

Shared decision-making in breast cancer care: Patient preferences and implications for clinical communication

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Abstract. *Introduction:* A new cancer diagnosis generates a situation of anxiety, fear and worry for both the present and the future. It is a time of loss, during which patients must choose between different possible ways to manage their disease. It is very important to identify patients' preferred roles in the decision-making process, together with the factors that can affect patients' involvement during consultation, so that oncologists can adjust their interpersonal style and communication, providing better patient-centered care. *Methods:* This study is part of a multi-center RCT and involved 308 early-stage breast cancer patients. We evaluated the preferred role and the variables associated with the patients' preferred level of involvement during their first consultation with an oncologist. *Results:* More than half of the subjects preferred a collaborative role and it was the most frequent choice among single and employed women. Patients who preferred a collaborative role asked more questions and had a longer consultation than those who preferred to take a more passive role. *Conclusion:* These results give rise to new research questions on the role that early-stage breast cancer patients would like to play in the decision-making process concerning their treatment, and on the variables that contribute to their attitudes towards such involvement. The findings suggest that oncologists need to interact with and listen to their patients in an active and empathetic manner, in order to acquire a full understanding of their needs.

Key words: breast cancer, patient preference, shared decision making, physician-patient relations, health communication, treatment decision, oncology, patient participation

Introduction

There has been increasing recognition of the importance of patient involvement in health care decision-making over recent decades. Many studies have investigated the preferred roles in decision-making amongst cancer patients, and the possible associated benefits of patient involvement in terms of improving patient satisfaction and health outcomes (1,2). There are three options for cancer patients when it comes to their role in the decision-making process: active (the patient has the final decision on treatment), collaborative (the patient and the doctor jointly decide

on the most appropriate treatment option), or passive (the doctor decides the best treatment option) (3,4). Studies have reported broad variations in cancer patient preferences: some studies have highlighted a trend towards a passive role (5,6), other studies have found a preference for sharing the decision-making process with the oncologist (7), few studies have reported preference for an active role (8,9). In a more recent study, Hahlweg et al. (10) found that the preferences for an active, collaborative, or passive role were equally distributed among cancer patients. Several factors influence the role preference. Younger people with a higher level of education prefer a more active role,

while older people with a lower level of education and socio-economic status are more likely to prefer a passive role (1,6,10-13). However, Yennurajalingam et al. (9) found that a higher level of education was associated with a more passive role, which in turn showed a positive correlation with better clinical characteristics and country of origin (Brazil, Singapore, South Africa and Jordan). Other studies found that the preference for a more active role was associated with poorer health-related quality of life during adjuvant chemotherapy (14), and with a greater demand for information about the disease and treatment (5). Moreover, people who are more inclined to express their emotions are more likely to choose an active role, whereas people with a higher level of emotional repression defense mechanisms prefer a more passive role (6). Role preference is also likely to develop over time, and may change at different stages of illness (15); in the field of oncology, the results are conflicting. Butow et al. (16) found that cancer patients attending their first consultation were more likely to seek greater involvement in decision-making than those attending follow-up. This result was confirmed by a later study that found that patients had the greatest need for information at beginning of treatment, with a decline over the course of treatment (17). In contrast, Degner et al. (18) found that breast cancer patients who were diagnosed less than 6 months previously were less likely to prefer an active role than those who were diagnosed more than 6 months earlier. Yennurajalingam et al. (9) found that in the context of palliative care for patients with advanced cancer, preference for a passive role seemed associated with an accurate perception of the curability of their cancer. A more recent study showed significant differences in patient role preferences according to stage, with the majority of stage 0 and III patients preferring active roles while the majority of stage I and II patients preferred a collaborative role. Few patients at any stage chose a passive decision-making role (19). Further studies are needed to identify the role preferences of cancer patients at different stages of illness, in particular in newly diagnosed breast cancer patients. In fact, a new cancer diagnosis generates a situation of uncertainty, anxiety, fear and worry for both the present and the future. It is a time of loss, during which patients must choose between different possible ways

to manage their disease, with important consequences for their health. This is why it is important to identify the preferred roles of early-stage patients in the decision-making process, and the associated factors, which enables oncologists to adapt their communication style according to the patient's needs and ensure optimal care for each individual cancer patient (20,21). Using patient-centered communication means taking into account not only their emotions, values and needs, but also aiming towards patient empowerment and understanding how involved they wish to be in medical decision making (22,23) concerning them. Several studies showed that patient-centered communication was strongly associated with better patient health outcomes (24,25). The aim of the present study was to evaluate the differences amongst breast cancer patients in terms of preferences towards an active, collaborative or passive role in the treatment decision-making process. The three different groups were compared in terms of the following factors: socio-demographic features; breast cancer characteristics; whether or not the patient was accompanied by a family member; clinical variables such as psychological well-being, anxiety and depression; the perception of the decision-making process during the consultation; length of the consultation; and the number of questions asked by the patient during consultation.

Materials and Methods

Description of the Randomized Controlled Trial (RCT)

This study is part of a multi-center RCT whose main outcome was to evaluate whether a pre-consultation intervention (Question Prompt Sheet-QPS) facilitated greater involvement of early-stage breast cancer patients in the decision-making process by increasing the number of questions made to the oncologist (26). The primary outcome showed that women who received the QPS did not ask more questions compared to women who did not receive QPS (27). The RCT had the additional aims of assessing the effect of the QPS in terms of patient satisfaction, need for information, and to explore the role of accompanying persons. The results of these secondary outcomes are published elsewhere (28-31).

The present study is focused on a further aim of the RCT, which was the assessment of the patients' preferred role in their treatment decision-making process. Cancer patients can take one of three different approaches affecting their involvement and satisfaction, and the health outcomes. There are several factors that affect a patient's preference, and the literature information is not always clear in this regard. Understanding the factors that are important to women when it comes to making decisions about cancer treatment is a mandatory step in designing customized and evidence-based decision support, to be offered by oncologists to women suffering this distressing experience.

Sample and procedure

The study was conducted in three oncology clinics in Northern Italy. Eligible patients were women with breast cancer at their first consultation with the oncologist. The patients had already been diagnosed with cancer, and almost all had already undergone breast surgery. During the first visit, the histological results were discussed, and further medical treatment was decided (e.g., chemotherapy, radiotherapy, etc.). Inclusion criteria were age 18-75 years, recent diagnosis of breast cancer, from stage I to stage III (according to the American Joint Committee of Cancer 7th Edition for Breast Cancer). Exclusion criteria were cognitive impairment and insufficient native language skills to complete the questionnaires. Patients were randomly placed into one of the two intervention groups: QPS and QL. QPS is a list of 50 specific questions that prompt patients to consider new ideas before the consultation and decide what questions they would like to ask during the consultation; QL is a control sheet where participants are asked to write up a list of questions, they would like to ask their oncologist. Before the consultation, patients completed a short form detailing their socio-demographic characteristics. All consultations were audio-recorded to allow for analysis of the consultation length, and the number of questions asked by the patient. All oncologists involved in the study were informed in advance and invited to participate and provided their informed consent. The oncologists performed their consultations as usual, according to the clinical practice of the institution.

The oncologists were blind to the assignment of the patients into the two groups, and did not know the results of their questionnaires before the consultation.

Measures

The following tools were administered pre-consultation:

Control Preference Scale (CPS): a self-reporting instrument that measures the patients' preference in terms of their role in the decision-making process (18). The CPS contains five cartoons/drawings with text, depicting different patient roles, from the most active role ("I prefer to make the decision about which treatment I will receive") to a collaborative role ("I prefer that my doctor and I share responsibility for deciding which treatment is best for me") to the most passive role ("I prefer to leave all decisions regarding treatment to my doctor"). According to the "pick one" approach proposed by the authors, five cards were shown to the patients, who were then asked to choose the vignette/drawing that they considered to be closest to the role they would prefer in deciding on their treatment. The five possible roles are grouped into three main clusters: Active (card 1 = active, card 2 = active-collaborative), Collaborative (card 3 = collaborative), Passive (card 4 = collaborative-passive, card 5 = passive).

State-Trait Anxiety Inventory-X1 (STAI-X1): a self-reporting instrument that consists of 20 items, each rated on a four-point Likert scale ranging from 1 (*not at all*) to 4 (*very much*) (32).

The Patient Health Questionnaire-9 (PHQ-9): a self-reporting questionnaire used for detecting the presence of depression, composed of 9 items with response options from 0 (*not at all*) to 3 (*almost every day*). The summative score ranges from 0 to 27 (cut-off ≥ 8) (33).

The General Health Questionnaire (GHQ-12): a self-reporting questionnaire that assesses psychological well-being, consisting of 12 items (34). Each item scores from 0 (*better than usual*) to 3 (*much worse than usual*). The standard 0-0-1-1 method of scoring was used in this study. In this method, a score of 0 was assigned to the first two low-stress alternatives, and a score of 1 was given to the two high-stress alternatives. The maximum score was 12 (cut-off > 3).

The following tools were administered post-consultation:

The *STAI-X1/R*, which is a modified version of the STAI-X1, specifically developed for the Cognitive Behavioral Assessment Project (35). The STAI-X1/R is a 10-item version of the STAI-X1, with responses reported in the same manner as in the STAI-X1. It specifically measures fluctuations in anxiety (STAI-DIFF) in terms of the difference between the STAI-X1 and the STAI-X1/R.

The *Shared Decision-Making Questionnaire (SDMQ-9)*: a self-reporting questionnaire, composed of 9 items, that assesses patient perceptions of the decision-making process and their level of involvement during the consultation, the information received with regards to therapeutic options, and potential risks and benefits regarding participation in the decision-making process (36). Patient responses are reported on a 4-point Likert scale, ranging from 0 (*completely agree*) to 3 (*disagree*). The scores range from 0 to 27: the higher the score, the less the participation in the decision-making.

Statistical analysis

Descriptive statistics for socio-demographic characteristics are given in terms of mean and standard deviation for continuous variables, whereas frequencies and percentages are reported for categorical variables. The t-test or the corresponding non-parametric Mann-Whitney test were used to compare the quantitative variables between the QPS and QL groups. The ANOVA test, applying a *Bonferroni* correction, was used to compare the quantitative variables among the groups (active, collaborative and passive). Effect sizes are reported for the differences among three preference roles using *Partial Eta Squared* (η^2) for ANOVA. In our analysis, 0.2 was considered a small effect, 0.5 a medium effect, and 0.8 or above a large effect. The Chi-square test was used to compare categorical variables among groups. We calculated the adjusted residuals (z-scores) and their associated p-values to identify positive ($z > 1.96$) and significant ($P < 0.05$) relationships among the variables analyzed. All tests were two-tailed, and the probability of a type I error was set at $P < 0.05$. All analyses were performed with SPSS 26.

Ethics

The study followed CONSORT guidelines and was approved by the Ethics Committee of the Hospital Trust of Verona (No 2397, Aug 28/2013), and by the Provincial Ethics Committee of Brescia (NP10, Oct 31/2010), and was conducted in accordance with the Declaration of Helsinki. Informed consent was obtained from all participants included in the study. For the RCT trial protocol, please see clinicaltrials.gov (NCT01510964).

Results

Comparison between the experimental group (QPS) and the control group (QL), according to the RCT design of the study

Three hundred and twenty-four patients were randomly assigned to two different intervention groups. After excluding inaudible consultations, the final sample resulted in 308 patients (158 QPS group and 150 QL group). Table 1 reports the features of the two groups. No difference was found between the groups in socio-demographic characteristics: in both groups, most participants were married, with a high level of education, and not in employment. The two groups were similar in terms of clinical variables and were comparable in both the number of questions asked by patients and length of consultation. In both groups, most of the sample was not accompanied by a family member, and more than half of the subjects preferred a collaborative role. Given that the QPS and QL groups did not differ in most of the variables considered, further analyses were then applied to the whole sample.

Preferred role, patient characteristics, length of consultation and number of questions asked by patients during consultation

For this analysis, two patients of the QL group were excluded because they did not fill out the CPS, thus the analysis on the preferred role was based on 306 subjects. Most patients chose a collaborative role (54.2%),

Table 1 - Comparison between the QPS group and the QL group (N= 308)

	QPS N= 158	QL N= 150	P-value
Marital Status, <i>n</i> (%)			
Single	20 (12.6)	14 (9.3)	NS ^a
Married	103 (65.3)	110 (73.3)	
Divorced/widowed	33 (20.8)	25 (16.7)	
Missing	2 (1.3)	1 (0.7)	
Education, <i>n</i> (%)			
Primary School	26 (16.5)	31 (20.7)	NS ^a
Secondary School	47 (29.7)	39 (26.0)	
High School	62 (39.2)	62 (41.3)	
University	21 (13.3)	18 (12.0)	
Missing	2 (1.3)	-	
Employment, <i>n</i> (%)			
Unemployed	86 (54.4)	86 (57.3)	NS ^a
Employed	71 (45.0)	64 (42.7)	
Missing	1 (0.6)	-	
Breast cancer stage*, <i>n</i> (%)			
I	56 (35.4)	64 (42.7)	NS ^a
II	37 (23.4)	37 (24.7)	
III	12 (7.6)	7 (4.6)	
Missing	53 (33.5)	42 (28.0)	
Accompanied by a family member, <i>n</i> (%)			
Yes	39 (24.7)	41 (27.3)	NS ^a
No	119 (75.3)	109 (72.7)	
CPS, <i>n</i> (%)			
Collaborative	89 (56.3)	77 (51.3)	NS ^a
Active	11 (7)	9 (6)	
Passive	58 (36.7)	62 (41.3)	
Age, mean (SD)	55.8 (11.0)	56.1 (11.2)	NS ^b
Number of questions, mean (SD)	13.4 (9.0)	15.8 (12.4)	NS ^c
Length of consultation, mean (SD)	47.6 (19.1)	49.0 (18.8)	NS ^c
GHQ-12, mean (SD)	4.5 (3.4)	4.8 (3.5)	NS ^c
PHQ-9, mean (SD)	6.1 (4.7)	6.5 (4.9)	NS ^c
STAI-X1, mean (SD)	46.6 (12.1)	49.3 (11.5)	NS ^c
STAI-X1/R, mean (SD)	18.8 (6.1)	20.0 (6.7)	NS ^c
STAI-DIFF, mean (SD)	-4.20 (6.9)	-5.02 (6.3)	NS ^c
SDMQ-9, mean (SD)	7.7 (6.7)	7.8 (6.6)	NS ^c

^aChi-squared test; ^bT-test; ^cMann-Whitney; NS= Not Significant; *Stage cancer according to the American Joint Committee of Cancer AJCC 7th Edition staging for Breast Cancer. Patients with stage IV were excluded from the study.

Table 2 - Comparison among socio-demographic characteristics and control preference roles in the total sample

	Active role (N= 20)	Collaborative role (N= 166)	Passive role (N=120)	P-value*
Marital status, <i>n</i> (%)				
Single	4 (20.0)	24 (14.4)	6 (5.0)	.030
Married	11 (55.0)	114 (68.7)	86 (71.7)	
Divorced/widowed	5 (25.0)	25 (15.1)	28 (23.3)	
<i>Missing</i>	-	3 (1.8)	-	
Education, <i>n</i> (%)				
≤ 8 years	8 (40.0)	68 (41.0)	66 (55.0)	NS
>8 years	12 (60.0)	96 (57.8)	54 (45.0)	
<i>Missing</i>	-	2 (1.2)	-	
Employment, <i>n</i> (%)				
Employed	10 (50.0)	91 (54.8)	33 (27.5)	<.001
Unemployed	10 (50.0)	74 (44.6)	87 (72.5)	
<i>Missing</i>	-	1 (0.6)	-	
Accompanied by a family, member, <i>n</i> (%)				
Yes	16 (80.0)	120 (72.3)	91 (75.8)	NS
No	4 (20.0)	46 (27.7)	29 (24.2)	
<i>Missing</i>	-	-	-	
Breast cancer stage, <i>n</i> (%)				
I	6 (30.0)	64 (38.5)	48 (40.0)	NS
II	4 (20.0)	39 (23.5)	31 (25.8)	
III	3 (15.0)	10 (6.0)	6 (5.0)	
<i>Missing</i>	7 (35.0)	53 (31.9)	35 (29.2)	
Type of breast surgery, <i>n</i> (%)				
Conservatory surgery	11 (55.0)	116 (69.9)	85 (70.8)	NS
Mastectomy	4 (20.0)	43 (25.9)	22 (18.3)	
<i>Missing</i>	5 (25.0)	7 (4.2)	13 (10.8)	
Breast reconstruction, <i>n</i> (%)				
Yes	5 (25.0)	31 (18.7)	11 (9.2)	.041
No	15 (75.0)	135 (81.3)	109 (90.8)	
<i>Missing</i>	-	-	-	

*Chi square; NS= Not Significant

followed by a passive role (39.2%). Only 6.5% chose an active role. Patients who chose a passive role were older (mean = 58.3 years, SD = 10.7) than those who chose an active role (mean = 54.1, SD = 12.5) or a collaborative role (mean = 54.5, SD = 11.0). The ANOVA showed significant differences in mean age among the three different preferred roles ($F = 4.493$, $P = .012$). The following post-hoc test, with *Bonferroni* correction, showed a difference between collaborative and

passive roles ($P = .012$). The effect size was small ($\eta^2 = .03$). As indicated in Table 2, single and employed patients more frequently preferred a collaborative role ($\chi^2 = 10.676$; $df = 4$; z -score = 2.1 and $\chi^2 = 21.885$; $df = 2$; z -score = 4.3, respectively). Those who had not had a previous breast reconstruction tended to prefer a passive role ($\chi^2 = 6.373$; $df = 2$; z -score = 2.4).

Those who preferred a collaborative role asked more questions than those who chose an active or a

Table 3 - Comparison among length of consultation and number of questions, and control preference roles in the total sample

	Active role (1) N= 20	Collaborative role (2) N= 166	Passive role (3) N= 120	P-value (post-hoc)*
Number of questions,				.043
<i>mean (sd)</i>	12.2 (6.7)	16.1 (12.2)	12.9 (9.1)	(2 vs 3)
Length of consultation				.012
(minutes),	44.6 (17.2)	51.5 (19.7)	44.9 (17.7)	(2 vs 3)
<i>mean (sd)</i>				
Number of questions per topic,				NS
<i>mean (sd)</i>				
• Symptoms	1.4 (1.5)	2.3 (2.9)	1.7 (2.0)	NS
• Aetiology	0.2 (0.4)	0.3 (0.8)	0.1 (0.4)	NS
• Prognosis	0.3 (0.5)	0.6 (1.1)	0.4 (0.9)	NS
• Treatment	4.9 (3.7)	6.6 (5.7)	5.4 (4.5)	NS
• Bureaucracy	4.8 (3.1)	4.9 (4.2)	4.5 (3.5)	.016
• Prevention	0.5 (0.8)	1.26 (1.8)	0.7 (1.1)	(2 vs 3)

**Bonferroni* correction; NS= Not Significant

passive role (Table 3). The ANOVA showed significant differences in mean number of questions asked during the consultation among the three different preference roles ($F = 3.557$, $P = .030$). The following post-hoc test, with *Bonferroni* correction, showed a difference between collaborative and passive roles. The effect size was small ($\eta^2 = .02$). Patients who preferred a collaborative role had a longer consultation than those who chose an active or a passive role. The ANOVA showed a significant difference between the mean duration in the three different preference roles ($F = 4.701$, $P = .010$). The subsequent post-hoc test, with *Bonferroni* correction, showed a difference between collaborative and passive roles. The effect size was small ($\eta^2 = .03$). Patients who preferred a collaborative role asked more questions on cancer prevention than those who chose an active or a passive role. The ANOVA showed significant differences in mean number of prevention questions among the three different preferred roles ($F = 5.114$, $P = .007$). The subsequent post-hoc test, with *Bonferroni* correction, showed a difference between collaborative and passive roles. The effect size was small ($\eta^2 = .03$).

Preferred role and mean scores in pre/post questionnaires

Table 4 shows the differences in total mean scores for the questionnaires administered pre and post consultation amongst the three groups (active,

collaborative and passive). No statistically significant difference was found among patients with different preferred roles. The same applied for the SDM-Q-9.

Discussion

The results showed that more than half of subjects preferred a collaborative role (54.2%), followed by a passive role (39%); while the choice of an active role was marginal (6.5%). This result is in line with findings obtained in some studies (1,7,19), but in contrast with others that found an active role to be second to the preferred collaborative role, and a passive role to be the least popular (15,37,38). Other studies have showed a trend towards a preference for a passive role, with percentages ranging from 40% to 72% (5,6). It is less common for an active role to be the most frequent choice (8). In another study, the authors found that the three roles were equally distributed (10). Finally, in Jabbour et al. (13), a study based on patients with head and neck cancer, females more frequently chose an active role. Therefore, literature shows huge variability in preferred role. This is probably due to the fact that the role preference is a dynamic phenomenon that changes over time, depending on when it is measured, and is more of a state than a trait (19). Besides, because all these studies were conducted in different

Table 4 - Comparison between questionnaires mean scores and control preference roles

	Active role (N= 20)	Collaborative role (N= 166)	Passive role (N=120)	P-value*
Assessment pre-consultation				
GHQ-12, mean (sd)	4.8 (3.1)	4.6 (3.6)	4.7 (3.4)	NS
STAI-X1, mean (sd)	50.9 (12.8)	47.9 (11.9)	47.4 (11.8)	NS
PHQ-9, mean (sd)	7.8 (4.1)	6.3 (4.8)	6.1 (5.0)	NS
Assessment post-consultation				
SDMQ-9, mean (sd)	7.3 (6.5)	7.0 (6.6)	8.9 (6.8)	NS
STAI-X1/R, mean (sd)	18.9 (5.3)	19.7 (6.7)	19.1 (6.1)	NS

*ANOVA; NS= Not Significant

countries, it is possible that the preferred role varies depending on cultural context. Country of origin may impact patient preferences depending on whether the treatment decision is viewed as a family or community responsibility, rather than the choice of the individual patient. Furthermore, beliefs about the disease, treatment and the patient's role in the decision-making process, which can be influenced by the culture to which patient belongs, can also affect the role that the patient would like to play in interaction with the physician. In this study, women who declared a preference for a collaborative role showed more active participation during consultation: their interviews lasted longer, and these women asked the oncologist more questions than women who chose a passive role. When considering different ideas, women who preferred a collaborative role asked more questions about cancer prevention than women who chose a passive role. The results of this study also show that the patients who chose a collaborative role were younger than women who chose a passive role. This result is in line with other studies, in which an older age was found to be a predictor for the choice of a passive role, while active or collaborative roles were mostly chosen by younger women (1,7,10). In this study, single and employed women tended to prefer a collaborative role. This may be related to the fact that these women were more independently inclined both in life and in their treatment choices, leading them to interact more with the oncologist. These results are in line with previous literature. To the best of our knowledge, there is only one longitudinal study (15), that found a statistically significant link between

marital status and preferred role expressed three years after surgical treatment. This study highlighted how widowed women were prone to adopt a passive role, while women in a relationship, divorced, separated or never married were more likely to choose active or collaborative approaches. Regarding employment status, this study confirms previous findings that show that participants who are employed seek greater engagement in the decision-making process than participants who are unemployed or retired (12).

Women who did not have a breast reconstruction chose a passive role. This is in line with other studies which show that having undergone surgical treatment in the past affects role preferences, increasing the probability of patients taking collaborative or active approaches, and decreasing the probability of taking a passive approach (37). Furthermore, a follow-up study on the trend of decision-making preferences showed that, after surgical treatment, the preference for a collaborative or active role increases over time, while it declines for a passive role (15). These results seem to corroborate the hypothesis that previous experience of illness and decision-making concerning surgical treatment leads women to prefer to participate more during consultation with their oncologist. Given the importance of the decision-making process in health care, it is essential for patients to have the opportunity to express and implement their own preferred role. This is even true in the case of breast cancer, which, in addition to the distress, uncertainty and concerns that are associated with a negative diagnosis, also affects the self-image of the patients, who are sometimes

subjected to invasive interventions. If the doctor interacts with the patients respecting their role preferences, the patients are more satisfied and this can have a positive effect on the health outcomes, e.g., increasing patient adherence to medical recommendations (39,40), improving patient adherence to/continuance of treatment (41), and their post-treatment quality of life (42,43). Unfortunately, in our study, we were unable to match the preferred role with the role played during the consultation (role concordance). In fact, there may be differences between the preferred role, measured before the consultation, with the role actually taken by the patient during the consultation. From the available literature, we know that patient's preferred role does not always coincide with the role actually played, although when it does coincide, the degree of satisfaction with the decision-making process is greater (38). In fact, patients with cancer who report high levels of discordance between their preferred role and actual role, tend to be less involved in the decision-making process with their oncologist. There are several factors that influence a consultation that can alter the patient's role, such as emotions or fears, or the lack of congruence between the patient's preferred role and that perceived by the oncologist, for example with the oncologist overestimating the willingness of a patient to participate actively in decisions about treatment (44). This highlights the importance of identifying tools or indicators that allow oncologists to understand the patient's preferred role. There may be different ways to assess patients' role preferences in clinical practice, such as questionnaires that could be administered before the consultation or interviews in which patients are asked how far they would like to be involved in the decision-making process regarding their cancer treatment, as well as about their needs and expectations. Oncologists could also be trained to in interpreting the verbal and non-verbal communication, behaviors, emotions and reactions of patients in order to assess their involvement and role preferences, collecting informal feedback on the desired degree of engagement in the decision-making process. Oncologists must be able to recognize the preferred role of patients if they are to adapt their interpersonal communication style to the needs of the individual patient, which is to the greatest benefit for the patient during

the decision-making process. Patients who are understood perceive greater satisfaction in their choices and this has a positive effect on the relationship between patient and oncologist. Patients are more satisfied when they receive treatment that is respectful of and responsive to their preferences, needs and values as defined by patient-centered care (45). For this reason, oncologists should follow continuous training on patient-centered communication. This study has several limitations due to the generalizability of the results, since the data were gathered only from a limited number of centers in northwestern Italy. Moreover, this study was conducted in a single country, therefore culture and values could have influenced the results. Another limitation is that this study assessed the preferred role before the consultation with the oncologist. We did not assess the actual role played by the patient during the consultation. Furthermore, there were also statistical limitations, due to the disparity in the size of the groups: most patients chose a collaborative role, followed by a passive role, and only 20 patients chose an active role. This may have contributed to lower effect size outcomes in all ANOVA comparisons and impeded multilevel analysis to take into account the center level.

Conclusions

There is increasing awareness of the important role patients can play in the decision-making process concerning their health in many clinical areas, including oncology. Further studies are needed to better understand the role that early-stage cancer patients would like to play in decisions about their treatment and related matters. Some studies have already been completed, although they have shown mixed results (9,16,18). Understanding the kind of involvement early-stage cancer patients would like in decisions about their condition is very important because it allows oncologists to tailor their communication style to patients' needs. Patient satisfaction with communication with the oncologist, information received and treatment decisions are important aspects that can affect the course of the disease and health outcomes (24,25). This study has shown that preference

is related to certain socio-demographic variables, such as age, marital and employment status, and to previous experiences of breast reconstruction, as well as to the number of questions to the oncologist, and length of consultation. These results may help oncologists to understand the variables on which they should focus when conducting consultations with breast cancer patients. Overall, these results underline the importance of implementing oncologist training programs on understanding how involved patients wish to be in the oncological treatment decisions, learning to adapt their communication style to patient preferences in terms of information-sharing and participation in the decision-making process.

Conflict of Interest: Each author declares that he or she has no commercial associations (e.g., consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

Ethical Approval and Consent to Participate: The study was approved by the Ethics Committee of the Hospital Trust of Verona (No 2397, Aug 28/2013), and by the Provincial Ethics Committee of Brescia (NP10, Oct 31/2010), and was conducted in accordance with the Declaration of Helsinki. Informed consent was obtained from all participants included in the study. For the RCT trial protocol, please see clinicaltrials.gov (NCT01510964).

Authors' Contribution: CB collected and analyzed the data, and wrote the first draft of the manuscript. DB analyzed the data, and wrote the first draft of the manuscript. HC analyzed the data. MAM, CG, and LDP collected the data and supervised the study. AG wrote the first draft of the manuscript, and supervised the study. All other authors revised the manuscript critically. All authors approved the final version of the manuscript.

References

1. Brown R, Butow P, Wilson-Genderson M, et al. Meeting the decision-making preferences of patients with breast cancer in oncology consultations: impact on decision-related outcomes. *J Clin Oncol.* 2012;30(8):857-862. doi: 10.1200/jco.2011.37.7952.
2. Brand PLP, Stiggelbout AM. Effective follow-up consultations: the importance of patient-centered communication and shared decision making. *Paediatr Respir Rev.* 2013;14(4):224-228. doi: 10.1016/j.prrv.2013.01.002.
3. Hubbard G, Kidd L, Donaghy E. Preferences for involvement in treatment decision making of patients with cancer: a review of the literature. *Eur J Oncol Nurs.* 2008;12(4):299-318. doi: 10.1016/j.ejon.2008.03.004.
4. Singh JA, Sloan JA, Atherton PJ, et al. Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the control preferences scale. *Am J Manag Care.* 2010;16(9):688-696.
5. Almyroudi A, Degner LF, Paika V, et al. Decision-making preferences and information need among Greek breast cancer patients. *Psychooncology.* 2011;20(8):871-879. doi: 10.1002/pon.1798.
6. Hyphantis T, Almyroudi A, Paika V, et al. Anxiety, depression and defense mechanisms associated with treatment decisional preferences and quality of life in non-metastatic breast cancer: a 1-year prospective study. *Psychooncology.* 2013;22(11):2470-2477. doi: 10.1002/pon.3308.
7. Nies YH, Islahudin F, Chong WW, et al. Treatment decision-making among breast cancer patients in Malaysia. *Patient Prefer Adherence.* 2017;11:1767-1777. doi: 10.2147/ppa.s143611.
8. Kokufu H. Conflict accompanying the choice of initial treatment in breast cancer patients. *Jpn J Nurs Sci.* 2012;9(2):177-184. doi: 10.1111/j.1742-7924.2011.00200.x.
9. Yennurajalingam S, Lu Z, Prado B, et al. Association between advanced cancer patients' perception of curability and patients' characteristics, decisional control preferences, symptoms, and end-of-life quality care outcomes. *J Palliat Med.* 2018;21(11):1609-1616. doi: 10.1089/jpm.2018.0186.
10. Hahlweg P, Kriston L, Scholl I, et al. Cancer patients preferred and perceived level of involvement in treatment decision-making: an epidemiological study. *Acta Oncol.* 2020;59(8):967-974. doi: 10.1080/0284186x.2020.1762926.
11. Wallberg B, Michelson H, Nystedt M, et al. Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. *Acta Oncol.* 2000;39(4):467-476. doi: 10.1080/028418600750013375.
12. Budden LM, Pierce PF, Hayes BA, et al. Australian women's pre-diagnostic decision-making styles, relating to treatment choices for early breast cancer treatment. *Res Theory Nurs Pract.* 2003;17(2):117-136. doi: 10.1891/rtnp.17.2.117.53178.
13. Jabbour J, Dhillon HM, Shepherd HL, et al. The relationship between role preferences in decision-making and level of psychological distress in patients with head and neck cancer. *Patient Educ Couns.* 2018;101(10):1736-1740. doi: 10.1016/j.pec.2018.05.023.
14. Moth E, McLachlan SA, Veillard AS, et al. Patients' preferred and perceived roles in making decisions

- about adjuvant chemotherapy for non-small-cell lung cancer. *Lung Cancer*. 2016;95:8-14. doi: 10.1016/j.lungcan.2016.02.009.
15. Watson P, Sinha L. Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psychooncology*. 2006;15(1):9-19. doi: 10.1002/pon.907.
 16. Butow PN, Maclean M, Dunn SM, et al. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol*. 1997;8(9):857-863. doi: 10.1023/a:1008284006045.
 17. Vogel BA, Bengel J, Helmes AW. Information and decision making: patients' needs and experiences in the course of breast cancer treatment. *Patient Educ Couns*. 2008;71(1):79-85. doi: 10.1016/j.pec.2007.11.023.
 18. Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res*. 1997;29(3):21-43.
 19. Gutnik L, McCarty Allen C, Presson AP, et al. Breast cancer surgery decision role perceptions and choice of surgery. *Ann Surg Oncol*. 2020;27:3623-3632. doi: 10.1245/s10434-020-08485-8.
 20. Maguire P, Faulkner A. How to improve the counseling skills of doctors and nurses in cancer care. *BMJ*. 1988;297:847-849. doi: 10.1136/bmj.297.6652.847.
 21. McWilliam CL, Brown JB, Stewart M. Breast cancer patients' experience of patient-doctor communication: a working relationship. *Patient Educ Couns*. 2000;39:191-204. doi: 10.1016/s0738-3991(99)00040-3.
 22. Bensing J. Bridging the gap. The separate worlds of evidence-based medicine and patient centered medicine. *Patient Educ Couns*. 2000;39:17-25. doi: 10.1016/s0738-3991(99)00087-7.
 23. Epstein RM, Street RL. A patient-centered approach to cancer communication research. In: Epstein RM, Street RL, editors. *Patient-centered communication in cancer care: promoting healing and reducing suffering*. Bethesda, MD: National Cancer Institute; 2007. p. 1-16. (NIH Publ No. 07-6225).
 24. Dowsett SM, Saul JL, Butow PN, et al. Communication styles in the cancer consultation: preferences for a patient-centered approach. *Psychooncology*. 2000;9:147-156. doi: 10.1002/(sici)1099-1611(200003/04)9:2<147:aid-pon443>3.0.co;2-x.
 25. Epstein RM, Franks P, Fiscella K, et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med*. 2005;61:1516-1528. doi: 10.1016/j.socscimed.2005.02.001.
 26. Goss C, Ghilardi A, Deledda G, et al. Involvement of breast cancer patients during oncological consultations: a multi-centre randomised controlled trial – the INCA study protocol. *BMJ Open*. 2013;2(3):e002266. doi: 10.1136/bmjopen-2012-002266.
 27. Bottacini A, Goss C, Mazzi MA, et al. The involvement of early-stage breast cancer patients during oncology consultations in Italy: a multi-centred, randomized controlled trial of a question prompt sheet versus question listing. *BMJ Open*. 2017;7(8):e015079. doi: 10.1136/bmjopen-2016-015079.
 28. Del Piccolo L, Mazzi MA, Mascanzoni A, et al. Factors related to the expression of emotions by early-stage breast cancer patients. *Patient Educ Couns*. 2019;S0738-3991(19)30127-2. doi: 10.1016/j.pec.2019.04.002.
 29. Mazzi MA, Perlini C, Deledda G, et al. Employment status and information needs of patients with breast cancer: a multicenter cross-sectional study of first oncology consultations. *BMJ Open*. 2020;10(9):e038543. doi: 10.1136/bmjopen-2020-038543.
 30. Buizza C, Ghilardi A, Mazzardi P, et al. Effects of a question prompt sheet on the oncologist-patient relationship. A multi-centred randomised controlled trial in breast cancer. *J Cancer Educ*. 2020;35:621-628. doi: 10.1007/s13187-019-01505-6.
 31. Buizza C, Cela H, Ferrari C, et al. Does being accompanied make a difference in communication during breast cancer consultations? Results from a multi-centered randomized controlled trial. *J Psychosoc Oncol*. 2021;39(2):189-203. doi: 10.1080/07347332.2020.1829775.
 32. Spielberger CD. *Manual for the State Trait Anxiety Inventory for Adults (Form Y)*. Palo Alto, CA: Mind Garden; 1983.
 33. Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16(9):606-613. doi: 10.1046/j.1525-1497.2001.016009606.x.
 34. Politi PL, Piccinelli M, Wilkinson G. Reliability, validity and factor structure of the 12-item General Health Questionnaire among young males in Italy. *Acta Psychiatr Scand*. 1994;90(6):432-437. doi: 10.1111/j.1600-0447.1994.tb01620.x.
 35. Sanavio S, Bertolotti G, Bettinardi O, et al. The cognitive behavioral assessment (CBA) project: presentation and proposal for international presentation. *Psychol Community Health*. 1986;2(3).
 36. Kriston L, Scholl I, Holzel L, et al. The 9-item Shared Decision-Making Questionnaire (SDM-Q-9): development and psychometric properties in a primary care sample. *Patient Educ Couns*. 2010;80(1):94-99. doi: 10.1016/j.pec.2009.09.034.
 37. Bruera E, Willey JS, Palmer JL, et al. Treatment decisions for breast carcinoma: patient preferences and physician perceptions. *Cancer*. 2002;94(7):2076-2080. doi: 10.1002/cncr.10393.
 38. Yamauchi K, Nakao M, Nakashima M, et al. Congruence between preferred and actual participation roles increases satisfaction with treatment decision making among Japanese women with breast cancer. *Asian Pac J Cancer Prev*. 2017;18(4):987-994. doi: 10.22034/apjcp.2017.18.4.987.
 39. Bartlett EE, Grayson M, Barker R, Levine DM, Golden A, Libber S. The effects of physician communications skills on patient satisfaction, recall, and adherence. *J Chronic Dis*. 1984;37:755-764.

40. DiMatteo MR. Variations in patients' adherence to medical recommendations: a quantitative review of 50 years of research. *Med Care*. 2004;42:200-209. doi: 10.1097/01.mlr.0000114908.90348.f9.
41. Willis CE, Holmes-Rovner M. Preliminary validation of the satisfaction with decision scale with depressed primary care patients. *Health Expect*. 2003;6:149-159. doi: 10.1046/j.1369-6513.2003.00220.x.
42. Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Med Decis Making*. 2003;23:281-292. doi: 10.1177/0272989x03256005.
43. Stalmeijer PFM, van Roosmalen MS, Verhoef LCG, et al. The decision evaluation scales. *Patient Educ Couns*. 2005;57:286-293. doi: 10.1016/j.pec.2004.07.010.
44. Caocci G, Voso MT, Angelucci E, et al. Accuracy of physician assessment of treatment preferences and health status in elderly patients with higher-risk myelodysplastic syndromes. *Leuk Res*. 2015;39(8):859-865. doi: 10.1016/j.leukres.2015.05.012.
45. Santana MJ, Manalili K, Jolley RJ, et al. How to practice a person-centred care: A conceptual framework. *Health Expect*. 2017; 21:429-440. doi: 10.1111/hex.12640.

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