Informational needs and the quality of life of patients in their first year after metastatic breast cancer diagnosis

Davinia SE Seah, MD, MPH,[a] Nancy U Lin, MD,[a] Carolyn Curley,[a] Eric P Winer, MD,[a] and Ann H Partridge, MD, MPH

[a]Dana-Farber Cancer Institute, Department of Medical Oncology, Boston, Massachusetts

Background Little is known about the informational needs and quality of life (QOL) of patients with metastatic breast cancer (MBC) within the first year of their diagnosis.

Objective To describe the informational needs and QOL of patients with MBC within the first year of diagnosis, and to identify sociodemographic and medical factors that may be associated with informational needs and QOL.

Methods 52 patients (50 women, 2 men) enrolled within a year of diagnosis of MBC completed a cross-sectional, self-administered paper survey that included patient demographics, the Toronto Informational Needs Questionnaire-Breast Cancer (TINQ), the Hospital Anxiety and Depression Scale (HADS), and Medical Outcomes Study Short Form-36 (SF-36). High informational need was defined as a TINQ score of ≥ 200.

Results Of the total 52 patients, 69% (35/52) had high informational needs, 20% met the criteria for anxiety (HADS-Anxiety score, ≥ 11), and 8% met the criteria for depression. SF-36 scores were lower in all 8 subscales compared with the general population. Multivariate analyses showed that patients who were married or living as married (OR, 6.1; 95% CI, 1.4-28.9) and patients with de novo MBC (OR, 2.8; 95% CI, 0.5-14.3) or a shorter disease-free interval (DFI; < 5 years; OR, 24.2; 95% CI, 3.1-187.4) were more likely to have more informational needs (C statistic, 0.824) than were patients with a longer DFI (≥ 5 years).

Limitations This is a small cross-sectional study of a single academic institution.

Conclusion Patients with recently diagnosed MBC have high informational needs and decreased overall QOL. Additional research and supportive services meeting the informational and psychosocial needs of patients living with MBC are warranted.

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Breast cancer is the second most common cause of cancer-related death in the United States, with more than 40,000 women dying of the disease each year.[1] Although only 5% of patients with newly diagnosed disease will present initially with metastatic breast cancer (MBC), about 20%-30% of patients presenting with early stage disease will eventually progress to MBC.[2] Recent advances in breast cancer treatment have significantly improved the duration of survival for MBC patients from about 1-2 years in the 1980s to 2-3 years today.[3-5] As a result of improved survival, the number of patients with MBC who are alive is growing and attention to the unique needs of this population is warranted.

A cancer diagnosis is stressful for most people and may be even more difficult for those with advanced disease. People seek information to better understand their experience when faced with a threatening and challenging situation.[6] Accurate and realistic information helps patients prepare for threatening events,[7] thus reducing their anxiety, and may lead to better outcomes and less emotional distress.[8,9] A lack of information may produce feelings of uncertainty, and can impede decision making.[10,11] Many patients with advanced cancer want prognostic information and to understand what to expect from their disease and the treatments.[12-16] As such, physicians should consider the amount and the type of information their patients prefer to receive in order to meet their needs. Although there is some literature on the informational needs of breast cancer patients,[17-21] there is limited specific information for patients with MBC. The experiences of patients with MBC are different from those of early-stage breast cancer patients, with many MBC patients experiencing major concerns such as fear of dying, worsening quality of life (QOL), treatment side effects, their ability to care for loved ones, and end of life care.[21] Identifying and prioritizing what information to provide these patients is important for physicians as they treat not only the disease, but the whole patient.

Most studies have focused on the QOL in patients with breast cancer, regardless of stage.[22,23] However, patients with MBC differ from patients with early-stage breast cancer as most have to undergo lifelong treatments despite the burdensome treatment-related side effects. In addition, pain and impending organ failure at the site of metastases may have a tremendous impact on the day-to-day activities of these patients.

The purpose of this study was to explore and describe the informational needs and QOL of patients with MBC in the first year after MBC diagnosis. The specific objectives were to determine and describe the informational needs of patients with MBC; describe the QOL of patients with MBC; and identify the influence of demographic, medical, and other psychosocial factors on patients' informational needs and QOL. Ultimately, this information should direct clinicians and researchers toward areas in which educational and supportive care interventions may be developed to improve the QOL of patients with MBC.

Methods

Participants and procedures

From October 2011 to May 2012, we conducted a cross-sectional self-administered paper survey at our institution's breast oncology outpatient clinic. Patients were eligible if they were older than 18 years, able to understand English, had been diagnosed with MBC within the past 12 months, and had signed consent to be part of a large, prospective metastatic cohort study at our institution to which this survey component was added for a subset of participants. Consecutive eligible patients were approached during the patient's visit and the purpose of the research was explained. Patients were encouraged to complete the questionnaire onsite, but were allowed to take it home. They were given a $5 gift certificate when the questionnaire was returned.

Measures

The questionnaire included sociodemographic questions and standardized measures as described hereinafter. Medical chart review was performed to obtain further medical history.

Toronto Informational Needs Questionnaire – Breast Cancer (TINQ)

The TINQ assesses how important it is for patients to have information about their disease, investigative tests, treatment, and physical and psychological needs. The TINQ used in this study was adapted from the original TINQ, which consisted of 52 items.[18,20] A 5-point Likert scale was used to rate informational needs, with 1 representing information being not important and 5 representing information being extremely important. For this study, the question

How to tell if the cancer has come back was removed because all of the patients who were completing the questionnaire had MBC. The resulting possible total minimum and maximum scores thus became 51 and 255, respectively. A total score of 200 or higher has been used previously to imply high informational needs.[18] This same threshold is used for scoring the adapted TINQ of this study.

Hospital Anxiety Depression Scale (HADS)

The HADS is a 14-item self-report instrument that was developed to detect anxiety and depression in a non-psychiatric hospital setting.[24] Seven items relate to anxiety, and 7 relate to depression, with each item on the questionnaire having a score of 0-3. Within a subscale, scores may range from 0 to 21. Scores ≥ 11 in each subscale represent high levels of anxiety or depression, and scores between 8-10 present borderline levels of anxiety or depression. For scoring, if a single item was missing from a subscale, its value was inferred by using the mean of the remaining 6 items. However, if more than 1 item of the subscale were missing, then the subscale was judged as invalid.[25] This tool has been extensively validated.[26]

Medical Outcomes Study SF-36

The Medical Outcomes Study SF-36v1 consists of 36 items comprising 8 subscales, including physical functioning, role limitations due to physical health or emotional problems, bodily pain, general health, vitality, social function, and mental health.[27] These subscales can also be scored as 2 summary scales – the Physical Component Summary (PCS) scale and the Mental Component Summary (MCS) scale. The means for the individual subscales and summary scales have been adjusted to norm-based scores, allowing comparisons of our study population with the general US population.[28] Scores above or below 50 can be interpreted as above or below the general population norms respectively. A clinically meaningful difference for the norm based scores has not been established, but a difference of ≥ 2.5 points from the general population mean of 50 is generally considered to be clinically meaningful.[29] This instrument has undergone extensive psychometric testing and has been found to have adequate internal consistency and validity.[28]

Statistical analysis

Descriptive statistics were used to summarize patient demographic, disease, and treatment characteristics. The outcomes of interest were TINQ, HADS, and SF-36. Scoring for these instruments used standard algorithms.[18,20,24,27,28,30] The predictors include disease-free interval (DFI), education, employment, marital status, total combined income, stage at initial disease, number of children, tumor subtype, receipt of adjuvant or neoadjuvant chemotherapy, whether

the patient was living alone, physical activity in the past month, cancer progression in the past month, number of metastatic sites at MBC diagnosis, and number of lines of chemotherapy. HADS-Anxiety, HADS-Depression, PCS, and MCS were included as predictors if they were not the outcome of interest.

Univariate analyses were performed to assess the relationship between patient characteristics, TINQ, HADS, and SF-36. For easy readability, the TINQ scores were analyzed as a dichotomous variable with high informational need defined as having a TINQ score of $\geq$ 200. HADS-Anxiety scores were analyzed as a dichotomous variable with scores $\geq$ 1 being classified as patients having anxiety. This was similar for HADS-Depression scores. Fisher's exact tests were used for categorical variables and Wilcoxon rank-sum tests were used for continuous variables. All tests were two-sided, with $P \leq .05$ considered statistically significant. Independent variables that were significant at $P < .2$ (2-tailed) were entered into multivariate logistic regression models for dichotomous outcomes and multivariate linear regression models for continuous outcomes. A manual stepwise backward elimination sequence was used, keeping all variables in the model that achieved significance at $P \leq .05$ (2-tailed), to identify the most parsimonious models.

Results

Fifty-two of the 57 eligible patients (91%; 50 women, 2 men) whom we approached completed the survey. Median age at MBC diagnosis was 52 years (range, 22-81) and the median time between MBC diagnosis and survey completion was 6 months (range, 1-12). Of the total, 92% were white, and 75% reported having completed college or post-graduation education (Table 1).

Informational needs – TINQ results

The TINQ scores ranged from 105 to 255, with 36/52 patients (69%) having a total score of $\geq$ 200, suggesting high informational need. The mean TINQ score was 212 (SD, 33.9), and the median score was 221. Of the 5 subscales, treatment information was the most important, followed by information about the disease, physical care, psychosocial needs, and investigative tests. The most important informational issues for patients were: whether there was cancer anywhere else in their body (mean, 4.78), how to deal with side effects (mean, 4.78), and whether there were ways to prevent treatment side effects (mean, 4.77; Table 2).

In univariate analyses with TINQ as the outcome, the only variables that reached statistical significance were DFI ($P = .0026$), with patients who had a shorter DFI requiring more information; and whether patients lived alone ($P = .0272$), with patients living with others having higher

TABLE 1 Characteristics of metastatic breast cancer patients

Characteristic	Value
Age, y (range)	
Median, at initial diagnosis	45.5 (22.3-76.8)
Median, at metastatic diagnosis	51.6 (22.4-80.8)
DFI,ᵃ years	
0	12
< 5	25
> 5	15
Median time between metastatic diagnosis and completion of questionnaire, mo (range)	5.5 (0.9-12.4)
Race, n (%)	
White	48 (92)
Black, Haitian, or African American	2 (4)
Did not provide	2 (4)
Children, n (%)	
0	9 (17)
1-2	24 (47)
> 3	19 (37)
Employment status, n (%)	
Employed	40 (77)
Unemployed	11 (21)
Unknown	1 (2)
Highest level of education, n (%)	
High-school graduate or GED	6 (12)
Technical/vocational	2 (4)
Some college	5 (10)
College graduate	23 (44)
Post graduate	16 (31)
Marital status, n (%)	
Married/living with domestic partner	34 (66)
Divorced/separated/widowed/ never married	18 (34)
Total combined income, n (%)	
Less than $11,999	3 (6)
$12,000-$15,999	3 (6)
$16,000-$24,999	3 (6)
$25,000-$34,999	1 (2)
$35,000-$49,999	3 (6)
$50,000-$75,999	7 (13)
$75,000-$99,999	6 (12)
> $100,000	25 (48)
Don't know	1 (2)

TABLE 1 *continued from page 349*

Characteristic	Value		Characteristic	Value
Disease stage, n (%)			**Sites of metastasis at baseline, n (%)**	
1	4 (8)		Brain	3 (6)
2	16 (31)		Liver	24 (46)
3	16 (31)		Lung	13 (25)
4	16 (31)		Bone	30 (58)
Tumor subtypes, n (%)			LN	20 (38)
Triple negative	12 (23)		Others	12 (23)
HER2+	10 (19)		**No. of metastatic sites, n (range)**	
ER+/PR+	29 (56)		Median	2 (1-5)
Unknown	1 (2)		Mean	2.02
Surgery type, n (%)			**Lines of therapy at time of completion of questionnaire, n (range)**	
Lumpectomy	16 (31)		Median	1 (1-4)
Mastectomy	21 (41)		Mean	1.38
NA	15(29)		**First-line metastatic therapy**	
Adjuvant/neoadjuvant chemotherapy, n (%)			No. patients still on first line at time of completion of questionnaire	36
Anthracycline only	4 (8)		Median duration, mo (range)	3.2 (0.0-9.1)
Taxane only	2 (4)		**Type**	
Anthracycline + taxane	22 (42)		Chemotherapy	20 (39)
Others	3 (6)		Hormonal	23 (44)
No chemotherapy	5 (10)		Anti-HER2	2 (4)
NA	16 (31)		Chemotherapy + anti-HER2	3 (6)
Adjuvant radiotherapy, n (%)			Anti-HER2 + hormonal	4 (8)
Yes	28 (54)		**Level of activity in past month, n (%)**	
No	8 (16)		Fully active, able to carry on all usual activities without restriction	28 (54)
NA	16 (31)		Not fully active	24 (46)
Adjuvant hormone, n (%)			**Status of breast cancer within past month**	
Yes	22 (42)		Worsened/progressed	5 (10)
No	13 (25)		Stable	15 (29)
Na	16 (31)		Shrunk	15 (29)
Adjuvant trastuzumab, n (%)			Don't know	17 (33)
Yes	4 (8)			
No	32 (62)			
NA	16 (31)			

DFI, disease-free interval; ER+, estrogen-receptor positive; GED, General Education Development test degree; HER2, Human epidermal growth factor receptor 2; LN, lymph nodes; NA, not applicable; PR+, progesterone-receptor positive

ᵃDe novo metastatic patients were not included in determining the median DFI.

informational needs. There were no other statistically significant differences between the 2 groups defined by high or low TINQ score for all the other variables. In the multivariate model with TINQ as the outcome, patients who were married or living as married were more likely to have high informational needs (odds ratio [OR], 6.1; 95% CI, 1.3-28.9). Patients with de novo MBC (OR, 2.8; 95% CI, 0.5-14.3) or a DFI of < 5 years (OR, 24.2; 95% CI, 3.1-

TABLE 2 Most important information as perceived by patients[a]

Rank	Question	Category	Mean score	SD
1	If there is cancer anywhere else in my body	Disease	4.78	0.636
2	If I have side effects, how to deal with them	Treatment	4.78	0.456
3	If there are ways to prevent treatment side effects	Treatment	4.77	0.421
4	Who I should call if I have questions while I am still getting treatment	Treatment	4.73	0.485
5	What types of treatment are available	Treatment	4.73	0.563
6	Why the doctor suggested this treatment plan for me	Treatment	4.73	0.629
7	How to prepare for my treatment	Treatment	4.71	0.497
8	If the breast cancer will come back	Disease	4.67	0.809
9	The possible side effects of my treatment	Treatment	4.67	0.548
10	What side effects I should report to the doctor/nurse	Treatment	4.67	0.676

[a]Patients were asked to rank how important this information was on a 5-point Likert scale on which 1 = *not important* and 5 = *extremely important*. Means scores are reported here.

187.4) were more likely to have more informational needs compared with patients with DFI ≥ 5 years (C statistic, 0.824).

Anxiety and depression – HADS results

In all, 20% of patients (10/51) met criteria for anxiety and 4/51 (8%) met criteria for depression by HADS (scores of ≥ 11). The mean scores were 6 and 4 for the anxiety and depression subscales, respectively. One patient had more than 1 missing answer in the anxiety subscale, and another patient had more than missing answer in the depression subscale. The respective subscales were thus deemed invalid for those 2 patients (Table 3).

In the univariate analysis with HAD S-Anxiety as the outcome, HADS-Depression ($P < .0001$) and MCS ($P = .0002$) were statistically significant variables. In the multivariate model with HADS-Anxiety as the outcome, patients with lower MCS scores were more likely to have a HADS-Anxiety score of ≥ 11 (OR, 1.2; 95% CI, 1.1-1.4; C statistic, 0.9). Analyses were not performed with HADS-Depression as an outcome because of the small number of events (4 people had scores > 11).

Quality of Life-SF-36 results

SF-36 scores were lower in all 8 subscales compared with the general population. In particular, scores for social functioning (mean, 39.2; SD, 14.1), role limitations due to physical functioning (mean, 40.6; SD, 12.1), and role limitations due to emotional problems (mean, 42.4; SD, 13.3) were diminished. The PCS and MCS mean scores were 44.4 (SD, 11.9) and 43.9 (SD, 11.5), respectively (Table 4).

In the univariate analysis with PCS as the outcome, total combined income ($P = .0134$) and the level of physical activity ($P < .0001$) were statistically significant variables ($P < .0001$). Patients with a lower total combined income had lower PCS scores and patients who were fully active had higher PCS scores compared with patients who were not fully active. In the univariate analysis with MCS as an outcome, patients who had an HADS-Anxiety or HADS-Depression score of ≥ 11 had lower MCS scores ($P = .0002$ and $P = .0142$, respectively).

In the multivariate model with PCS as an outcome, 2 variables were statistically significant; physical activity in the past month and educational level. Patients who were fully active had higher PCS scores by 16.2 points, compared with patients who were not fully active (95% CI, 11.5 to 21.0). Patients who had higher education levels had higher PCS scores by 7.3 points, compared with patients with lower education levels (95% CI, 1.8 to 12.7). The multivariate analysis for MCS revealed very similar results as the multivariate analysis for the HADS-Anxiety, and the results are not presented here.

Discussion

We conducted a cross-sectional evaluation of patients within the first year of MBC diagnoses to explore and describe the informational needs and QOL of this understudied population. We found that most patients had high informational needs and were most interested in the information about treatment and disease. Overall, these patients also had poorer QOL compared with the general population, with a small proportion of patients experiencing significant anxiety and a few patients experiencing significant depressive symptoms.

Our results are consistent with the literature, with information about treatments and disease being highly impor-

TABLE 3 Hospital Anxiety and Depression Scale scores

	HADS-Anxiety	HADS-Depression
Patients responding, n	51[a]	51[a]
Mean score (SD)	6.3 (4.4)	3.8 (3.5)
Median score	5	3
Observed range	0-17	0-13
Grouped results, n (%)		
0-7 (normal)	33 (65)	43 (84)
8-10 (borderline)	8 (16)	4 (8)
11-21 (substantial)	10 (20)	4 (8)

[a]One patient had more than 1 missing answer in the subscale was thus deemed invalid.

tant to patients.[15,21] Mayer and colleagues administered 2 questionnaires to patients with MBC: an online needs assessment of 618 patients, and a global survey of 1,342 patients living in 13 countries. In addition to having high informational needs about treatment and disease, 73% of patients who completed the online needs assessment reported seeking information daily or weekly, and 76% of patients in the global survey reported that they took an active role in searching for more information on MBC. [21] Our study, along with Mayer's results, implies that patients with MBC have high informational needs. However, our study used the TINQ, a validated standardized questionnaire[19,20,31] that allows for comparison across studies. Of note, the TINQ addresses the perceived importance of various types of information, and does not specifically focus on patients' unmet needs.

To our knowledge, there have been no previous studies examining the relationship of living with others and requiring more information in the cancer setting. It is possible that patients who live with others or have significant people in their lives, may require more information as the patients may need to consider how their disease may affect their loved ones.

There is also limited literature about DFI and the need for information. Our study suggests that patients who had shorter a DFI required more information. A shorter DFI typically suggests poorer prognosis, and it is conceivable that patients who are in close proximity to their original cancer diagnosis may require more information. These results need to be taken with caution as this study was conducted in a small number of patients and larger studies would needed to verify these results.

The proportion of patients (20%) who met criteria for anxiety in the HADS is lower in our study than that in a study by Turner and colleagues, who reported that 35%-60% of patients with MBC experience anxiety. [26] Although cross-study comparisons are limited because of the differ-

ences in the study populations, the patients in Turner's cohort were patients who had been diagnosed with metastatic disease for less than 6 months and who had a mean time of 10 weeks since diagnosis of metastatic or recurrent disease. Our study, which recruited patients who had been diagnosed with metastatic disease within the past year, had a median time since diagnosis of metastatic disease of 5.5 months (mean, 6.2 months) and more likely reflects patients' experiences as they are adjusting to the diagnosis of MBC. Further research using longitudinal studies should be performed to confirm the relationship between anxiety and time in patients with MBC, and optimal management strategies.

Our patients had lower scores in all subscales in the SF-36 compared with the general population. This is consistent with findings from Frost and colleagues, who found that patients with recurrent breast cancer often experienced more difficulties with their well-being compared with patients who were newly diagnosed, who were receiving adjuvant therapy, and who had stable disease.[32] In our cohort, the subscales with the lowest scores were social functioning, role limitations due to physical health, and role limitations due to emotional problems. This is in contrast to the Frost study in which the subscales with the lowest scores were physical functioning, role limitations due to physical health, and health perception. A possible reason for this difference may be because of the different comparative groups. As our study included 2 male patients, our study compared SF-36 scores to the general population. Frost and colleagues compared the scores of patients with recurrent disease with other patients with breast cancer. [32]

Although it was reassuring that the level of physical activity (univariate $P < .0001$) was a significant predictor of PCS, total combined income was also a significant predictor (univariate $P = .0134$). Patients with lower total combined incomes had lower PCS scores suggesting that they had worse health-related QOL. In the multivariate model, lower levels of physical activity and education predicted worse PCS scores. Given that lower socioeconomic status has been shown in previous studies to be associated with lower QOL, in particular physical health, future studies should continue to evaluate financial concerns in this population. [33,34]

We note there is potential overlap between the HADS and the MCS, but were reassured that these scores were similar and generally reflected that patients with lower MCS scores were more likely to have a HADS-Anxiety score of ≥ 11.

Limitations
This study was performed in a single, academic institution which may attract patients who seek more information,

increasing the likelihood that these patients will have high informational needs. In addition, this study displayed a disproportionately large proportion of younger patients, compared with the general population of patients with MBC. It is however, reassuring that the findings are consistent with those of Mayer and Turner and their colleagues.[21,26] Most of the patients were white, well educated, and had annual incomes of more than $50,000. The homogenous nature of this cohort might have limited the generalizations to other populations of patients with MBC. Larger studies will be required to determine more definitively patient factors influencing informational needs and QOL. This study was also of a modest size and was an exploratory project aiming to characterize more fully the informational needs and QOL of this understudied population. Future studies are warranted to determine the relationship between informational needs and QOL in this population. In addition, we recognize that this is a cross-sectional survey of patients diagnosed within the first year of MBC. Informational needs may change depending on the course of disease, and longitudinal evaluation may help elucidate informational needs over time.

Implications

We found that patients with MBC in our cohort have high informational needs, with treatment and disease information being highly important. Although we acknowledge that our results represent the results of a group rather than individual needs, this is meant to provide a guide for providers. The perception of the informational needs of patients by health care providers has been shown to differ from what information patients actually want.[31] In addition, patients may not raise questions about treatment or disease to their physicians for a variety of reasons. As good medical care would dictate, practices should routinely ask patients about symptoms and some are developing systems to do this more systematically.[35,36]

Our findings suggest that clinicians should routinely ask patients how much information they would like to know, what information they would find useful and whether they feel that they have been given sufficient useful information. Such inquires could even be done as part of a simple questionnaire while patients are waiting to be seen by their physician. There may also be many instances where the informational needs of patients cannot be met- where there is no evidence-based information or where there is no clear answer for questions that patients may have. In these situations, other approaches such as helping patients deal with ambiguity and uncertainty may play a bigger role in helping patients cope with their disease.

Our recommendation, along with others, is for steps to be taken within health care organizations to ensure that there are ongoing informational needs assessments and

TABLE 4 Descriptive data on quality of life based on the Medical Outcomes Study Short Form-36

Variable	Mean[a]	SD	Median
Physical functioning	45.2	10.6	46.7
Role-physical	40.6	11.7	42.1
Bodily pain	46.2	11.7	46.5
General health	45.3	12.3	48.5
Vitality	45.6	11.1	46.7
Social functioning	39.2	13.9	38.1
Role-emotional	42.4	13.9	44.8
Mental health	46.8	10.2	48.2
PCS	44.4	11.9	45.9
MCS	43.9	11.7	44.7

PCS, Physical Component Summary scale; MCS, Mental Component Summary scale
[a]General population mean score, 50 (SD, 10). Scores < 50 reflect functioning less than the general population.

education as a routine part of comprehensive cancer patient care.[37,38] Educational tools such as booklets and online sites attempting to enhance the information exchange experience for patients with advanced disease should be considered. As a result of this study, we presented the data to our colleagues at our educational meeting, and highlighted the importance of giving patients the opportunity to ask questions, especially about treatment and disease. We have also organized a metastatic breast cancer forum, addressing some of the informational needs of the patients. The forum received positive feedback, and we have received requests for more of similar events to be organized.

The overall QOL seems to be worse in patients with MBC compared with the general population. In particular, the roles and functioning status of these patients seem to be particularly affected. Interventions to improve symptom management and psychosocial support for these patients should be continued to be developed and assessed. Given that patients with MBC are living longer, it is imperative that living longer does not mean living longer suffering, but living a good QOL in one's remaining days.

Conclusions

In summary, patients with recently diagnosed MBC have high informational needs and decreased QOL. The overall QOL seems to be worse in this population of patients compared with the general population. There is also a subset of patients who are dealing with significant anxiety and depression. Additional research, education, and supportive care services aimed at meeting the informational and psychosocial needs of patients living with MBC are warranted.

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