Palliative chemotherapy or best supportive care? A prospective study explaining patients’ treatment preference and choice

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In palliative cancer treatment, the choice between palliative chemotherapy and best supportive care may be difficult. In the decision-making process, giving information as well as patients’ values and preferences become important issues. Patients, however, may have a treatment preference before they even meet their medical oncologist. An insight into the patient’s decision-making process can support clinicians having to inform their patients. Patients (n=207) with metastatic cancer, aged 18 years or older, able to speak Dutch, for whom palliative chemotherapy was a treatment option, were eligible for the study. We assessed the following before they consulted their medical oncologist: (1) socio-demographic characteristics, (2) disease-related variables, (3) quality-of-life indices, (4) attitudes and (5) preferences for treatment, information and participation in decision-making. The actual treatment decision, assessed after it had been made, was the main study outcome. Of 207 eligible patients, 140 patients (68%) participated in the study. At baseline, 68% preferred to undergo chemotherapy rather than wait watchfully. Eventually, 78% chose chemotherapy. Treatment preference (odds ratio (OR) = 10.3, confidence interval (CI) 2.8–38.0) and a deferring style of decision-making (OR = 4.9, CI 1.4–17.2) best predicted the actual treatment choice. Treatment preference (total explained variance = 38.2%) was predicted, in turn, by patients’ striving for length of life (29.5%), less striving for quality of life (6.1%) and experienced control over the cause of disease (2.6%). Patients’ actual treatment choice was most strongly predicted by their preconsultation treatment preference. Since treatment preference is positively explained by striving for length of life, and negatively by striving for quality of life, it is questionable whether the purpose of palliative treatment is made clear. This, paradoxically, emphasises the need for further attention to the process of information giving and shared decision-making.

Keywords: palliative chemotherapy; best supportive care; decision-making; treatment preference; treatment choice

Eventually, almost 50% of cancer patients will have metastatic disease (Dutch Cancer Foundation, 1999). Still, making treatment decisions in palliative cancer treatment is a complex task for patients as well as physicians. This is particularly true because there is no evident ‘best’ option. This paper reports a prospective study on patients having to make a choice between palliative chemotherapy and best supportive care. Palliative chemotherapy aims at the alleviation of symptoms or postponing future symptoms of the disease and thus maintaining or enhancing quality of life. Survival gains, if present, are modest. For an individual patient, it is uncertain whether symptom alleviation or survival gain can be achieved while side effects are likely to occur. Best supportive care is the alternative option and aims at enhancing quality of life by the relief of symptoms once they occur. At the same time, limited survival gain, even a few extra months, may be important from the patient’s perspective.

Whether a patient with metastatic cancer should be treated with palliative chemotherapy or choose best supportive care is therefore not always evident. Clinically seen, individual patients may benefit from palliative chemotherapy. However, contradicting evidence can be found in the literature on the effects of chemotherapy on the quality of life. There are studies in which chemotherapy appears to enhance patients’ quality of life (Thatcher et al, 1997; Stockler et al, 1998; Tannock, 1998; Geels et al, 2000; Doyle et al, 2001). Ramirez et al (1998) found that only 25% of the patients benefited from chemotherapy in her study, and there are several studies in which no improvement or even deterioration of quality of life was reported (Quintin et al, 2000; van Andel et al, 2000; Barras et al, 2001; Schiller et al, 2001). Values of patients thus become more important. Knowledge of the factors upon which patients’ preferences or the patients’ actual choice are based is necessary in guiding the patient through the decision-making process.

Four factors influencing cancer patients’ treatment choice have been distinguished by Richards et al (1995): patients’ attitudes and beliefs, doctors’ attitudes, the way information is presented and the nature of the risk and benefit involved in the different treatment options. Patients’ attitudes and beliefs are thought to be based on
To understand the decision-making process in palliative chemotherapy, we investigated the actual treatment choice of patients with metastatic cancer. Owing to its indicative value, we prospectively studied their strength of preference for palliative chemotherapy or best supportive care in cancer patients before they consulted their medical oncologist. Finally, we investigated whether this treatment preference, patient or disease characteristics, quality of life, attitudes or preference for information and participation in decision-making were predictive of the actual treatment choice.

Our conceptual model is presented in Figure 1.

PATIENTS AND METHODS

This prospective study took place between June 1998 and April 2000. Patients with various types of metastatic cancer, aged above 18 years, able to understand and speak Dutch, referred because palliative chemotherapy had become a treatment option were eligible for the study. The patients were approached as soon as an appointment with their medical oncologist was scheduled. After informed consent was given, an appointment was made for an interview prior to the first consultation with their medical oncologist. After the decision concerning palliative chemotherapy or best supportive care had been made, the treatment choice was checked. To facilitate participation, the interview was held at the patient’s home.

Medical oncologists (n = 37) from three academic and seven nonacademic hospitals participated in the study. They completed a disease-related checklist for each patient after they had seen the patient during consultation. The oncologist informed the researchers about the treatment decision as soon as it was made. This was checked with the patient within 3 weeks. Ethical approval was obtained from the ethics committee of each participating hospital.

Measures

Dependent variables For ethical reasons, we did not want to interfere with the expectations or knowledge of patients before the consultation took place. Therefore, we first asked them in an open-ended question as to what treatment they expected their physician would propose in the upcoming consultation. Next, the strength of preference for chemotherapy was assessed in those patients who expected their medical oncologist to propose chemotherapy as one of the options with a single question on a seven-point Likert scale (‘strong aversion to chemotherapy’ to ‘strong preference for chemotherapy’). If a patient did not mention chemotherapy, the part of the questionnaire concerning chemotherapy was skipped.

Patients’ choices were assessed, as described, after the actual decision was made.

Predictor variables The independent variables, that is (1) socio-demographic patient characteristics, (2) disease-related variables, (3) quality-of-life indices and (4) attitudes were assessed at baseline (1, 3, 4) or obtained from the oncologist (2).

Demographic variables included gender, age, marital status, having children and educational level. Disease-related variables comprised type of cancer and performance status, the Karnofsky index (Karnofsky and Burchenal, 1949)

Quality of life was measured with the Rotterdam Symptom Checklist (RSCL) (de Haes et al, 1990). The RSCL is a validated, cancer-specific questionnaire and covers physical distress (22 items, Cronbach’s ɑ = 0.80 in the present study), psychological distress (eight items, ɑ = 0.89) and the daily activity level (eight items, ADL; ɑ = 0.86). The item scores range from 1 to 4. Sum scores were transformed to the same scale. Low scores on the physical and psychological distress scale reflect a better quality of

![Figure 1 Conceptual model (explanatory variables, intermediate variable and outcome variable).](image-url)
life, whereas low scores on the activity level scale indicate a worse quality of life.

Several attitudes were assessed. The Cancer Locus of Control Scale (CLOC) covers the attitude of patients towards the origin and the course of their illness (Pruyn et al, 1988; Watson et al, 1990). It consists of three subscales: internal control over the disease process ($\chi = 0.74$), internal control over the cause of the disease ($\chi = 0.64$) and religious control ($\chi = 0.88$). Item scores range from 1 to 4, a higher score indicating a higher level of control.

The patient’s decision style was assessed with The Michigan Assessment of Decision Style (MADS) (Pierce, 1993, 1995). The MADS is developed for decision-making in early-stage breast cancer, and validated. It was translated into Dutch for the current study by two bilingual individuals, using a forward–backward translation procedure. It covers: (1) avoidance (four items, e.g. ‘I prefer not knowing the possibility that unexpected things could happen to me’, $\chi = 0.55$); (2) deferring responsibility (three items, e.g. ‘I would follow the recommendations of my physician’, $\chi = 0.66$); (3) information seeking (four items, e.g. ‘I would spend as much time as I could gathering information’, $\chi = 0.83$); and (4) deliberation (five items, e.g. ‘I would carefully consider the risks of each option as I was making a choice’, $\chi = 0.73$). The scale scores were linearly converted to a 0–100 scale, with higher scores indicating a higher level of avoidance, deferring of responsibility, information seeking and deliberation.

Patients’ attitudes towards striving for length (quantity) (four items, $\chi = 0.75$) or quality of life (four items, $\chi = 0.69$) were assessed by the ‘QQ-Questionnaire’ (QQQ) (Stiggelbout et al, 1996). High scores on the quantity or quality scale indicate the importance of length and quality of life, respectively.

Preference for information was measured using a 10-point rating scale, ranging from score 1 (wanting as little information as possible) to score 10 (wanting all the information there is) (Blanchard et al, 1988). Patients’ preference for participation in decision-making was assessed on a five-point rating scale ranging from score 1 (wanting as little information as possible) to score 10 (wanting all the information there is) (Sutherland et al, 1989; Degner and Sloan, 1992).

Statistical analyses

Univariate associations between baseline preference for treatment and demographic characteristics, disease-related factors, quality of life and attitudes were established with Pearson’s product moment correlations and point biserial correlation coefficients.

Significant predictors of treatment preference (with $P$ set at <0.25) identified from the univariate analyses were then entered into a multiple linear regression analysis, with a forward selection strategy, using the F-statistic with $P = 0.05$ as the criterion level for selection in the multivariate analyses.

Possible predictors of treatment choice were analysed with the $\chi^2$ statistic and expressed in crude relative risk (RR) estimates with their 95% confidence intervals (CI). Continuous variables were dichotomised by using the median split method. For baseline treatment preference, however, a content-related split was made (either having or not having a preference for chemotherapy). Due to skewness, the preference for information scale scores were recoded as ‘do not prefer as many details as possible’ (1–9), and ‘prefer as many details as possible’ (10). Additionally, all variables univariately associated with treatment choice ($P$-value set at <0.25) were entered in a logistic regression model to assess their independent prognostic value for treatment choice. Effect sizes were expressed in odds ratios (ORs) (with their 95% CI). Calibration of the regression model was assessed with the Hosmer–Lemeshow goodness-of-fit test. In this test, a high $P$-value indicates that the model is acceptable. All analyses were performed in SPSS (version 10.0.7).

RESULTS

Patients

Of 242 patients, recruited over a 2-year period, 35 patients were not eligible because they were treated with curative intent or were not offered the choice of palliative chemotherapy. Of the remaining 207 patients, 140 patients were interviewed (68% response). Reasons for not willing to participate at baseline were as follows:

| Table 1 | Patient characteristics (n = 140)* |
|---------|----------------------------------|
| **N** | **%** |
| **Socio-demographic** | | |
| Gender | | |
| Male | 85 | 61 |
| Female | 55 | 39 |
| Age (years) | | |
| 26–50 | 27 | 19 |
| 51–60 | 40 | 29 |
| 61–70 | 45 | 32 |
| 71–82 | 28 | 20 |
| Children | | |
| Yes | 119 | 85 |
| No | 21 | 15 |
| Education | | |
| Primary school | 30 | 22 |
| High school | 81 | 58 |
| College or higher | 28 | 20 |
| **Disease-related** | | |
| Type of cancer | | |
| Breast cancer | 14 | 10 |
| Head and neck cancer | 22 | 16 |
| Gastric-intestinal cancer (sum) | 68 | 49 |
| Stomach | 7 | 5 |
| Colon | 28 | 20 |
| Pancreatic | 9 | 6 |
| Rectum | 14 | 10 |
| Non-small-cell lung cancer | 9 | 6 |
| Other | 27 | 19 |
| Performance status | | |
| 100 | 53 | 39 |
| 90 | 48 | 35 |
| 80 | 23 | 17 |
| 70 | 9 | 7 |
| 60 | 3 | 2 |
| **Quality of life** | | |
| Physical distress | M = 1.50; s.d. = 0.34 |
| Psychological distress | M = 1.74; s.d. = 0.64 |
| ADL activity level | M = 3.70; s.d. = 0.52 |
| **Attitudes** | | |
| Locus of control | | |
| Disease process | M = 3.18; s.d. = 0.60 |
| Cause of the disease | M = 1.80; s.d. = 0.54 |
| Religious | M = 2.13; s.d. = 1.16 |
| Decision-making style | | |
| Information seeking | M = 2.66; s.d. = 0.93 |
| Deliberation | M = 3.98; s.d. = 0.56 |
| Avoidance | M = 2.43; s.d. = 0.65 |
| Deferring | M = 3.98; s.d. = 0.58 |
| Striving for length of life | M = 3.35; s.d. = 1.13 |
| Striving for quality of life | M = 3.74; s.d. = 0.99 |
| Preference for information | M = 8.91; s.d. = 1.99 |
| Preference for participation | M = 3.07; s.d. = 0.79 |

*Due to missing values, the numbers do not always add to 140. s.d. = standard deviation.
poor physical condition ($n = 39$), reported psychological distress ($n = 2$), time constraints ($n = 10$) or unspecified ($n = 16$). The actual treatment decision could be confirmed by 131 patients. Nonresponse was due to being too ill ($n = 6$) or death ($n = 3$).

Patient characteristics are presented in Table 1. More than half of the sample was male (61%); the mean age was 60 years (s.d. 11.6).

**Treatment preference and actual choice**

Most patients ($n = 114$; 81%) expected that their medical oncologist would propose chemotherapy. Subsequently their preference for chemotherapy could be assessed. Patients who did not answer that they expected the physician to propose chemotherapy ($N = 26$) were older ($P < 0.01$).

The distribution of the baseline treatment preference is presented in Figure 2. Most patients (68%) favoured chemotherapy at baseline. The majority of these had a very strong preference for chemotherapy. Eventually 78% chose to undergo chemotherapy. In Figure 2 the actual choice is shown, per treatment preference category. The original treatment preference and the eventual treatment choice turned out to be related. Almost all patients who preferred chemotherapy before they visited their medical oncologist chose chemotherapy after they had discussed their treatment. Approximately half of the patients (56%) who had no clear treatment preference before they met with their oncologist chose chemotherapy. Of those who had an aversion towards chemotherapy (7%), almost all chose best supportive care, eventually.

**Explaining treatment preference at baseline**

In Table 2, the relation between preference for chemotherapy and the explanatory variables is presented.

Younger patients had a stronger preference for chemotherapy. Neither other demographic variables nor disease-related or quality-of-life-related variables were significantly related to the patients’ preference for palliative chemotherapy, although some attitudes were. High levels of internal control concerning the disease process, having a stronger deferring decision style, striving for length of life and having a low preference for participating in the decision-making were associated with a stronger preference for chemotherapy. Striving for quality of life was negatively related to the strength of preference for chemotherapy.

Multivariate analyses indicated that patients’ preferences for chemotherapy were best explained by striving for length of life ($\beta = 0.38$, partial $R^2 = 29.5\%$), whereas less striving for quality of life added $6.1\%$ ($\beta = -0.29$) to the explained variance. Feeling internal control concerning the cause of the disease added an additional percentage of $2.6\%$ ($\beta = 0.16$).

**Explaining treatment choice**

In Table 3, the univariate relations between explanatory factors and treatment choice are shown. None of the socio-demographic variables was significantly related to the treatment chosen, nor were disease-related variables and quality of life; however, attitudes were. Having a deferring decision style, striving for more length of life and less for quality, as well as having a strong preference for palliative chemotherapy at baseline were all significantly predictive of an eventual choice for palliative chemotherapy.
Table 3  Relation between patient characteristics and preference for chemotherapy at baseline, and the patients’ actual treatment choice (n = 131)\textsuperscript{a}

| Background factors | Treatment choice (N) | | | | |
|--------------------|----------------------|------|----------------|----------------|------|
|                    | Chemotherapy         | Best supportive care | Crude RR\textsuperscript{b} | 95% CI | P |
| Socio-demographic  |                      |                  |                            |          |    |
| Sex                |                      |                  |                            |          |    |
| Female             | 42                   | 9                | 1.10                       | 0.92–1.31 | 0.32 |
| Male               | 60                   | 20               |                            |          |    |
| Age (years)        |                      |                  |                            |          |    |
| >61                | 46                   | 15               | 0.94                       | 0.78–1.13 | 0.53 |
| ≤61                | 56                   | 14               |                            |          |    |
| Children           |                      |                  |                            |          |    |
| Yes                | 87                   | 25               |                            |          |    |
| No                 | 15                   | 4                |                            |          |    |
| Education          |                      |                  |                            |          |    |
| High               | 26                   | 8                |                            |          |    |
| Low                | 75                   | 21               | 0.98                       | 0.79–1.21 | 0.84 |
| Disease-related    |                      |                  |                            |          |    |
| Type of cancer     |                      |                  |                            |          |    |
| Breast cancer      |                      |                  |                            |          |    |
| Yes                | 12                   | 1                | 1.21                       | 1.00–1.46 | 0.19 |
| No                 | 90                   | 28               |                            |          |    |
| Head/neck cancer   |                      |                  |                            |          |    |
| Yes                | 15                   | 5                | 0.92                       | 0.77–1.11 | 0.39 |
| No                 | 87                   | 24               |                            |          |    |
| Gastric-intestinal cancer (sum) |  |                  |                            |          |    |
| Yes                | 47                   | 16               |                            |          |    |
| No                 | 55                   | 13               |                            |          |    |
| Lung cancer        |                      |                  |                            |          |    |
| Yes                | 8                    | 1                |                            |          |    |
| No                 | 94                   | 28               | 1.15                       | 0.90–1.48 | 0.41 |
| Performance status |                      |                  |                            |          |    |
| ≤90                | 53                   | 21               | 0.84                       | 0.70–1.00 | 0.06 |
| >90                | 48                   | 8                |                            |          |    |
| Quality of life    |                      |                  |                            |          |    |
| Physical distress  |                      |                  |                            |          |    |
| High (>1.47)       | 49                   | 12               |                            |          |    |
| Low (≤1.46)        | 53                   | 17               | 1.06                       | 0.88–1.27 | 0.53 |
| Activity level (ADL)|                  | |    | | |
| High (>3.76)       | 62                   | 15               |                            |          |    |
| Low (≤3.75)        | 40                   | 14               | 1.09                       | 0.90–1.32 | 0.38 |
| Psychological distress |                  | |    | | |
| High (>1.51)       | 49                   | 15               |                            |          |    |
| Low (≥1.50)        | 53                   | 14               | 0.97                       | 0.81–1.16 | 0.73 |
| Attitudes          |                      |                  |                            |          |    |
| Locus of control   |                      |                  |                            |          |    |
| Disease process    |                      |                  |                            |          |    |
| High control (>1.5) | 54                   | 13               |                            |          |    |
| Low control (≤1.5) | 48                   | 15               | 1.06                       | 0.88–1.27 | 0.54 |
| Cause of the disease |                  | |    | | |
| High control (>3.37) | 44                   | 14               |                            |          |    |
| Low control (≤3.37) | 58                   | 15               | 0.95                       | 0.79–1.15 | 0.62 |
| Decision-making style |                  | |    | | |
| Information seeking |                      |                  |                            |          |    |
| High (>2.75)       | 50                   | 17               |                            |          |    |
| Low (<2.75)        | 52                   | 12               | 0.92                       | 0.77–1.10 | 0.36 |
| Deliberation       |                      |                  |                            |          |    |
| High (>4.0)        | 55                   | 19               |                            |          |    |
| Low (<4.0)         | 47                   | 10               | 0.90                       | 0.75–1.08 | 0.27 |
| Avoidance          |                      |                  |                            |          |    |
| High (>2.5)        | 55                   | 18               |                            |          |    |
| Low (<2.5)         | 47                   | 11               | 0.93                       | 0.78–1.11 | 0.44 |
| Deferring          |                      |                  |                            |          |    |
| High (>4.0)        | 41                   | 3                |                            |          |    |
| Low (<4.0)         | 61                   | 26               | 1.33                       | 1.13–1.56 | <0.01 |
| Striving for length of life |          | |    | | |
| Length more important (>3.4) | 5         | 23               |                            |          |    |
| Length less important (≤3.4) | 43                   | 24               | 1.44                       | 1.18–1.74 | <0.001 |
| Striving for quality of life |          | |    | | |
| Quality more important (>3.4) | 45                   | 22               |                            |          |    |
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Table 3 Continued

| Background factors | Treatment choice (N) | Crude RRb | 95% CI | P |
|--------------------|----------------------|-----------|--------|---|
| Quality less important (≤3.4) Preference for information 57 7 0.75 0.62–0.91 <0.01 |
| Strong (10) 69 16 |
| Weak (0–9) 33 13 1.13 0.92–1.39 0.21 |
| Preference for participation Strong (3–5) 89 27 |
| Weak (1, 2) 13 2 0.89 0.71–1.11 0.38 |
| Preference for chemotherapy Preference (1–3) 67 6 |
| No preference (4–7) 15 18 2.02 1.38–2.95 <0.001 |

Table 4 Factors explaining treatment choice (n = 131)

| Background factors | ORb | 95% CI | P |
|--------------------|-----|--------|---|
| Performance status 2.5 0.64–7.55 0.21 |
| Deferring decision style 4.9 1.40–17.18 0.01 |
| Striving for length of life 1.7 0.43–6.96 0.44 |
| Striving for quality of life 1.1 0.29–4.16 0.89 |
| Preference for information 2.5 0.74–8.20 0.14 |
| Preference for chemotherapy 10.3 2.80–37.96 <0.001 |

From Table 4, presenting the multivariate analysis explaining patients’ actual treatment choices, it appears that only ‘baseline preference for chemotherapy’ and ‘a deferring decision style’ explain the eventual treatment choice. Patients with a strong baseline preference for chemotherapy were substantially more likely to choose chemotherapy (OR = 10.3). Patients who had a deferring decision style were also more likely to start chemotherapy (OR = 4.9). The Hosmer–Lemeshow goodness-of-fit statistic (P = 0.73) indicated that the multiple regression model was well calibrated.

DISCUSSION

The most remarkable finding in our study is, in our view, that the patients’ preference for chemotherapy as assessed before they met with their medical oncologist, most strongly predicted their eventual treatment choice. Patients seem to make up their minds about starting or forgoing palliative chemotherapy before they are informed by their medical oncologist and, thus, outside the consultation room. A conclusion therefore must be that what was said during the consultation did not change much of the patient preference and eventual choice.

Another striking finding is that the initial treatment preference was strongly explained by striving for length of life. Oncological consensus is that the expected outcomes of palliative chemotherapy and best supportive care differ little in survival in most tumour types (Glimelius et al, 2001; Ragnhammer et al, 2001). Still, patients chose to be treated with chemotherapy, seemingly clinging to the hope that this chemotherapy would extend their life duration. They may thus not have received some basic information or, alternatively, not have heard it. Alternatively, patients did not want to hear this information or did not believe it and chose palliative chemotherapy, being fully aware of its limited possibilities regarding lengthening of life. Additionally, both a preference for chemotherapy and choosing palliative chemotherapy were negatively associated with striving for quality of life. Bearing in mind the purpose of palliative chemotherapy, the enhancement or maintenance of quality of life (Porzsolt, 1993; Porzsolt and Tannock, 1993), one would expect striving for quality of life to be positively associated with preference and choice for palliative chemotherapy. Therefore, one can question whether the purpose of palliative chemotherapy has been clearly explained to and is understood by all patients.

Of the patients in our study, 68% had a preference for chemotherapy, before they had received information from their medical oncologist about treatment options; 78% of the patients decided to undergo palliative chemotherapy eventually. In other words, in absolute sense the impact of the consultation on the treatment chosen is limited. The relationship between preference for treatment and the actual treatment choice has not been investigated thoroughly (Yellen and Cella, 1995; Jansen et al., 2001). In retrospect, it is less surprising that the treatment preference at baseline is so closely related to the actual treatment choice. For patients and physicians, choosing an active treatment option, that is, palliative chemotherapy, seems obvious. Best supportive care is often perceived as ‘doing nothing’ (Charles et al., 1998). For medical oncologists, the patient’s wish is an important determinant of their own preference for treatment (Charles et al., 1998; Koedoot et al., 2002). Moreover, they also prefer to ‘do something’, that is, offering chemotherapy, rather than offering best supportive care (de Haes and Koedoot, 2003). Thus, patients’ and oncologists’ treatment preferences seem to coincide, making a choice for chemotherapy more likely.

Treatment choice was also predicted by having a deferring style of decision-making. Patients having such decision-making style were more likely to undergo chemotherapy than others. Since medical oncologists, being experts in systemic treatment, want to offer a treatment, and spend more time explaining chemotherapy than explaining best supportive care, they may convey the suggestion that they prefer palliative chemotherapy (Koedoot et al., 1996). It is then likely that a deferrer, who would like to lean on the oncologist’s advice, is inclined to choose chemotherapy. The absence of an association between a deferring decision-making style and baseline preference for chemotherapy is not surprising, since at baseline deferrers are not yet aware of the oncologist’s preference. They have not had an opportunity to defer the decision to their oncologist yet.

Some limitations of our study have to be mentioned. Firstly, there is most likely a referral bias. Patients, who visit a medical oncologist, often have a positive attitude towards treatment already. Indeed, two-thirds of our patients preferred to be treated with palliative chemotherapy before the consultation. Secondly, for
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