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Shared decision making in cancer treatment: A Dutch national survey on patients' preferences and perceptions

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Abstract

Objective: Shared decision making (SDM) for cancer treatment yields positive results. However, it appears that discussing essential topics for SDM is not fully integrated into treatment decision making yet. Therefore, we aim to explore to what extent discussion of therapy options, treatment consequences, and personal priorities is preferred and perceived by (former) cancer patients.

Methods: An online questionnaire was distributed by the Dutch Federation of Cancer Patient Organisations among (former) cancer patients in 2018.

Results: Among 3785 (former) cancer patients, 3254 patients (86%) had discussed treatments with their health care provider (HCP) and were included for analysis. Mean age was 62.1 ± 11.5 ; 55% were female. Discussing the option to choose no (further) treatment was rated by 2751 (84.5%) as *very important* (median score 9/10—IQR 8–10). Its occurrence was perceived by 28% ($N = 899$), and short- and long-term treatment consequences were discussed in 81% ($N = 2626$) and 53% ($N = 1727$), respectively. An unmet wish to discuss short- and long-term consequences was reported by 22% and 26%, respectively. Less than half of the (former) cancer patients perceived that personal priorities (44%) and future plans (34%) were discussed.

Conclusion: In the perception of (former) cancer patients, several essential elements for effective SDM are insufficiently discussed during cancer treatment decision making.

KEYWORDS

communication, neoplasms, patient preference, perception, shared decision making, treatment

1 | INTRODUCTION

Over the last decades, health care has shifted away from its former paternalistic attitude towards a more patient-centred approach

(Barry & Edgman-Levitan, 2012). Shared decision making (SDM) is a key component of patient-centred care (Barry & Edgman-Levitan, 2012; Härter et al., 2017). SDM is defined as “an approach where clinicians and patients share the best available evidence

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when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elwyn et al., 2010). It requires active participation from both health care provider (HCP) and patient, as they collaboratively weigh different treatment options in the light of priorities and values of the patient. The process of SDM is dynamic and complex but essentially consists of four key steps: (1) raising awareness of the fact that patients have a choice, (2) talking through the different options and discussing consequences of each option, including their probabilities, (3) discussing a patient's values, and—after some time for deliberation, supported by their HCP—(4) taking a decision based on informed preferences (Stiggelbout et al., 2015). There are multiple reasons why, especially in the field of oncology, there is great value in SDM. First, an increasing variety of cancer treatments is being developed and multiple treatment options are suitable with side-effects that may significantly affect the patients “quality of life” (Kane et al., 2014; Politi et al., 2011; Whitney et al., 2008). Second, the process of SDM ensures the discussion of treatment consequences and their probabilities (Berger, 2015; Kane et al., 2014; Ménard et al., 2012). This is important since—as a result of rising survival rates—an increasing number of former cancer patients are living with long-term consequences of their treatment (Khan et al., 2011). Thirdly, the fact that HCPs are insufficiently able to accurately predict patients' values (Kunnehan et al., 2014; Lee et al., 2010; Stalmeier et al., 2007) underlines the importance of discussing patients' values (SDM step 3). Finally, SDM in cancer care, compared to the traditional style of communication, is associated with a higher perceived satisfaction with, and confidence in, treatment decisions (Kane et al., 2014), greater levels of treatment adherence (Kahn et al., 2007), perceived quality of life (Hack et al., 2006) and mental health (Arora et al., 2009).

Despite the need for SDM and its positive effects, it has been reported that SDM is not yet fully integrated into the decision-making process for cancer treatment (Covvey et al., 2019; Kunnehan et al., 2016; Müller et al., 2016), especially concerning steps 2 and 3 of SDM. For instance, observations of consultations in multiple cancer care settings show that HCPs regularly steer towards active treatment while the option to choose no (further) treatment is left underexposed (Brom et al., 2017; Engelhardt et al., 2016). Furthermore, the amount of information provided to cancer patients during treatment decision processes may be insufficient (Rood et al., 2017). Observations also suggest that patients' values (SDM step 3) may be underexposed, since essential elements such as exploring a patient's expectations and concerns are only discussed in half of patients (Couët et al., 2015; Pieterse et al., 2019). In order to improve the integration of SDM in daily practice, it is important to know which elements of SDM are currently lacking in the cancer treatment decision-making process.

Therefore, we aim to explore to what extent (1) therapy options, (2) their consequences and (3) personal preferences are discussed during the SDM process, as perceived by (former) cancer patients and what patients would have wished to discuss regarding these topics.

2 | METHODS

In 2018, an online questionnaire on how cancer patients perceived their decision-making process was developed and distributed by the Dutch Federation of Cancer Patient Organisations (NFK in Dutch) among their network of (former) cancer patients. NFK is an umbrella organisation in the Netherlands representing 19 cancer patient organisations. Annually, they develop and send out several questionnaires to explore cancer patients' needs and experiences.

2.1 | Questionnaire development and content

The questionnaire (Appendix A) was developed by NFK, together with representatives of affiliated cancer patient organisations. Preferences and perceptions of (former) cancer patients regarding their treatment decision process were assessed with numeric, multiple-choice questions and open-ended questions. Conditional logic was applied. First, a validation question was asked to confirm that respondents have (had) cancer. Of the (former) cancer patients, patients who reported that they did not discuss one or more treatments were excluded from further analysis. Respondents were able to quit the questionnaire at any time. Responses were only included if respondents finished all demographic questions in addition to at least one decision-making-related question.

Basic demographic information was collected: type of cancer, time since the last cancer treatment decision was made, and time since the last treatment. Then, using the structure of the key steps of SDM (Stiggelbout et al., 2015), questions were asked to explore the extent to which patients perceived that SDM took place during their treatment process. SDM step 2 was explored with use of questions 9, 12–19, and 22 and 23; SDM step 3 was explored with use of questions 20 and 21. This included discussing the option to choose no (further) treatment and its perceived importance rated on a scale of 1 to 10 (1 = *not important*, 10 = *very important*). It also included exploring to which extent patients perceived that short- and long-term consequences were discussed, and if not, should preferably have been discussed in retrospect. Finally, respondents were asked to rate to which extent—in their perception—the topics “what is important to patients in daily life” and “their future plans,” were discussed during their decision-making process.

The survey was reviewed for content and face validity by co-authors with expertise in the field of SDM and patient involvement, through a continuous process of reflection within the team, resulting in an iterative version of the questionnaire.

2.2 | Distribution and data collection

The questionnaire was distributed by NFK in October 2018 among members and followers of affiliated cancer patient organisations, by email, newsletter and/or website. NFK also posted a direct link to the

questionnaire on their website and all their social media channels, and asked affiliated organisations to post the questionnaire. Furthermore, a group of cancer patients who volunteered to participate in NFK's questionnaire panel received an invitation via email to fill out the questionnaire. Recipients were given 2 weeks to complete the survey. Data were collected anonymously with the use of the online tool "Survey Monkey."

2.3 | Data analysis

IBM SPSS Statistics version 25 was used for all analyses. Categorical variables are presented as numbers and percentages, continuous variables are presented as mean and standard deviation if normally distributed and otherwise as the median and interquartile range (IQR). Percentages were calculated by consistently using the total of patients included in our study as a denominator. Descriptive analyses were performed to explore differences for subgroups of our population, based on cancer type.

3 | RESULTS

3.1 | Study population

A total of 3785 (former) cancer patients filled out the questionnaire. Of these respondents, 3254 (86.0%) patients discussed one or multiple treatments with their HCP and were included. Patient characteristics are presented in Table 1. The mean age was 62.1 (± 11.5) and 55.1% of participants were female. The most prevalent cancer types were breast (27.2%), haematological (17.8%), and colon (17.3%) cancer. A majority of patients (88.1%; $N = 2867$) expressed a preference for SDM regarding their cancer treatment.

3.2 | SDM step 2: Discussing the different treatment options and their consequences

Forty-two per cent of patients ($N = 1352$) reported that only one treatment was discussed during the decision-making process. The importance of discussing the option to choose no (further) treatment was rated by 2751 (84.5%) patients, with a median score of 9 out of 10 (IQR 8–10). Twenty-eight per cent of patients ($N = 899$) reported that the option to choose no (further) treatment was discussed.

Of all included patients, 80.7% ($N = 2626$) reported that short-term consequences of their treatment had been discussed (Table 2) and 53.1% ($N = 1727$) reported the discussion of long-term consequences. The short- and long-term consequences discussed are presented in Table 2.

When asked "Are there any short-term consequences that were left undiscussed, which you would have preferred to have discussed" patients answered "yes" in 22.4% of cases ($N = 728$) (Table 3). Most reported short-term consequences that patients would like to have

TABLE 1 Characteristics of the study population ($N = 3254$)

| | | |
|---|------|--------|
| Age, years (SD) | 62.1 | (11.5) |
| Sex, female (%) | | |
| ≤ 60 years old | 1054 | (77.3) |
| > 60 years old | 738 | (39.0) |
| Diagnosis, (%) | | |
| Breast cancer | 886 | (27.2) |
| Haematological cancer | 579 | (17.8) |
| Colon cancer | 563 | (17.3) |
| Prostate cancer | 400 | (12.3) |
| Bladder cancer | 195 | (6.0) |
| Melanoma/skin cancer | 120 | (3.7) |
| Gynaecological cancer | 118 | (3.6) |
| Lung cancer | 77 | (2.4) |
| Other | 316 | (9.7) |
| Median time since last treatment (IQR) | 2 | (0–5) |
| Median time since last treatment decision (IQR) | 2 | (0–5) |
| Hospital type where patients were treated (%) | | |
| Academic (or specialised in cancer-care) | 1013 | (31.1) |
| "Top-clinical" | 1277 | (39.2) |
| General | 917 | (28.2) |
| Other | 47 | (1.4) |
| Median number of HCPs involved (IQR) | 1 | (1–2) |

Abbreviations: HCPs, health care providers; IQR, interquartile range; SD, standard deviation.

discussed, but were not, were fatigue (6.8%), diminished physical capacity (6.6%), and concentration problems (5.4%).

Of all included patients, 25.6% ($N = 833$) reported the preference to talk about long-term consequences that were left undiscussed. The most reported long-term consequences which were preferred but were left undiscussed again included fatigue (10.4%), diminished physical capacity (8.3%), and concentration problems (8.1%).

3.3 | SDM step 3: Discussing patient's values

Forty-four per cent of patients ($N = 1434$) reported that their HCP discussed with them what they consider important in daily life (Table 4). The discussion of future plans was reported by 33.6% of patients ($N = 1093$).

4 | DISCUSSION

Our study explores to what extent (1) therapy options, (2) their short- and long-term consequences, and (3) patients' personal preferences are part of the SDM process in cancer treatment decision-making. Our results suggest that essential topics—such as the option to

TABLE 2 Perceived discussion of short- and long-term consequences in SDM process (SDM step 2)

| Discussion of short-term consequences, % (N) | 80.7 (2626) | |
|--|---|--|
| Discussion of long-term consequences, % (N) | 53.1 (1727) | |
| | Discussion of short-term consequences % (N) | Discussion of long-term consequences % (N) |
| Fatigue | 47.8 (1557) | 25.1 (816) |
| Diminished physical capacity | 38.5 (1254) | 18.7 (610) |
| Sexual dysfunction | NA | 15.8 (515) |
| Nausea/vomiting | 28.9 (940) | NA |
| Gastrointestinal complaints | 24.6 (802) | 10.0 (324) |
| Osteoporosis | NA | 9.0 (293) |
| Hair loss | 24.0 (780) | NA |
| Weight shift/problems eating or drinking | 21.4 (696) | 6.8 (220) |
| Pain | 19.6 (637) | 6.7 (219) |
| Neuropathy | 18.2 (592) | 10.9 (354) |
| Cardiological problems | NA | 5.9 (191) |
| Hormonal dysfunction | 16.2 (527) | 9.0 (293) |
| Oral/dental problems | 15.6 (507) | 4.4 (143) |
| Concentration problems | 13.2 (428) | 8.2 (266) |
| Incontinence | 11.2 (364) | 7.9 (257) |
| Lymphedema | 9.9 (321) | 6.0 (196) |
| Memory problems | 8.8 (286) | 5.9 (191) |
| Depressive symptoms | 8.8 (285) | 5.3 (174) |
| Fertility problems | NA | 4.9 (160) |
| Secondary tumours | NA | 4.0 (130) |
| Dyspnoea/shortness of breath | 6.1 (199) | NA |
| Stress | 5.9 (192) | 3.0 (99) |
| Anxiety | 5.4 (176) | 3.3 (107) |

Note: Higher means or medians indicate more discussion.

Abbreviations: NA, not applicable; SDM, shared decision making.

choose no (further) treatment or long-term consequences of treatment—are insufficiently discussed during the cancer treatment decision-making process

Of the patients who discussed their treatments with their HCP, less than half reported discussing only one treatment. Only a quarter reported discussing the option to choose no (further) treatment, even though patients rated this option as *very important* to discuss. An

unmet wish to have short- and long-term consequences discussed was reported by one in four and one in five patients, respectively. Less than half of the respondents perceived that personal priorities (44%) and future plans (34%) were discussed. These findings suggest that there is room for improvement in the extent to which essential elements of the SDM process are part of the conversation(s) between cancer patients and their HCPs. Our finding that the option to choose no (further) treatment is currently underexposed is especially worrisome for patients with palliative cancer, as we assume that the discussion of this option is even more relevant to them, compared to patients with curative cancer. Unfortunately, we were unable to stratify our results based on prognosis (i.e., curative or palliative treatment), since this information was not collected in the questionnaire. Our results are supported by previous research in which consultations concerning preference-sensitive neo-adjuvant treatment decisions in breast and rectal cancer patients were audiotaped. In none of the 100 consultations, the option to choose no (further) treatment was the topic of conversation (Kunneman et al., 2016). This was confirmed in an observational study among patients with advanced cancer (Brom et al., 2017). Discussing and presenting the option of choosing no (further) treatment with cancer patients seems warranted, particularly since discussing this option was rated as *very important* by patients.

Our data also demonstrate that patients perceive more frequently that they are informed about short-term consequences (81%) than about long-term consequences (53%). In hindsight, the most frequently omitted consequences that patients preferred to talk about were; fatigue, diminished physical capacity and concentration problems. Kunneman, Marijnen, Rozema, et al. (2015), who studied radiotherapy decisions for rectal cancer, showed comparable proportions in which short- and long-term consequences were discussed. In their study, short- and long-term consequences of treatment were discussed in 65% and 70% of consultations, respectively. The slight difference in results may be due to the different study methods, treatment options and study populations.

Discussion of what is important to patients in their daily life and their future plans was experienced by less than half of patients. Similar results were found in rectal cancer treatment decisions: patient's values were considered in only one in five consultations (Kunneman, Marijnen, Baas-Thijssen, et al., 2015). Additionally, a study in cancer patients with a median life expectancy of less than 1 year showed that values were discussed in only 48% of consultations (Henselmans et al., 2017). This lack of discussion of patients' values is also reported in other specialties. In a study performed on 35 patients with an abdominal aortic aneurysm, patient's priorities were discussed in only 18%–31% of consultations, depending on the size of the aneurysm (Knops et al., 2010).

A recent systematic review showed that patients often prefer, but not experience a shared decisional role for cancer treatment (Noteboom et al., 2021). Our study provides direct clues on how to improve patient involvement in SDM. In short, our findings are in line with observations from previous studies, and support the idea that vital steps (2 and 3) of the SDM process may be improved by increasing the extent to which both short and long-term treatment

TABLE 3 Preferred but not perceived discussion of short- and long-term treatment consequences (SDM step 2)

| Total | Breast cancer N = 886 | | Haematological cancer N = 579 | | Colon cancer N = 563 | | Prostate cancer N = 400 | | Other cancer types N = 826 | |
|--|--------------------------|------------|----------------------------------|------------|-------------------------|-----------|----------------------------|-----------|-------------------------------|------------|
| | Short-term | Long-term | Short-term | Long-term | Short-term | Long-term | Short-term | Long-term | Short-term | Long-term |
| Preferred but not perceived discussion consequences ^a | 26.7 (273) | 36.2 (321) | 20.4 (118) | 25.6 (148) | 17.4 (98) | 17.6 (99) | 13.3 (53) | 17.0 (68) | 22.5 (186) | 23.8 (197) |
| Fatigue ^a | 10.3 (91) | 16.4 (145) | 5.5 (32) | 10.2 (59) | 4.6 (26) | 7.1 (40) | 3.3 (13) | 4.0 (16) | 7.0 (58) | 9.6 (79) |
| Diminished physical capacity ^a | 10.2 (90) | 13.3 (118) | 4.3 (25) | 7.4 (43) | 5.3 (30) | 5.0 (28) | 3.0 (12) | 4.3 (17) | 7.0 (58) | 7.6 (63) |
| Sexual dysfunction ^a | NA | 9.8 (87) | NA | 4.5 (26) | NA | 6.9 (39) | NA | 6.5 (26) | NA | 5.2 (43) |
| Gastrointestinal complaints ^a | 3.3 (29) | 3.0 (27) | 4.1 (24) | 3.3 (19) | 3.7 (21) | 2.3 (13) | 2.5 (10) | 2.8 (11) | 3.8 (31) | 3.6 (30) |
| Osteoporosis ^a | NA | 7.8 (69) | NA | 2.9 (17) | NA | 1.8 (10) | NA | 2.5 (10) | NA | 2.8 (23) |
| Weight shift/problems eating or drinking ^a | 5.8 (51) | 6.7 (59) | 2.8 (16) | 2.1 (12) | 3.2 (18) | 2.3 (13) | 1.0 (4) | 1.0 (4) | 3.0 (25) | 3.5 (29) |
| Pain ^a | 6.5 (58) | 10.2 (90) | 2.6 (15) | 2.9 (17) | 2.3 (13) | 1.8 (10) | 2.0 (8) | 1.5 (6) | 4.0 (33) | 4.1 (34) |
| Neuropathy ^a | 8.1 (72) | 11.5 (102) | 5.2 (30) | 7.4 (43) | 2.1 (12) | 3.7 (21) | 0.3 (1) | 0.8 (3) | 3.3 (27) | 3.9 (32) |
| Cardiological problems ^a | NA | 7.1 (63) | NA | 4.1 (24) | NA | 0.9 (5) | NA | 0.8 (3) | NA | 1.7 (14) |
| Hormonal dysfunction ^a | 6.5 (58) | 10.2 (90) | 1.9 (11) | 1.2 (7) | 0.9 (5) | 1.2 (7) | 2.5 (10) | 2.0 (8) | 1.5 (12) | 2.1 (17) |
| Oral/dental problems ^a | 8.0 (71) | 9.0 (80) | 2.6 (15) | 3.6 (21) | 1.2 (7) | 0.9 (5) | 1.3 (5) | 1.3 (5) | 2.1 (17) | 3.0 (25) |
| Concentration problems ^a | 9.1 (81) | 15.3 (136) | 5.5 (32) | 8.5 (49) | 3.0 (17) | 3.2 (18) | 1.0 (4) | 1.3 (5) | 5.2 (43) | 6.9 (57) |
| Lymphedema ^a | 6.8 (60) | 9.1 (81) | 0.7 (4) | 0.3 (2) | 0.5 (3) | 0.5 (3) | 1.5 (6) | 1.5 (6) | 1.5 (18) | 3.9 (32) |
| Memory problems ^a | 8.8 (78) | 14.2 (126) | 4.8 (28) | 7.8 (45) | 2.7 (15) | 2.3 (13) | 1.0 (4) | 1.5 (6) | 4.4 (36) | 6.1 (50) |
| Depressive symptoms ^a | 8.8 (78) | 9.1 (81) | 3.3 (19) | 4.7 (27) | 2.5 (14) | 2.3 (13) | 2.3 (9) | 4.0 (16) | 5.8 (48) | 6.1 (50) |
| Secondary tumours ^a | NA | 3.2 (28) | NA | 2.8 (16) | NA | 1.1 (6) | NA | 1.3 (5) | NA | 1.7 (14) |
| Stress ^a | 5.3 (47) | 4.6 (41) | 2.6 (15) | 2.9 (17) | 1.1 (6) | 2.1 (12) | 1.5 (6) | 0.8 (3) | 2.8 (23) | 4.2 (35) |
| Anxiety ^a | 5.3 (47) | 6.8 (60) | 3.5 (20) | 2.6 (15) | 3.2 (18) | 2.3 (13) | 1.0 (4) | 2.3 (9) | 4.7 (39) | 5.1 (42) |
| Dyspnoea/shortness of breath ^a | 4.7 (42) | NA | 1.7 (10) | NA | 0.7 (4) | NA | 0.5 (2) | NA | 1.7 (14) | NA |

Note: The following treatment consequences were reported by less than 2% of the study population and are not presented in this table: nausea, hair loss, incontinence, and fertility problems. Higher means or medians indicate higher levels of preferred but not perceived discussion.

Abbreviations: NA, not applicable; SDM, shared decision making.

^aResults presented as % (N).

TABLE 4 Perceived discussion of patient's preferences (SDM step 3)

| Total | All included patients N = 3254 | Breast cancer N = 866 | Haematological cancer N = 579 | Colon cancer N = 563 | Prostate cancer N = 400 | Melanoma/skin cancer N = 120 | Other cancer types N = 706 |
|--|-----------------------------------|--------------------------|----------------------------------|-------------------------|----------------------------|---------------------------------|-------------------------------|
| Perceived discussion of what is important in daily life, % (N) | 44.1 (1434) | 40.4 (350) | 42.3 (245) | 46.0 (259) | 50.0 (200) | 30.0 (36) | 48.7 (344) |
| Perceived discussion of future plans, % (N) | 33.6 (1093) | 27.0 (234) | 34.0 (197) | 35.9 (202) | 41.5 (166) | 25.0 (30) | 37.4 (264) |

Abbreviation: SDM, shared decision making.

consequences and personal priorities are discussed with cancer patients. Some promising interventions were developed in an attempt to improve the extent to which essential elements are discussed. One of these interventions is the “time out consultation,” where patients take time to discuss their situation with their own family physician before they proceed with the cancer treatment-decision with their medical specialist (Noteboom et al., 2020). Other promising interventions that have been reported recently are training and feedback on consultations (Henselmans et al., 2019; van Veenendaal et al., 2021), and the coaching of patients (by a nurse or other health care provider) in developing skills necessary for SDM, such as using medical information, raising questions and clarifying values (O'Connor et al., 2008). These interventions may help close the gap between the preferred and actual level of SDM implementation in cancer care.

4.1 | Strengths and limitations

A major strength of this study is its large sample size and the variation of cancer types within the study population. Even though this supports generalisability and reliability of findings for our study domain and offers insight into differences between cancer types, the approach used in our study also has limitations, which must be taken into consideration when interpreting our results. The questionnaire was distributed by NFK and affiliated cancer patient organisations. This convenience sampling may lead to selective participation. First, because members and followers of these patient organisations may have different (i.e., more informed or critical) opinions than the average cancer patient. Since participation in the study is voluntary, it may be possible that people who were very satisfied or very unsatisfied concerning their decision-making process are overrepresented. The response rate would therefore be relevant, but cannot be estimated: the number of patients that were reached with the request to participate is unknown as—in addition to other routes—social media were used to distribute the questionnaire.

Second, the types of cancers represented by the organisations affiliated with NFK are not a direct reflection of the incidence of cancer types in the Netherlands (Netherlands Cancer Registry, n.d.). For example, due to the participation of a large haematological cancer patient organisation, patients with haematological cancers are overrepresented in our study population. This selective participation should be taken into account when generalising our findings. Another

limitation is potential recall bias. It has been reported that patients' memory for medical information is far from optimal, especially in case of the emotional stress following a diagnosis of cancer (Jansen et al., 2008; Kessels, 2003; Sep et al., 2014). Our results are based on patients' perceptions of a situation that sometimes occurred several years ago (median time since treatment was 2 years, IQR 0–5). Therefore, patients may underestimate the extent to which the elemental SDM topics were actually discussed. Previous studies have shown that patients only recall about half of the information provided in cancer consultations (Jansen et al., 2008; Kessels, 2003). Also, when cancer patients were asked how many adverse effects of treatment were discussed, they recalled a median of two adverse effects while a median of eight was discussed (Pilote et al., 2019). Additionally, some patients may have perceived adverse effects of their treatment, possibly affecting the preferences regarding discussed issues during their treatment decision-making process. Given the fact that our study provides a hindsight view, our findings should be interpreted as the extent to which patients remember discussing elemental SDM topics.

Finally, we restricted our study population solely to (former) cancer patients who reported that one or multiple treatments had been discussed, since we assumed that if treatment had not been discussed, treatment consequences and corresponding patient values would also be left undiscussed. Therefore, 14% (N = 531) of patients who did not recall a treatment to be discussed were excluded. The finding that one in seven patients did not recall discussing treatments at all is worrisome, particularly given the need for “choice awareness” (Kunneman et al., 2016) in the SDM process. Since we did not include this 14% of patients in our results, our results possibly overestimate the extent to which essential elements of SDM are implemented in cancer treatment decision making.

Our study suggests that essential elements in the SDM process are insufficiently experienced in cancer treatment decision making. This includes the perception of a treatment choice, awareness of treatment options and their consequences, and weighing options in the light of personal values. Particularly, in the perception of patients, the option to choose no (further) treatment and long-term consequences for daily life is insufficiently discussed. Consequently, cancer patients may currently be insufficiently equipped to make the important treatment decisions that they must face. The HCPs guiding these patients may need to improve the way in which they actively accompany and lead cancer patients through the steps required to attain an informed and shared cancer treatment decision.

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CONFLICT OF INTEREST

The views presented in this research are the sole responsibility of the authors. The subsidiser of the study was informed regularly about the study during the course of the project and approved the study concept and the final results of the study. The subsidy provider was not allowed to propose participants for the questionnaires or to comment on the content of the study.

DATA AVAILABILITY STATEMENT

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

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APPENDIX A

Questionnaire (originally in Dutch)

1. This questionnaire is meant for people who were diagnosed with cancer. Does this apply to you?
 - Yes, I've had a cancer diagnosis
 - No → *end of questionnaire*
2. What is your sex?
 - Male
 - Female
3. What is your year of birth?
4. What type of cancer were you diagnosed with? *In case of multiple diagnoses, please fill out the most recent one.*
5. How long ago was your most recent treatment?

6. How long ago was your most recent treatment decision?
7. In what hospital were you a patient when this last treatment decision was made?
8. Do you feel a need for shared decision making regarding your cancer treatment
 - Yes
 - No
 - Do not know/not applicable
9. Did a care provider discuss one or multiple treatment options with you? (during your most recent treatment decision process)?
 - Yes, one treatment option
 - Yes, multiple treatment options
 - No, no treatment options were discussed → skip to question 20
 - Do not know/not applicable → skip to question 20
10. Who discussed one or multiple treatment options with you (during your most recent treatment decision process)? (*multiple answers possible*)
 - Oncologist/internist
 - Surgeon
 - Urologist
 - Gynaecologist
 - Haematologist
 - Radiotherapist
 - Other doctor in hospital
 - Specialised nurse/nurse practitioner
 - Other nurse in hospital
 - General practitioner
 - Do not know/not applicable
 - Other, namely ...
11. In what way were you informed about one or multiple treatment options with you (during your most recent treatment decision process)? (*multiple answers possible*)
 - Orally (e.g., during consultation with your care provider)
 - Written (e.g., in brochures)
 - Digitally (e.g., via websites)
 - Through a printed decision aid
 - Through a digital decision aid
 - Do not know/not applicable
 - Other, namely ...
12. Were short-term consequences of treatments discussed with your care provider (during your most recent treatment decision process)?
 - Yes
 - No → skip to question 14
 - Do not know/not applicable → skip to question 16
13. Which short-term consequences of treatments were discussed with your care provider (during your most recent treatment decision process)?
 - Fatigue
 - Pain
 - Concentration problems
 - Memory problems
 - Incontinence
 - Diminished physical capacity
 - Neuropathy (nerve pain)
 - Depressive symptoms
 - Anxiety
 - Stress
 - Hormonal dysfunction
 - Nausea/vomiting
 - Hair loss
 - Gastrointestinal complaints
 - Oral/dental problems
 - Lymphedema
 - Dyspnoea
 - Weight change/problems eating or drinking
 - Do not know/not applicable
 - Other, namely ...
14. Are there short-term consequences of treatments that were not discussed, but you wish they would have been discussed?
 - Yes
 - No → skip to question 16
 - Do not know/not applicable → skip to question 16
15. Which short-term consequences of treatments that were not discussed do you wish would have been discussed?
 - Fatigue
 - Pain
 - Concentration problems
 - Memory problems
 - Incontinence
 - Diminished physical capacity
 - Neuropathy (nerve pain)
 - Depressive symptoms
 - Anxiety
 - Stress
 - Hormonal dysfunction
 - Nausea/vomiting
 - Hair loss
 - Gastrointestinal complaints
 - Oral/dental problems
 - Lymphedema
 - Dyspnoea
 - Weight change/problems eating or drinking
 - Do not know/not applicable
 - Other, namely ...
16. Were long-term consequences of treatments discussed by your care provider (during your most recent treatment decision process)?
 - Yes
 - No → skip to question 18
 - Do not know/not applicable → skip to question 20
17. Which long-term consequences of treatments were discussed by your care provider (during your most recent treatment decision process)?
 - Fatigue

- Memory problems
 - Concentration problems
 - Sexual problems
 - Incontinence
 - Diminished physical capacity
 - Neuropathy (nerve pain)
 - Depressive symptoms
 - Anxiety
 - Stress
 - Hormonal dysfunction
 - Osteoporosis
 - Cardiological problems
 - Oral/dental problems
 - Lymphedema
 - Pain
 - Fertility problems
 - Secondary tumours
 - Gastrointestinal problems
 - Weight change/problems eating or drinking
 - Do not know/not applicable
 - Other, namely ...
18. Are there long-term consequences of treatments that were not discussed, but you wish they would have been discussed?
- Yes
 - No → *skip to question 20*
 - Do not know/not applicable → *skip to question 20*
19. Which long-term consequences of treatments that were not discussed do you wish they would have been discussed?
- Fatigue
 - Memory problems
 - Concentration problems
 - Sexual problems
 - Incontinence
 - Diminished physical capacity
 - Neuropathy (nerve pain)
 - Depressive symptoms
 - Anxiety
 - Stress
 - Hormonal dysfunction
 - Osteoporosis
 - Cardiological problems
 - Oral/dental problems
 - Lymphedema
 - Pain
 - Fertility problems
 - Secondary tumours
 - Gastrointestinal problems
 - Weight change/problems eating or drinking
 - Do not know/not applicable
 - Other, namely
20. Cancer treatment can influence your daily life. Therefore, we feel that it is important for your care provider to know what is important to you in your daily life, so that this can be taken into account during the treatment decision process.
- Did a care provider talk to you about what is important to you in daily life (during your most recent treatment decision process)?
- Yes
 - No
 - Do not know/not applicable
21. Cancer treatment can have long-term consequences. Therefore, we feel that it is important for your care provider to know what is important to you in your future, so that this can be taken into account during the treatment decision process.
- Did a care provider talk to you about your future plans or wishes (during your most recent treatment decision process)?
- Yes
 - No
 - Do not know/not applicable
22. Choosing no (further) cancer treatment can be an option too, for example if the advantages of treatment do not outweigh the disadvantages of treatment. Or if patients do not wish (further) treatment.
- Did a care provider talk to you about the option to choose no (further) cancer treatment (during your most recent treatment decision process)?
- Yes
 - No
 - Do not know/not applicable
23. How important do you think it is that a care provider discusses the option to choose no (further) treatment? Please give a score between 1 and 10. (1 = *not important at all*, 10 = *very important*).
24. Who eventually took the treatment decision?
- Me
 - My loved ones
 - My care provider(s)
 - Me, together with my loved ones
 - Me, together with my care provider(s)
 - My loved ones, together with my care provider(s)
 - Me, together with my loved ones and care provider(s)
 - Do not know/not applicable
 - Other, namely ...
25. How content are you with the support you received from your care provider during your most recent treatment decision process? Please give a score between 1 and 10. (1 = *not content at all*, 10 = *very content*).
26. How important do you think it is to receive support from your care provider during a treatment decision process? Please give a score between 1 and 10. (1 = *not important at all*, 10 = *very important*).
27. How much time for deliberation was given to you by your care provider, before a final decision was made (in your most recent treatment decision process)?
- No time for deliberation
 - Less than 1 day
 - 1–3 days
 - 4–6 days

- 1–2 weeks
 - More than 2 weeks
 - Do not know/not applicable
28. Retrospectively, how do you feel about the time for deliberation that was given to you by your care provider, before a final decision was made (in your most recent treatment decision process)?
- Precisely enough time
- I would have wanted more time
 - I would have wanted less time
 - Time for deliberation was not possible in my situation
 - Do not know/not applicable
29. This is the final question of this questionnaire. If something you would like to tell us about shared decision making that has not been addressed in this questionnaire, please leave a comment.