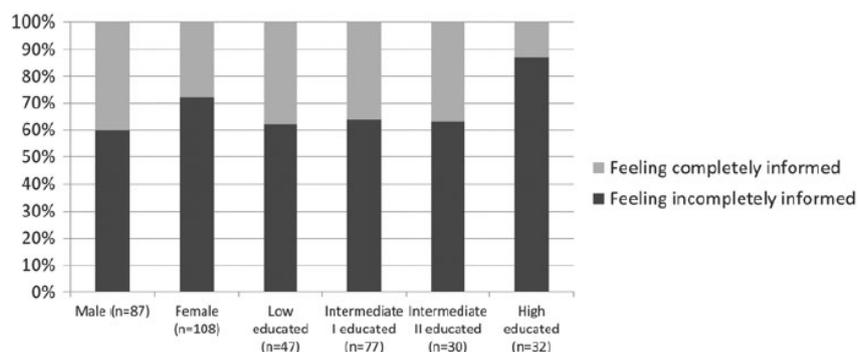


FIG. 1. Association between gender/education and feeling informed. From the 212 included participants, not all completed all measures. Hence, the number of participants per association varies.

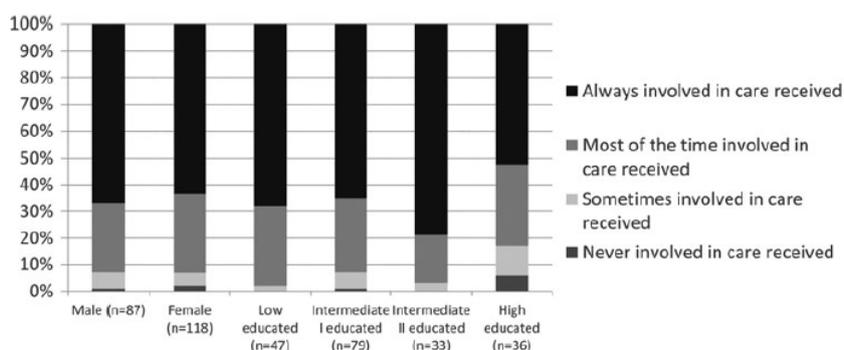


FIG. 2. Association between gender/education and feeling involved. From the 212 included participants, not all completed all measures. Hence, the number of participants per association varies.

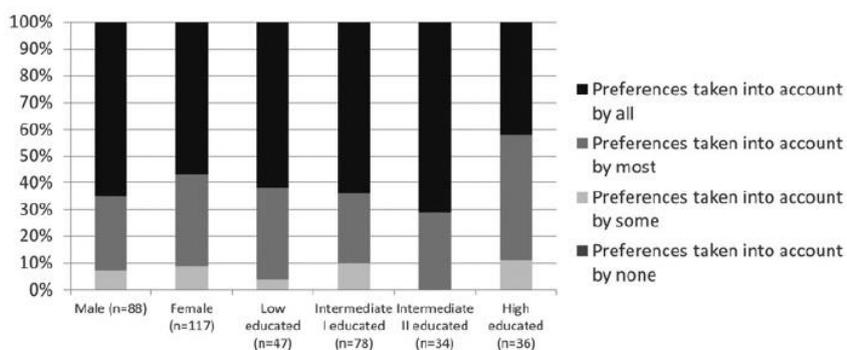


FIG. 3. Association between gender/education and feeling preferences taken into account. From the 212 included participants, not all completed all measures. Hence, the number of participants per association varies.

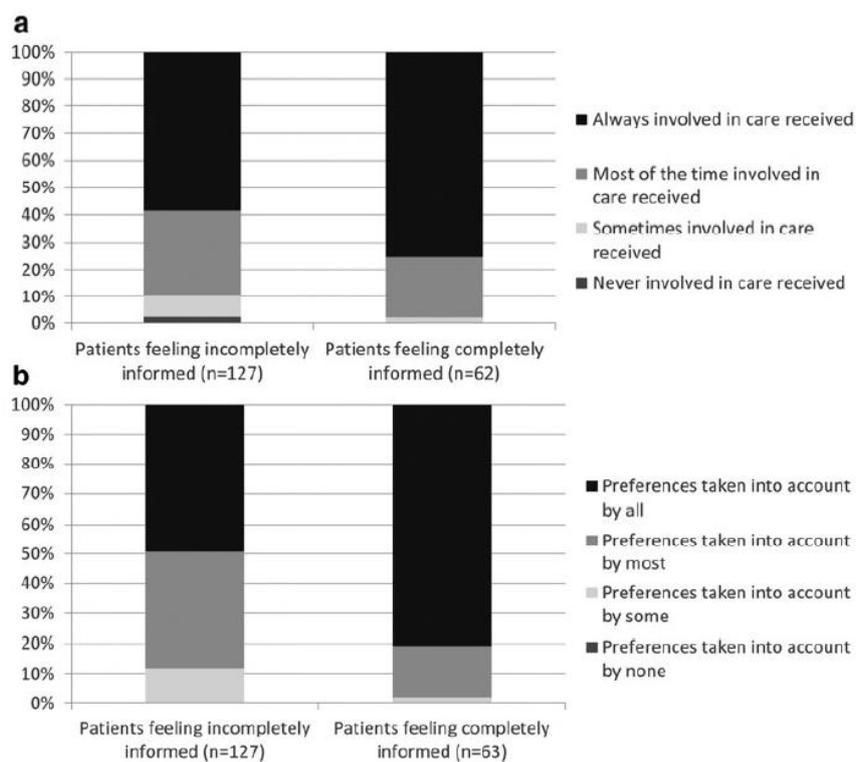


FIG. 4. (a) Association between feeling informed and feeling involved. From the 212 included participants, not all completed all measures. Hence, the number of participants per association varies. (b) Association between feeling informed and feeling preferences taken into account. From the 212 included participants, not all completed all measures. Hence, the number of participants per association varies.