

Assessing Breast Cancer Survivor Needs for Treatment Decision Support

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Introduction

- As breast cancer treatment advances, survivors are confronted with more complex treatment decisions; yet, patients are not fully prepared for communicating effectively with their doctor (IOM, 2007).
- In order to understand gaps in care and to inform future directions for innovative programming in decisional support, the Cancer Support Community asked a series of treatment decision related questions to breast cancer survivors who participate in the *Breast Cancer M.A.P. (Mind Affects the Physical) Project*, an online registry designed to examine the social and emotional needs of breast cancer survivors.

Purpose

- Identify the quality of decision support breast cancer survivors receive in making treatment choices that relate to:
 - gathering information
 - asking questions
 - arriving at a decision
- Assess survivor needs and inform future directions for community-based decision support interventions

Methods

- Over 2,900 breast cancer survivors have joined the *Breast Cancer M.A.P. Project*, an online registry designed to examine the psychosocial impact of breast cancer.
- In October 2010, 962 registrants were asked to log back into their *M.A.P. Project* account and answer a series of questions about their treatment decision process and communications with the medical team.

Sample Characteristics (N=962)

Female: 99%
 Ethnicity: 88% Caucasian
 Mean Age: 55
 Education: 71% At least a college degree
 Employment: 41% Work full time (40 hrs/week)
 Annual Household Income: 18% ≤ \$40K
 Mean Age at Diagnosis: 50
 Years Since Diagnosis: 5.5
 Stage: Over half Stage II +
 Recurrence: 13%

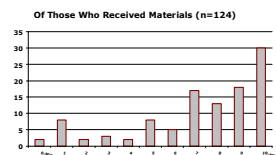
Results

- 80% (767 of 958) reported a surgeon was the first specialist they saw, 16% (158 of 958) saw a medical oncologist, 1% (11 of 958) a radiation oncologist, and 3% (22 of 958) other.

Gathering Information

- 15% (128 of 880) reported that their doctor provided them information materials prior to the first visit with the specialist.
- Of those who received information materials before the first visit, 30% were completely satisfied with the materials they received.

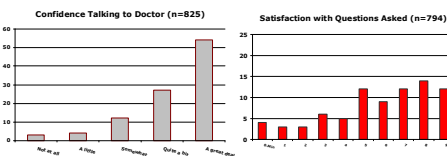
Satisfaction with Materials Received before 1st Visit



- 54% (439 of 819) reported it was of maximum importance (10/10 rating) to get "help with gathering information before your first meeting with a surgeon/oncologist".

Asking Questions

- 54% (448 of 825) of registrants felt "a great deal" or "quite a bit" of confidence talking with their doctor.
- Virtually all (96%, 826 of 858) registrants reported asking questions on their first visit with their breast specialist.
- Of those who asked questions on the first visit, the mean level of satisfaction with the questions they asked was 6.7 out of ten (SD=.10; n=794), with 10 indicating maximum satisfaction.
 - 11% were completely satisfied (10/10 rating) with the questions they asked their doctor on the first visit.



Results, cont.

- 54% (407 of 761) of registrants brought a written list of questions to their first visit with a breast specialist. However, 34% (279 of 834) of registrants answered that "yes" they forgot to ask questions during their first visit.
- When asked what registrants may need help to prepare for their visit with a breast cancer specialist,
 - 65% (531 of 816) of registrants stated that it was of maximum importance (10/10 rating) for getting assistance with taking notes during their first visit
 - 59% (485 of 820) reported it was of maximum importance (10/10 rating) to get assistance with developing a written list of questions, goals and concerns before their first visit

Arriving at a Decision

- More than half (52%, 441 of 832) of registrants arrived at a treatment decision during their first visit.
- Those who made a treatment decision during the first visit were significantly more satisfied with their doctor's explanation of the risks and side effects of each treatment option than those who did not make a treatment decision at the first visit (p<.01).
- Those who made a treatment decision at the first visit were also significantly more satisfied with their doctor's explanation of the benefits of each treatment (p<.001).



- Registrants rated maximum difficulty (10/10 rating) making the following treatment decisions:
 - 13% (69 of 533) reconstruction
 - 12% (92 of 757) adjuvant therapy
 - 10% (69 of 722) symptom management
- 43% (341 of 800) were completely satisfied (10/10 rating) with the outcome of the treatment they chose.
- 42% (347 of 821) were completely satisfied (10/10 rating) with how much they participated in the treatment decision.
- 40% (326 of 810) were completely satisfied (10/10 rating) with how they arrived at a treatment decision.

Conclusion

- Survivorship starts at the time of diagnosis because the treatment decisions patients make have long-term implications on their quality of life. Over half of patients are making treatment decisions on the first visit with the breast cancer specialist following their diagnosis. We also learned from the *M.A.P.* registrants:
 - Very few receive information materials from their doctor prior to the first visit with the breast cancer specialist
 - Among those who received information materials, a substantial proportion were not fully satisfied
 - Approximately one-third forgot to ask questions that they wished they had asked on the first visit, and only 21% were completely satisfied with the questions they asked the doctor
 - Several want assistance with developing a written list of questions prior to the first visit taking notes during the first visit audio taping the first visit
 - Those who are more satisfied with their doctor's explanation of the risks and benefits of their treatment options are more likely to make a treatment decision at the first visit. This merits further exploration.

Future Directions

- Innovative programs need to be evaluated and developed to:
 - Connect patients with high quality treatment-related information prior to meeting with the breast cancer specialist
 - Help patients manage complex decision making required by providing decision support before the initial meeting with the doctor
 - Assist patients in identifying their concerns, values, goals for treatment and in developing a written list of questions that they share with their doctor
 - Provide support for note-taking and audio-recording of consultations so that patients can review and process the information provided by their doctor
 - Screen for distress around treatment decisions and provide referrals for decisional support
 - Train professionals to help patients at critical treatment decision making junctures

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Introduction: As breast cancer treatment advances, survivors are confronted with more complex treatment decisions; yet, patients are not fully prepared for communicating effectively with their doctor (IOM, 2007). The Cancer Support Community asked a series of questions about the quality of decision support received in making treatment choices to assess survivor needs and inform future directions for community-based decision support interventions.

Methods: Over 2,700 breast cancer survivors have joined the *Breast Cancer M.A.P. Project*, an online registry designed to examine the psychosocial impact of breast cancer. In October 2010, 962 registrants answered study-specific questions about their treatment decision process and communications with the medical team. This sample was 99% female, 83% Caucasian. The mean age was 55. 71% had at least a college degree. The average time since diagnosis was 5.5 yrs (mean age at diagnosis was 50). Over half were Stage II + and 13% had a recurrence.

Results: 52% came to a treatment decision during the first visit with a breast cancer specialist. Only 14% received materials before the first visit and 20% were dissatisfied with the materials they received. 50% brought a written list of questions to the first visit, and 34% forgot to ask questions they had formulated. 17% were dissatisfied with the questions they asked. Of those who were dissatisfied with the questions they asked, 27% were unsure what to ask and 22% were too overwhelmed. On a 10-point scale, a majority of registrants rated 10 on the importance of: gathering information (52%) and developing a written question list (58%) prior to the first visit; and taking notes during the consultation (66%).

Conclusion: While the majority of patients make their treatment decisions within their first consultation with a specialist, a significant proportion arrive at the meeting unprepared and leave with “question regret”, not having asked questions they wish they had. These findings suggest the need for patient support and information before and during the initial consultation with the breast cancer specialist.