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Longitudinal Changes in Advance Care Planning Engagement, Patient Preferences, and Patient-Family Concordance in Japanese Breast Cancer Patients and Their Families: A One-Year Follow-Up Study

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Longitudinal changes in advance care planning engagement, patient preferences, and patient-family concordance in Japanese breast cancer patients and their families: A one-year follow-up study

Running title: Longitudinal change in advance care planning in breast cancer

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Presentation

The content of this one-year follow-up study is scheduled to be presented at the San Antonio Breast Cancer Symposium (SABCS) 2026; the exploratory stratified result was updated after abstract submission (see the exploratory analysis in Results). The present study extends the group's cross-sectional analysis of the same cohort, which was presented at SABCS 2025 (#2025-A-2256) and subsequently published in The Breast (reference 8). Intended submission: Breast Cancer.

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Longitudinal Changes in Advance Care Planning Engagement, Patient Preferences, and Patient-Family Concordance in Japanese Breast Cancer Patients and Their Families: A One-Year Follow-Up Study

Abstract

Background

Advance care planning (ACP) is meant to be revisited, but whether patients' end-of-life values, and the values their families attribute to them, change during breast cancer follow-up is unknown. We examined how ACP behaviours, patients' own and family-attributed values, and patient–family agreement changed.

Methods

At a Japanese breast cancer centre, patients and family members answered the same 24-item questionnaire on end-of-life values and treatment preferences at two surveys, a median of 502 days apart. Family members answered as they believed the patient would. In the second survey, respondents were briefly informed of the first survey's results and the value of revisiting planning. We compared the surveys in 284 patients and 164 patient–family dyads. The primary outcome was the number of items on which the patient and family disagreed.

Results

The proportion of patients who had asked someone to speak on their behalf rose from 44.3% to 54.6% (+10.3 percentage points, 95% CI [+3.5, +17.1]). Seven of the 24 patient items changed significantly after multiple-comparison correction. Six rose, including freedom from pain and suffering, and the wish for maximal treatment fell (−8.5 percentage points, 95% CI [−13.7, −3.2]). None of the family's predicted answers changed. Discordant items fell from a median of

8 to 6 (Hodges–Lehmann change −1.00, 95% CI [−2.00, −0.50]). Agreement change did not differ clearly by the onset of family discussion; disease worsening was too rare to assess.

Conclusions

Patients' end-of-life values moved towards comfort, while their families' predictions did not. Clinicians revisiting ACP should ask both patient and family again.

Keywords: advance care planning; breast cancer; end-of-life care; patient preference; family.

Introduction

Advance care planning (ACP) is the process by which people with serious illness reflect on their values and goals, discuss them with family members and clinicians, and prepare for future medical decisions should they become unable to speak for themselves. Landmark work has repeatedly documented that seriously ill patients' preferences are often not known or not honoured, motivating structured efforts to elicit and record them [1]. Contemporary consensus definitions frame ACP not as the completion of a document at a single moment but as an ongoing, iterative process that evolves as illness, circumstances, and relationships change [2, 3]. If this framing is correct, then the values patients hold and the degree to which those values are understood by the people who may one day speak for them should be expected to shift over time, particularly during active cancer treatment and follow-up.

Breast cancer provides an informative setting for examining this question. It is common, it is frequently diagnosed at a curable stage yet carries a meaningful risk of recurrence, and its management often unfolds over years, during which patients repeatedly weigh the benefits of treatment against its burdens. Family members are typically closely involved, and in many

cultural contexts, including Japan, families play a central role in end-of-life decision-making, with comfort, dignity, and avoiding burdening others featuring prominently in Japanese conceptions of a good death [4, 5]. Yet family members do not always share the patient's priorities [6, 7]. In a prior cross-sectional analysis of the present cohort, we found substantial discordance between patients and their families in end-of-life values: patients tended to prioritise independence and not becoming a burden, whereas families more often prioritised longevity and continued treatment [8]. That analysis captured a single moment and could not tell us whether such discordance is fixed or modifiable.

Three things about that picture remain unsettled. It is not known whether engagement in ACP grows during breast cancer follow-up, with more patients naming someone to speak for them and more families discussing the patient's wishes. Whether the values and preferences that a family member attributes to the patient shift over time has rarely been examined. Longitudinal studies of end-of-life preferences have mostly followed patients alone [9]. Nor can measurement at one time point show whether the discordance we documented is fixed or narrows while patients and families keep engaging.

This study aimed to describe how, during follow-up, (1) ACP behaviours, (2) patients' own and family-attributed values and treatment preferences, and (3) patient–family agreement changed. Two further questions were exploratory. One was whether the change in agreement differed between dyads that had just begun a family conversation and those that had not. The other was whether disease worsening between the two surveys accounted for the changes. Because both sides answered the same items in both surveys, the design can show which side's answers shifted as agreement changed.

Methods

Study background

This was a single-centre, longitudinal, questionnaire-based follow-up study conducted at the Breast and Thyroid Center of Jyoban Hospital of the Tokiwa Foundation (Iwaki, Japan). Patients and their family members independently completed the same ACP questionnaire at two timepoints. The first survey (T1) was conducted between August 2024 and August 2025, and the second (T2) between October 2025 and June 2026. When the second questionnaire was distributed, patients and families were given a brief explanation of the first survey's findings and of the value of revisiting ACP; the questionnaire was then completed at home and returned at a later date.

The survey dates of patients and families fell into two waves, with few responses in September 2025, so responses dated on or before 31 August 2025 were assigned to T1 and those dated on or after 1 October 2025 to T2. Family responses were not matched to the patient by date, because families returned their questionnaires well after the patient in the first survey. A small number of records dated in September 2025 could not be assigned to a wave and were excluded from all analyses.

The baseline cohort comprised the 470 patients who provided a patient response at T1, corresponding to the population of our prior cross-sectional report [8]. Of these, 284 also responded at T2, and 186 did not. Changes in patient engagement and patient preferences were assessed among the 284 patients who responded at both time points. Change in the family-attributed values (each family member's prediction of the patient) and in patient–family agreement was assessed in dyads in which both the patient and a family member responded at both timepoints: 164 dyads in the main analysis, for which the responding family member was

not required to be the same individual at T1 and T2, and 154 of these dyads in a confirmation analysis, for which the same family member had to respond at both timepoints. Fig. 1 shows how each analysis set was reached.

When more than one family member responded for a patient at a survey, one response was used for that survey. A member who had also responded to the other survey was taken first, and failing that, the patient's spouse. Failing both, the response returned earliest was used, with ties broken by order of data entry. When two or more members had responded to both surveys, one of them was kept at both.

Patients and family members completed the same instrument. It comprised 24 items covering what matters to the respondent near the end of life and how the respondent would wish to be treated. Fourteen are values, such as freedom from pain and suffering, not burdening family, living as long as possible, receiving the maximum possible treatment, and independence in daily activities. Six are care preferences, such as keeping treatment minimal while staying as usual, being told or not being told in detail what lies ahead, and continuing preferred lifestyle habits. Four concerns where treatment would be given: entrusting the decision to a trusted physician, hospital, a care facility, or home. Each item was recorded as selected or not selected.

Two further items captured ACP behaviors: for patients, whether they had asked designated people to speak on their behalf; and for families, whether they had discussed the patient's wishes with the patient, answered as "have discussed", "have not discussed," or "do not wish to discuss". Family members answered each of the 24 items as they believed the patient would, allowing the two sides to be compared item by item.

Outcomes

The primary outcome was the number of 24 items on which the patient's answer and the family member's answer differed, counted for each dyad at each time point. It takes whole values from 0 to 24, and a lower value means closer agreement. The 24 items are those set out above, and both sides were asked all of them.

There were three secondary outcomes. The first was the two ACP behaviours: whether the patient had asked someone to speak on their behalf, and whether the family had discussed the patient's wishes with the patient. The second was each of the 24 items, taken separately for patients and for family members. The third was the number of items a respondent selected from the 24, again taken separately for patients and family members.

Variables

The exposure was time: the first survey (T1) against the second survey (T2), with the same respondents answering the same items on both occasions. Age was taken at T1 and clinical stage from the finalised staging dataset covering all 470 patients. An interval disease-worsening event was defined as a new recurrence or metastasis, or a change of treatment driven by progression, occurring between the patient's T1 and T2 responses, and was ascertained by review of medical records. Patients with stage IV disease at diagnosis or with a recurrence diagnosed before the first survey were grouped as having stage IV or recurrent disease at the first survey. For the exploratory subgroup comparison, dyads in which the family reported no discussion at T1, that is "have not discussed" or "do not wish to discuss", were divided according to whether the family reported having discussed the patient's wishes by T2.

Statistical analysis

Analyses proceeded in seven stages.

(1) The first stage established whether the patients retained to T2 differed at baseline from those lost. T1 characteristics of responders and non-responders were compared with the Mann–Whitney U test for age and with the chi-square test, or Fisher's exact test where an expected count fell below 5, for categorical variables, with standardised mean differences reported alongside (Table 1). Supplementary Table S1 lists the denominator of every item, which differs from the column total where an item was left blank.

(2) The second stage measured how the two ACP behaviours changed. Change from T1 to T2 was assessed with the McNemar test for the binary surrogate item and with the Bowker test of symmetry for the three-category family discussion item (Table 2). All families who answered the discussion item in both surveys were included, regardless of whether the patient responded at T2.

(3) The third stage measured how the patients' own answers changed. Change in each of the 24 items was assessed using the McNemar test, and change in the number of items a patient selected was assessed using the Wilcoxon signed-rank test (Table 3). The number of items selected was counted over the items the respondent answered at both time points.

(4) The fourth stage did the same for the family members' answers. The two stage 3 analyses were applied to the family members' answers in the main-analysis dyads, alongside the patients' answers in those same dyads (Supplementary Table S2 and Fig. 2), and were repeated in the confirmation-analysis dyads (Supplementary Table S3).

(5) The fifth stage measured how far the two sides agreed and whether that changed. Change in the number of discordant items was assessed with the Wilcoxon signed-rank test and summarised by the Hodges–Lehmann estimate with its 95% confidence interval and by the matched-pairs rank-biserial correlation, in the main and in the confirmation analysis set (Table 4 and Fig. 3).

Agreement on each individual item was assessed with the McNemar test (Supplementary Table S4).

(6) The sixth stage took up the first exploratory question. The change in the number of discordant items was compared between dyads that had newly begun a family conversation and those that had not, using the Mann–Whitney U test with the rank-biserial correlation as the effect size (Supplementary Table S5).

(7) The seventh stage took up the second exploratory question. Changes in patients' items and in agreement were described separately for patients with and without an interval disease-worsening event (Supplementary Table S6). No test was applied, because such events were too few.

For each paired binary comparison, a risk difference in percentage points is reported with its 95% confidence interval, obtained from the counts of discordant pairs (those that change in each direction).

The 24 items were entered with a blank stored as not selected, so a blank cannot be distinguished from a deliberate non-selection. Family questionnaires on which all 24 items and all three discussion categories were blank were treated as non-responses, and 2 dyads were excluded from the main analysis on that ground.

When 24 tests were run on the same set of items, Benjamini–Hochberg false discovery rate q-values are reported alongside the p-values.

The analysis plan was written in advance. Because only 11 interval disease-worsening events occurred, the analysis that would have used them as an explanatory variable was changed, before the main analyses were run, into a description and an exploratory check. Deviations from the plan, together with the data corrections applied before analysis, are listed in Supplementary Table S7.

Reporting follows the STROBE statement for observational studies (Supplementary Table S8). All analyses were performed in R version 4.5.1.

Results

Table 1 presents the T1 characteristics of the 284 patients who responded at both time points and the 186 who responded only at T1. Fig. 1 shows how each analysis set was reached. The median interval between a patient's two responses was 502 days (interquartile range [450, 544], range 273 to 664), about 16 months. Median age was 61.0 [52.0, 72.0] years among responders and 63.5 [51.2, 76.0] years among non-responders (p=0.148). The distribution of clinical stage did not differ (p=0.568). The number who had asked someone to speak on their behalf at baseline was 125 (44.3%) among responders and 75 (40.5%) among non-responders (p=0.419).

Table 1 also shows that three of the 24 items differed between the groups. A wish to receive the maximum possible treatment was selected by 147 (51.8%) of responders and 71 (38.4%) of non-responders (p=0.005). Freedom from financial worry was selected by 160 (56.3%) and 87 (46.8%) (p=0.042). Knowing in detail what lies ahead was selected by 228 (80.3%) and 129 (69.4%) (p=0.007). By standardised mean difference, the largest differences were for a wish for maximal treatment (0.27) and knowing in detail what lies ahead (0.25).

Table 2 gives the change in the two ACP behaviours. Among the 282 patients who answered the surrogate item at both timepoints, the number who had asked someone to speak on their behalf rose from 125 (44.3%) to 154 (54.6%). The risk difference was +10.3 percentage points (95% CI [+3.5, +17.1]), and the McNemar test gave p=0.005. In all, 64 patients were newly reported a surrogate, and 35 no longer did. Among the 143 families who answered the discussion item at both time points, the shift across the three categories was not significant (Bowker, p=0.069).

Taking “have discussed” against the other two answers, the number rose from 77 (53.8%) to 93 (65.0%). That is a risk difference of +11.2 percentage points (95% CI [+2.5, +19.9]).

Table 3 gives the change in the patients’ own answers. Patients selected more items from the 24 at T2 than at T1. Counting over the items a patient answered on both occasions, the total selected rose from 3,280 to 3,464. That is a mean of 11.55 items per patient at T1 and 12.20 at T2. Across the 24 items, there were 722 transitions from not selected to selected, against 538 in the opposite direction (binomial $p<0.001$).

Table 3 also gives the results for each item. Eight items changed at $p<0.05$, and seven of these stayed below a false discovery rate of 0.05. Six of the seven rose. Four concerns are comfort and not being a burden: accepting less suffering even if death were hastened, freedom from pain and suffering, not burdening family, and not being a nuisance to others. The other two concern the intensity and the place of care: keeping treatment minimal while staying as usual, and accepting treatment in a care facility. The largest rise was for accepting less suffering even if death were hastened, at +8.8 percentage points (95% CI [+3.5, +14.1]). The remaining item fell: a wish to receive the maximum possible treatment, by −8.5 percentage points (95% CI [−13.7, −3.2]).

Supplementary Table S2 presents the family members’ answers to the same 24 items in the 164 main-analysis dyads, alongside the patients’ answers in those dyads. Fig. 2 plots the two sides together. Not one of the 24 items changed on the family side; the smallest p-value was 0.212, and every q-value was 1.000. The number of items a family member selected did not change significantly either, from a mean of 11.43 at T1 to 11.53 at T2 (Wilcoxon $p=0.960$). The same analyses for the 154 confirmation dyads yielded the same results, with no item changing significantly and no q-value below 1.000 (Supplementary Table S3).

The totals in Supplementary Table S2 set the two sides against each other in the same 164 dyads. Across the 24 items, the family side recorded 427 transitions from not selected to selected against 411 the other way, a net gain of 16 selections (+0.10 items per dyad; binomial p=0.604), whereas the patients recorded 432 against 316, a net gain of 116 (+0.71 items per dyad; p<0.001). On the item asking about receiving the maximum possible treatment, the number of these patients selecting it went from 87 (53.0%) to 71 (43.3%). The number of their family members who selected it decreased from 93 (56.7%) to 90 (54.9%). Within these dyads, the patient and the family member gave the same answer to this item in 63.4% of dyads at T1 and 65.2% at T2 (Supplementary Table S4).

Table 4 and Fig. 3 give the change in agreement. In the 164 main-analysis dyads, patient and family differed on a median of 8 [5, 10] of the 24 items at T1 and 6 [4, 9] at T2. The Wilcoxon signed-rank test gave p=0.002. The Hodges–Lehmann change was −1.00 items (95% CI [−2.00, −0.50]), and the matched-pairs rank-biserial correlation was +0.296. The number of items in disagreement fell in 84 dyads, remained unchanged in 17, and rose in 63. The 154 confirmation dyads gave the same median change, from 8 to 6 (p=0.002), with a Hodges–Lehmann change of −1.00 items (95% CI [−2.00, −0.50]). When evaluated one item at a time, no item achieved a false discovery rate below 0.05 in either analysis set (Supplementary Table S4).

Supplementary Table S2 also gives, for each item, the absolute difference between the proportions of patients and family members who select it. Summed over the 24 items, this was 203.4 percentage points at T1 and 216.3 at T2 (a mean of 8.5 and 9.0 per item), narrowing on 13 items and widening on 11.

Supplementary Table S5 gives an exploratory comparison by the onset of a family conversation. Of the 63 main analysis dyads in which the family reported no discussion at T1, 26 reported

having discussed the patient's wishes by T2, and 37 did not. The change in the number of discordant items did not differ significantly between the two groups (Mann–Whitney p=0.089; rank-biserial correlation -0.253). In the confirmation analysis, the corresponding groups numbered 24 and 33, and that comparison was likewise not significant (p=0.091; rank-biserial −0.264). The number of items the patient changed was the same in both groups, with a median of 4 items in each group. That comparison gave p=0.476 in the main analysis and p=0.843 in the confirmation analysis.

Supplementary Table S6 gives the changes by interval disease-worsening event. An interval event occurred in 11 of the 284 patients: 8 of the 32 patients with stage IV or recurrent disease at the first survey and 3 of the other 252. The median number of items a patient changed was 3.0 [3.0, 6.0] among the 11 with an event and 4.0 [3.0, 6.0] among the 273 without one. Among the main-analysis dyads, the median change in the number of discordant items was −0.5 [−1.0, 2.2] for the 6 dyads in which the patient had an event. It was −1.0 [−3.0, 2.0] in the other 158. No test was applied.

Discussion

Over about 16 months, engagement in ACP increased: more patients had asked someone to speak on their behalf, and more families reported a discussion with the patient, though the shift across the three answer categories was not significant. Patients' own answers moved in one direction. They selected more of the values offered, above all, comfort and not burdening others, and fewer wished for maximal treatment, while their families' predictions moved in no overall direction. Agreement within dyads rose modestly, by about one item in 24.

Changes in patients' end-of-life preferences over time are well documented; a systematic review found that a substantial minority of patients change their preferences [9]. Among seriously ill

older adults, treatment burden and the prospect of surviving with impairment weighed against choosing it [10]. The shift we observed, towards comfort and away from maximal treatment, is consistent with patients placing greater weight on that burden during treatment and follow-up. Although disease worsening was uncommon, most patients had early-stage disease (Table 1).

The family side behaved differently. Family members changed about as many answers as patients did, but their changes cancelled out (Supplementary Table S2). This fits what is known about surrogates. They predict patients' treatment preferences with only modest accuracy, and neither designation nor prior discussion improves it [6]. Their predictions tend to follow their own preferences [11], and in a randomised trial, completing and discussing an advance directive did not make them more accurate [12]. In our earlier analysis, families more often than patients prioritised longevity and continued treatment [8]. Inthe second survey, the picture had not moved, while the patients had.

In our cohort, engagement rose without a structured planning programme. More patients named a surrogate for follow-up, yet the family's account of the patient did not reflect the patient's changing views. Dyads that began a family discussion showed a somewhat larger improvement in agreement, but with 26 and 37 dyads, the difference was not significant ($p=0.089$; Supplementary Table S5). Our findings suggest that prompting engagement alone, without revisiting the family's beliefs, may not keep the family's picture current.

The modest gain in agreement occurred within dyads, not from patients and families converging as a group. The difference between the proportions of patients and of family members selecting each item did not narrow (Supplementary Table S2). Both sides changed many answers, which made and broke matches, and on balance, more dyads ended closer than further apart (Table 4).

Only the patients' answers moved in a consistent direction, so the gain most likely came from patients' answers shifting towards what their families had already predicted.

For clinicians in breast cancer follow-up, the practical question is whose answer to trust, and when. For most patients here, the decisions that are still to be planned lie ahead. In Japan, families commonly take a central part in those decisions [4, 5]. Our findings suggest that once a family forms an impression of what the patient wants, it tends to stay fixed even as the patient's own views change. When revisiting care planning, clinicians should ask the patient again, ask the family what they now believe the patient wants, and compare the two. The fact that patients' values shifted within a year while their families' predictions did not shows that preferences are not static. As survival lengthens, advance care planning is better understood as a repeatable process that begins at diagnosis than as something reserved for the terminal phase. In settings where practice ties it to that phase, with high patient volumes, short stays, and death-associated framing, starting earlier and focusing on how patients wish to live may lower the barrier.

Limitations

This single-centre study enrolled mostly early-stage patients, so change may differ where the disease is more advanced. Of the baseline cohort, 40% did not respond at the second survey, and those retained more often wished for maximal treatment at baseline, so the size of that fall may not generalise. Respondents were briefly told the first survey's findings before the second survey and completed the questionnaire at home over the following days, so the patients' change may reflect participation in the first survey, the explanation at the second survey, or discussion in the interval, which this design cannot separate. Families received the same information, yet their predictions did not change, and the exploratory analyses did not identify the driver of the shift from discordance to concordance. A blank could not be told apart from a deliberate non-

selection, and answers changed often on both sides, so item-level results carry noise; more complete answering would add to the rises in individual items but not to the fall in the wish for maximal treatment. The answering family member could vary across surveys, but a confirmation analysis restricted to the same member yielded the same results. Change was measured once, over 273 to 664 days, so its course is unknown, and too few patients had disease worsening to show whether it drives change.

Conclusion

At one Japanese breast cancer centre, more patients named someone to speak for them for about 16 months. Patients' own end-of-life values shifted toward comfort and away from maximal treatment, whereas their families' predictions of those values did not. Agreement within dyads rose slightly, but on maximal treatment, the two answers still differed in about one dyad in three. Clinicians revisiting ACP should ask both the patient and the family again and compare their answers, above all on treatment intensity.

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Compliance with ethical standards

Ethical approval. The study was approved by the Institutional Review Board of Jyoban Hospital of Tokiwa Foundation (JHTF-2024-016) and was conducted in accordance with the ethical standards of the 1964 Declaration of Helsinki and its later amendments.

Informed consent. Completion of the questionnaire constituted consent; patients could complete it in the clinic or at home, and family assistance was permitted when needed.

Conflict of interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Akihiko Ozaki reports a relationship with MNES that includes consulting or advisory; and relationships with Kyowa Kirin Inc, Becton Dickinson and Company, Pfizer, Daiichi Sankyo Inc, and Taiho Pharmaceutical Co Ltd that include speaking and lecture fees. The remaining authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Author contributions

Akihiko Ozaki: Conceptualization, Data curation, Methodology, Project administration, Supervision, Writing - review & editing. Akemi Hara: Conceptualization, Formal analysis, Investigation, Methodology, Writing - original draft. Kazunoshin Tachibana: Conceptualization, Writing - review & editing. Ayu Ajitomi: Conceptualization, Data curation, Investigation, Methodology, Writing - original draft. Yoshitake Takebayashi: Conceptualization, Investigation, Methodology, Writing - review & editing. Michio Murakami: Conceptualization, Investigation, Methodology, Supervision, Writing - review & editing. Kenji Gonda: Conceptualization, Writing - review & editing. Masahiro Wada: Conceptualization, Writing - review & editing. Mika Nashimoto: Conceptualization, Writing - review & editing. Rui Omori: Conceptualization, Writing - review & editing. Megumi Arai: Conceptualization, Writing - review & editing. Kayoko Konuma: Conceptualization, Writing - review & editing. Yudai Kaneda: Conceptualization, Writing - review & editing. Toyoaki Sawano: Conceptualization, Writing - review & editing. Yoshiaki Kanemoto: Conceptualization, Writing - review & editing. Hirotomo Miyatake: Conceptualization, Writing - review & editing. Tomohiro Kurokawa: Conceptualization, Writing - review & editing. Yukiko Kouchi: Conceptualization, Writing -

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Data availability

The de-identified data supporting the findings of this study are available from the corresponding author on reasonable request, subject to institutional and ethical constraints.

Use of artificial intelligence

Large language model-based tools were used to help draft and edit the text and to help write the R code for the analyses and figures. No AI-generated images are included. All analyses, results, and wording were checked and approved by the authors, who take full responsibility for the content.

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Table 1 First-survey characteristics, by whether the patient responded at the second survey*

Characteristic	Responders (n = 284)	Non-responders (n = 186)	p**	SMD***
Demographics and follow-up	—	—	—	—
Age at T1, years	61.0 [52.0, 72.0]	63.5 [51.2, 76.0]	0.148	−0.12
Interval between the two responses, days†	502 [450, 544]	—	—	—
Clinical stage‡	—	—	0.568	—
Stage 0	15 (5.3%)	17 (9.1%)	—	−0.15
Stage I	131 (46.1%)	78 (41.9%)	—	0.09
Stage II	97 (34.2%)	64 (34.4%)	—	−0.01
Stage III	14 (4.9%)	11 (5.9%)	—	−0.04
Stage IV	18 (6.3%)	9 (4.8%)	—	0.07
Other or indeterminate	1 (0.4%)	1 (0.5%)	—	−0.03
Not recorded§	8 (2.8%)	6 (3.2%)	0.799	−0.02
ACP engagement	—	—	—	—
Had asked someone to speak on their behalf¶	125 (44.3%)	75 (40.5%)	0.419	0.08
Values and preferences	—	—	—	—
Enjoyment/purpose in life	203 (71.5%)	130 (69.9%)	0.711	0.04
Fulfilling roles at work/home	155 (54.6%)	103 (55.4%)	0.865	−0.02
Time with family and friends	202 (71.1%)	128 (68.8%)	0.592	0.05
Independence in daily activities	245 (86.3%)	156 (83.9%)	0.473	0.07
Living as long as possible	111 (39.1%)	59 (31.7%)	0.104	0.15
Being supported by faith	17 (6.0%)	10 (5.4%)	0.781	0.03
Freedom from financial worry	160 (56.3%)	87 (46.8%)	0.042	0.19
Receiving maximal treatment¶	147 (51.8%)	71 (38.4%)	0.005	0.27
Being treated as a person	127 (44.7%)	91 (48.9%)	0.371	−0.08
Not being a nuisance to others	205 (72.2%)	134 (72.0%)	0.974	0.00
Not burdening family	222 (78.2%)	136 (73.1%)	0.209	0.12
Not showing a weakened self	63 (22.2%)	39 (21.0%)	0.755	0.03
Conveying what matters to loved ones	152 (53.5%)	94 (50.5%)	0.527	0.06
Freedom from pain and suffering	191 (67.3%)	126 (67.7%)	0.912	−0.01
Knowing in detail what lies ahead	228 (80.3%)	129 (69.4%)	0.007	0.25
Not being told what lies ahead	12 (4.2%)	10 (5.4%)	0.563	−0.05
Sufficient treatment until satisfied	89 (31.3%)	51 (27.4%)	0.364	0.09
Minimal treatment, staying as usual	157 (55.3%)	104 (55.9%)	0.893	−0.01
Less suffering even if death hastened	202 (71.1%)	127 (68.3%)	0.510	0.06
Continuing preferred lifestyle habits¶	49 (17.3%)	27 (14.6%)	0.435	0.07
Entrusting to a trusted physician	176 (62.0%)	101 (54.3%)	0.098	0.16
Treatment in hospital¶	100 (35.3%)	50 (26.9%)	0.055	0.18
Treatment in a facility	13 (4.6%)	4 (2.2%)	0.168	0.14
Treatment at home	54 (19.0%)	45 (24.2%)	0.178	−0.13

* Values are median [first quartile, third quartile] or n (%). T1 is the first survey and T2 is the second. — means not applicable.

** p from the Mann–Whitney U test for age, and from the chi-square test, or Fisher's exact test, where an expected count fell below 5, for categorical variables.

*** SMD, standardised mean difference, calculated for each category against all the other categories combined.

† Range 273 to 664 days. Shown for responders only, because non-responders have no second response.

‡ p from Fisher's exact test across the six recorded stage categories, used because an expected count fell below 5. The patients whose stage was not recorded were excluded from that test and compared separately.

§ p from the chi-square test comparing patients whose stage was not recorded against the rest.

¶ The denominator differs from the column total because some patients left the item blank: designated a surrogate 282 and 185, receiving maximal treatment 284 and 185, continuing preferred lifestyle habits 283 and 185, and treatment in hospital 283 and 186. Supplementary Table S1 gives every denominator.

Table 2 Change in the two advance care planning behaviours between the two surveys*

(a) Both behaviours

Behaviour	n**	T1, n (%)	T2, n (%)	Newly reported	No longer reported	Risk difference, percentage points [95% CI]	p***
Patient had asked someone to speak on their behalf	282	125 (44.3%)	154 (54.6%)	64	35	+10.3 [+3.5, +17.1]	0.005
Family had discussed the patient's wishes†	143	77 (53.8%)	93 (65.0%)	29	13	+11.2 [+2.5, +19.9]	0.069

(b) Transitions in the family discussion item

T1 answer	Have discussed, at T2	Have not discussed, at T2	Do not wish to discuss, at T2	Total
Have discussed	64	12	1	77
Have not discussed	27	36	0	63
Do not wish to discuss	2	1	0	3
Total	93	49	1	143

* ACP, advance care planning. T1 is the first survey and T2 is the second.

** n is the number answering the item at both timepoints.

*** p from the McNemar test for the patient item and from the Bowker test of symmetry across the three categories for the family item.

† The risk difference compares "have discussed" with the other two answers combined. Panel (b) gives the transitions across the three categories on which the Bowker test was run. All families who answered the item at both surveys are included, whether or not the patient responded at the second survey: 137 of the 143 are dyads in the main analysis, and 6 are families whose patient did not respond at T2.

Table 3 Change in each of the 24 patient items between the two surveys*

Category	Preference item	T1, n (%)**	T2, n (%)**	Newly selected	No longer selected	Risk difference, percentage points [95% CI]	McNemar p	BH q***
Values	Enjoyment / purpose in life	203 (71.5%)	198 (69.7%)	25	30	−1.8 [−6.9, +3.4]	0.590	0.745
Values	Fulfilling roles at work/home	155 (54.6%)	155 (54.6%)	33	33	0.0 [−5.6, +5.6]	1.000	1.000
Values	Time with family and friends	202 (71.1%)	210 (73.9%)	32	24	+2.8 [−2.3, +8.0]	0.350	0.599
Values	Independence in daily activities	245 (86.3%)	256 (90.1%)	25	14	+3.9 [−0.4, +8.2]	0.109	0.262
Values	Living as long as possible	111 (39.1%)	106 (37.3%)	24	29	−1.8 [−6.8, +3.3]	0.583	0.745
Values	Being supported by faith	17 (6.0%)	18 (6.3%)	7	6	+0.4 [−2.1, +2.8]	1.000	1.000
Values	Freedom from financial worry	160 (56.3%)	172 (60.6%)	44	32	+4.2 [−1.8, +10.2]	0.207	0.452
Values	Receiving maximal treatment	147 (51.8%)	123 (43.3%)	18	42	−8.5 [−13.7, −3.2]	0.003	0.017
Values	Being treated as a person	127 (44.7%)	145 (51.1%)	36	18	+6.3 [+1.3, +11.4]	0.021	0.062
Values	Not being a nuisance to others	205 (72.2%)	228 (80.3%)	40	17	+8.1 [+3.0, +13.2]	0.004	0.017
Values	Not burdening family	222 (78.2%)	243 (85.6%)	33	12	+7.4 [+2.8, +11.9]	0.003	0.017
Values	Not showing a weakened self	63 (22.2%)	71 (25.0%)	26	18	+2.8 [−1.7, +7.4]	0.291	0.583
Values	Conveying what matters to loved ones	152 (53.5%)	166 (58.5%)	39	25	+4.9 [−0.6, +10.4]	0.104	0.262
Values	Freedom from pain and suffering	191 (67.3%)	215 (75.7%)	41	17	+8.5 [+3.3, +13.6]	0.003	0.017
Care	Knowing in detail what lies ahead	228 (80.3%)	231 (81.3%)	26	23	+1.1 [−3.8, +5.9]	0.775	0.930
Care	Not being told what lies ahead	12 (4.2%)	16 (5.6%)	10	6	+1.4 [−1.3, +4.2]	0.453	0.680
Care	Sufficient treatment until satisfied	89 (31.3%)	89 (31.3%)	28	28	0.0 [−5.2, +5.2]	1.000	1.000
Care	Minimal treatment, staying as usual	157 (55.3%)	180 (63.4%)	48	25	+8.1 [+2.3, +13.9]	0.010	0.040
Care	Less suffering, even if death hastened	202 (71.1%)	227 (79.9%)	43	18	+8.8 [+3.5, +14.1]	0.002	0.017
Care	Continuing preferred lifestyle habits	49 (17.3%)	48 (17.0%)	26	27	−0.4 [−5.4, +4.7]	1.000	1.000
Place	Entrusting to a trusted physician	176 (62.0%)	170 (59.9%)	30	36	−2.1 [−7.7, +3.5]	0.538	0.745
Place	Treatment in the hospital	100 (35.3%)	108 (38.2%)	38	30	+2.8 [−2.9, +8.5]	0.396	0.634
Place	Treatment in a facility	13 (4.6%)	27 (9.5%)	21	7	+4.9 [+1.3, +8.5]	0.014	0.048
Place	Treatment at home	54 (19.0%)	62 (21.8%)	29	21	+2.8 [−2.1, +7.7]	0.322	0.595
	All 24 items combined†	3,280 (11.55 per patient)	3,464 (12.20 per patient)	722	538	—	<0.001	—

* All 284 patients who responded at both timepoints. Items are listed in questionnaire order. The Category column groups each item as a value (14 items), a care preference (6 items), or a preference regarding place of treatment (4 items), as defined in the Methods. T1 is the first survey and T2 is the second. — means not applicable.

** The denominator is the number of patients who answered the item at both time points, which is 284 for every item except treatment in hospital and continuing preferred lifestyle habits, for which it is 283. Supplementary Table S1 gives every denominator.

*** BH q, Benjamini–Hochberg false discovery rate across the 24 items.

† Counts of selections rather than of patients, summed over the items each patient answered at both timepoints. The p value is from a binomial test of the newly selected count against the no longer selected count.

Table 4 Change in patient–family disagreement between the two surveys*

Analysis set	n	T1, median [Q1, Q3]**	T2, median [Q1, Q3]**	T1, mean	T2, mean	Hodges–Lehmann change [95% CI]***	Rank-biserial correlation†	Dyads in which the number fell / did not change / rose	p‡
Main analysis	164	8 [5, 10]	6 [4, 9]	7.77	6.67	−1.00 [−2.00, −0.50]	+0.296	84 / 17 / 63	0.002
Confirmation analysis	154	8 [5, 10]	6 [4, 9]	7.89	6.68	−1.00 [−2.00, −0.50]	+0.298	80 / 15 / 59	0.002

* The measure is the number of the 24 items on which the patient's answer and the family member's answer differed, from 0 to 24; a lower value means closer agreement. The main analysis does not require the same family member at both timepoints; the confirmation analysis does. T1 is the first survey, and T2 is the second.

** Q1 and Q3 are the first and third quartiles.

*** Hodges–Lehmann estimate with 95% confidence interval from the Wilcoxon signed-rank test, normal approximation with correction for ties. A negative value means fewer items in disagreement at T2.

† Matched-pairs rank-biserial correlation. A positive value means a shift towards fewer items in disagreement.

‡ p from the Wilcoxon signed-rank test.

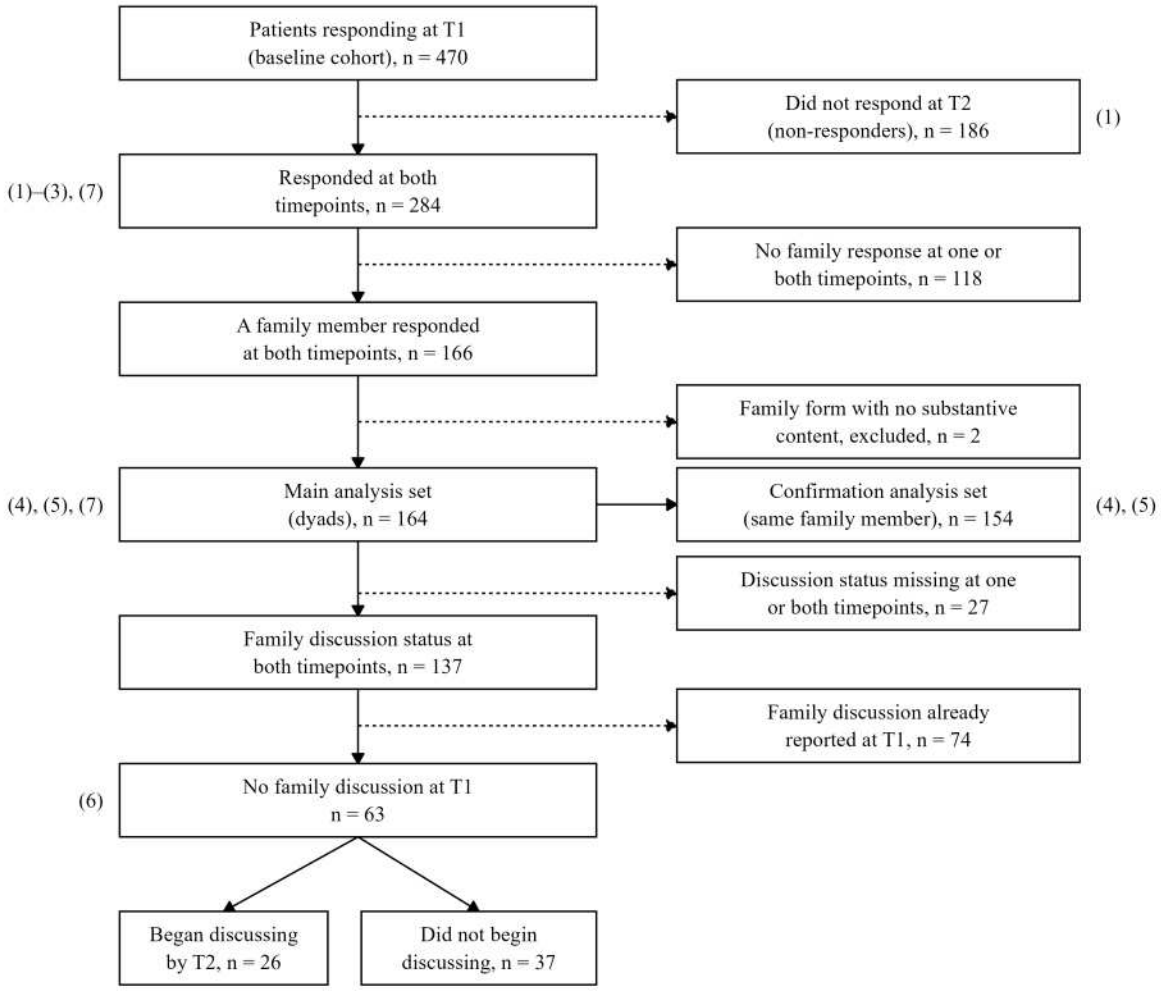


Fig. 1 Selection of the analysis sets*

* Patients who answered the first survey (T1) form the baseline cohort. Those who also answered the second survey (T2) form the set used for the patient analyses. Dyads in which a family member answered at both timepoints form the main analysis set, and dyads in which the same family member answered at both form the confirmation analysis set. Solid arrows follow the sets carried forward; broken arrows show the patients or dyads leaving at each step. The numbers beside a box are the stages of the Statistical analysis in Methods that use that set. Stage (2) used all 143 families who answered the discussion item at both surveys, including 6 whose patient did not respond at T2, and is therefore not shown as a single box.

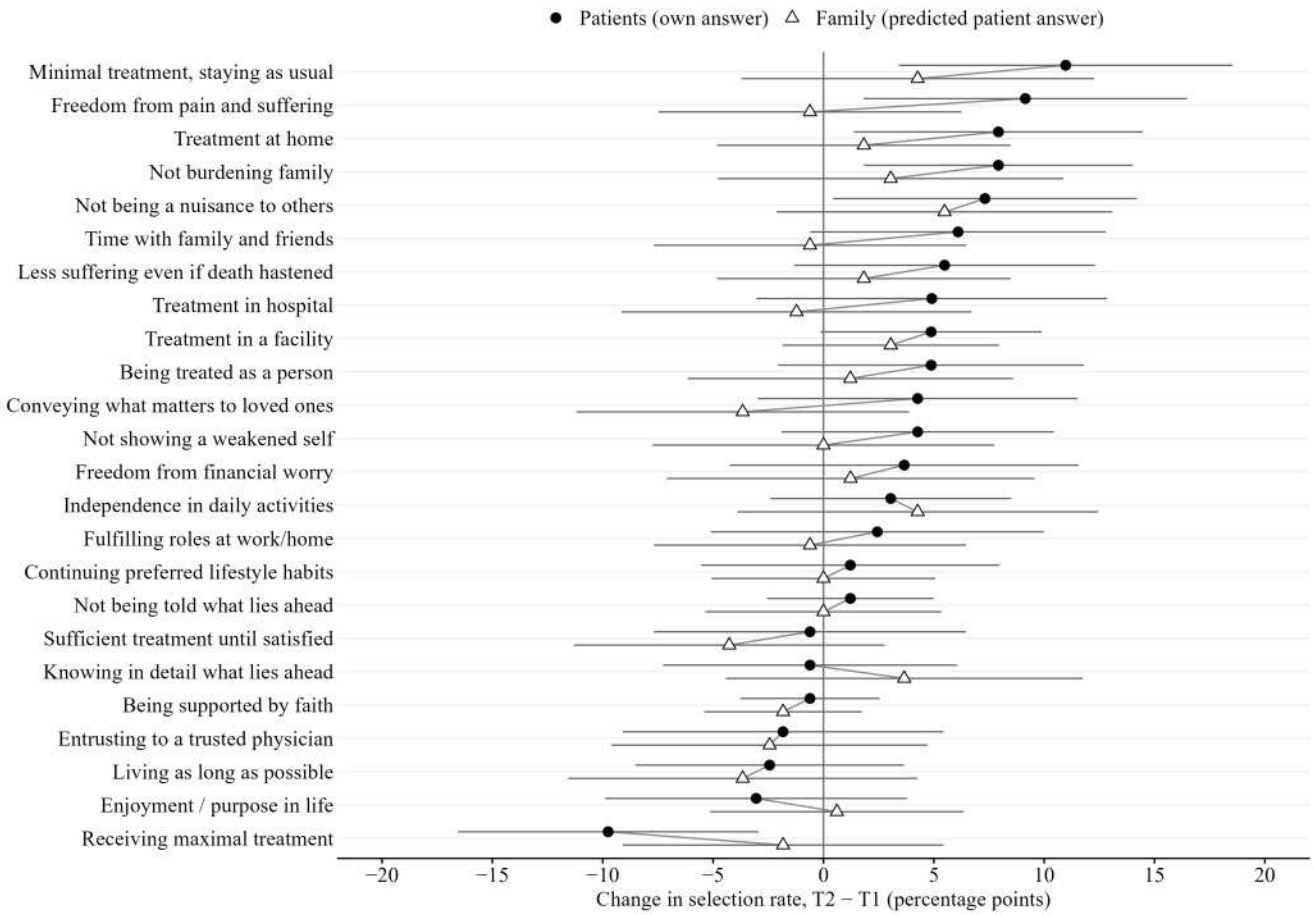


Fig. 2 Change in the selection of each of the 24 items between the two surveys, for patients' own answers and for the family members' predictions of the patient's answers*

* Both sides are the 164 dyads in the main analysis. Each point is the change in the percentage selecting the item between the first survey (T1) and the second (T2), in percentage points, and the horizontal line through it is the 95% confidence interval. Filled circles are the patients' own answers and open triangles the family members' predictions of what the patient would answer; a grey line joins the two sides of the same item. Items are ordered by the patients' change. A value above zero means the item was selected more often at T2. The numbers behind the figure are in Supplementary Table S2.

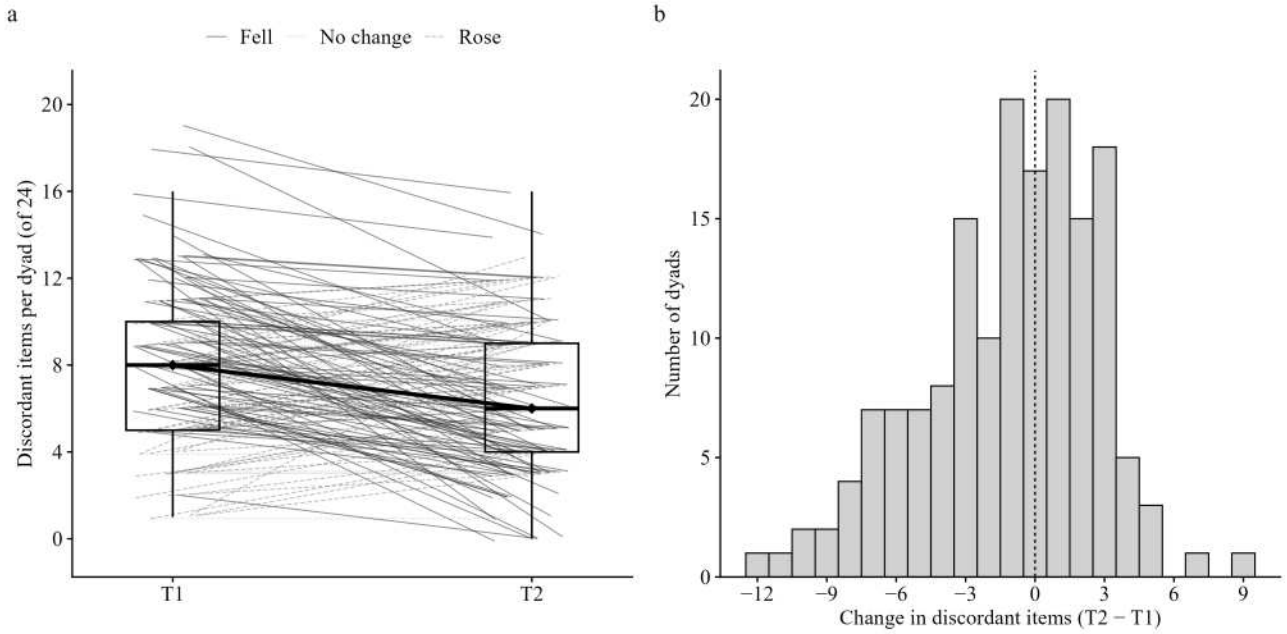


Fig. 3 Change in the number of items on which the patient and the family member disagreed*

* The 164 dyads of the main analysis, between the first survey (T1) and the second (T2). The measure runs from 0 to 24 items; a lower value means closer agreement. In (a) each faint line is one dyad: solid where the number of items in disagreement fell, dotted where it did not change, dashed where it rose. Points are offset slightly so that overlapping dyads stay visible. The box plots show the median and the quartiles at each timepoint, and the bold line joins the two medians, which fell from 8 to 6. In (b) the bars give the distribution of the change. The number of items in disagreement fell in 84 dyads, did not change in 17 and rose in 63. The Hodges–Lehmann change was −1.00 items (95% CI [−2.00, −0.50]), from the Wilcoxon signed-rank test, normal approximation with correction for ties.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Supplementaryv2920261017.docx