

International Survey Identifies Key Support and Lifestyle Needs of Metastatic Breast Cancer (MBC) Patients

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Background: METAvivor Research and Support, a metastatic breast cancer (MBC) patient-led nonprofit organization, conducted a survey to identify lifestyle and support issues that have the greatest impact on the MBC community and to highlight categories of greatest need. **Methods:** A 2011 MBC patient online survey was distributed through cancer organizations, patient networks and Facebook. **Results:** The 827 respondents from 20 countries were representative of the typical Internet user demographic profile: US (91%), Caucasian (92%), and married or living with a partner/friend (75%). As might be expected for this relatively young cohort (21% aged 45 and under and 37% aged 46-55), 42% still had children at home. Disease status was relatively good (15% NED, 4% in remission and 52% stable), with 72% within four years of diagnosis. A majority of patients (59%) were coping well; some were positive by nature, others by design: *"I work very hard to stay positive and concentrate on the good."* Yet these patients acknowledged their vulnerability: *"I know my circumstance can change at any time."* Most (85%) credited family and friends with helping them cope, along with inner strength (77%), spirituality and religion (53%), exercise (40%), support groups (37%) and hobbies (35%). While some avoided contact with other patients, thinking it would be *"too depressing,"* 80-85% of the more than half who did participate in support programs gave these programs high marks. In-person programs were highly sought after, but the convenience and availability of online communities made them invaluable. *"Discussion boards helped me with nearly every treatment decision and allowed me to make optimal choices that in part led to my NED status".* A significant number (40%) of respondents felt *"outcast"* and *"isolated."* Some expressed anger at the disinterest shown by breast cancer organizations, the media's failure to make MBC a public issue, and the very small amount of MBC research being done. At the time of diagnosis, 75% of respondents were employed, 58% full-time. Half of those employed stopped working, most within a year of diagnosis. Although the majority of these returned to work, nearly half soon stopped again. Life was extremely difficult for the 31% who said they struggled financially: *"I was a stay-at-home mom so have insufficient work credits to collect disability and can't find work."* Finances temporarily interrupted treatment for only 2%, but sacrifices to stay in treatment could be high: *"I'm facing surgery with no place to live."* **Conclusions:** This survey demonstrates critical patient support and lifestyle needs for these predominantly US MBC patients. Immediate disability and health insurance coverage, national and/or regional financial solution hotlines, an educational media campaign, and wide availability of in-person support programs are needed.