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Abstract BP120

Background: META Vivor 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.

Survey Design

Objectives

- To determine the impact of MBC on patient lifestyles
- To determine the availability and relevance of support for the patient
- To determine the most critical support and lifestyle needs

Method: Internet survey

Respondents

- 827 patients from 20 countries
- Mostly US (91%), Caucasian (92%), female (98%), w/partner (75%)

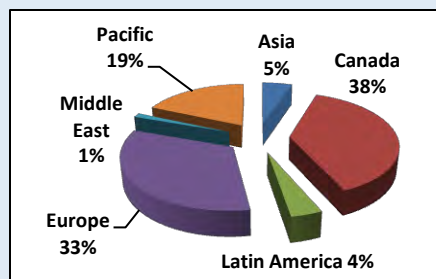
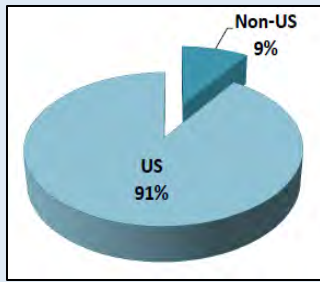


Fig 1. Locations of Non-US Respondents

Fig 2. US vs Non-US Respondents



Age, Spread and Status

- Majority aged 55 and younger
- Almost half had children at home
- Most prevalent spread was bone, liver, lymph nodes and lungs
- Over 70% stable or in remission
- Only 20% of respondents reached five years

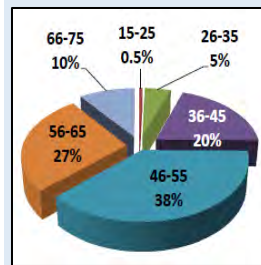


Fig 3. Respondent Age

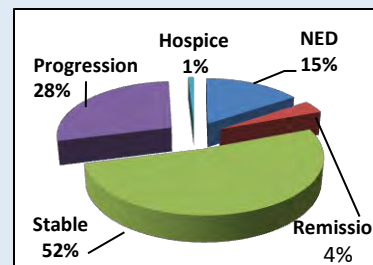


Fig 4. Disease Status

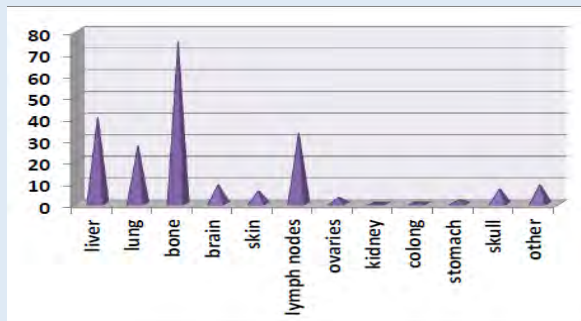


Fig 5. Locations of Spread

Diagnosis

- 19% were initially diagnosed at stage 0 or stage I
- Stage II patients had a higher metastasis rate than stage III
- Recurrence was most common within 9 years of diagnosis; but was reported as late as 25 and more years later
- 31% were initially diagnosed at stage IV

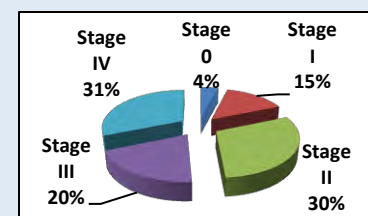


Fig 6. Stage at Primary Diagnosis

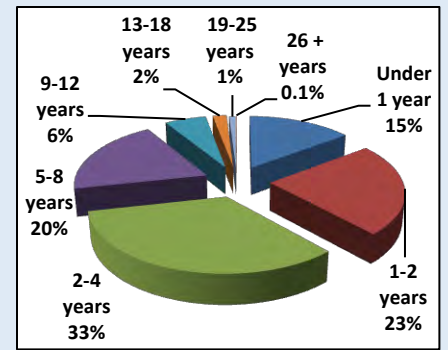


Fig 7. Years Living with MBC

Employment

- Most were employed full-time at diagnosis
- Majority were sole or primary wage earners
- Half initially stopped work due to illness
- Some continued to work or returned to work by choice; others due to financial necessity
- Many families incurred financial hardships

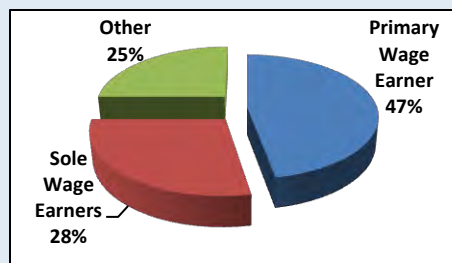


Fig 8. Financial Contribution to Household

Fig 9. Employment Status at Time of Diagnosis

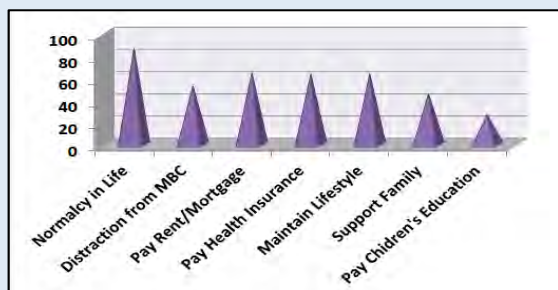
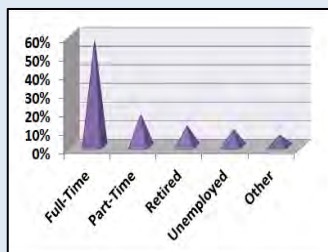


Fig 10. Reasons to Continue Work

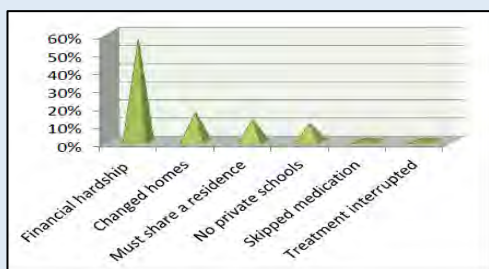


Fig 11. Repercussions of Financial Hardship

Disability Eligibility (USA)

- There is no policy to inform patients of disability rights and resources
- Over 25% unaware they qualified for Social Security Disability (SSDI)
- Most but not all were qualified for SSDI, but many could not stop work for 6-month no-work period needed to qualify

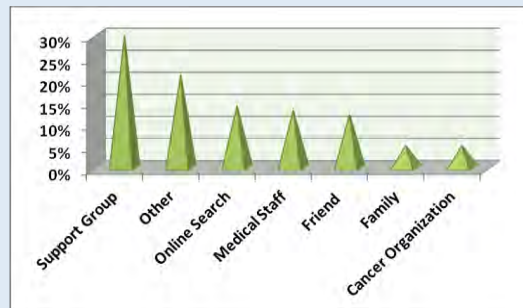


Fig 12. How Patients Learned of SSDI Eligibility

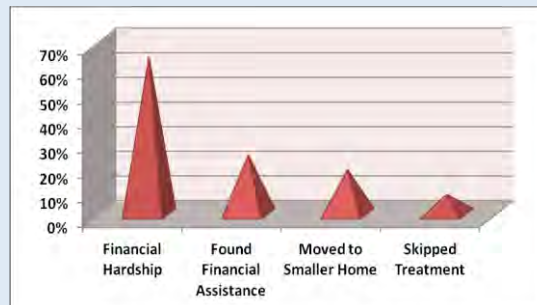


Fig 13. Results of 6-Month "No Work" Delay to Qualify for SSDI

Reason for USA-only disability/insurance sections: Some US respondents also answered the non-US disability/ insurance questions, thus invalidating those results.

Health Insurance (USA)

- Most had health insurance at time of survey
- Most were satisfied with their insurance
- Very few had been without insurance at any time since diagnosis
- Almost half unaware that if on SSDI, you receive Medicare 24-months later

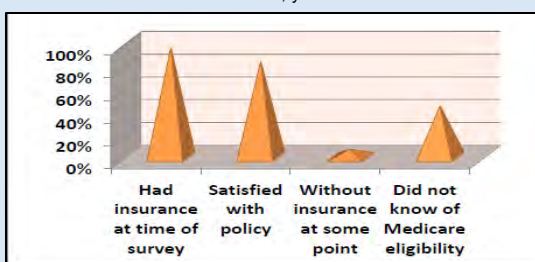


Fig 14. Health Insurance Status

Coping Skills

- A majority coped well
- Family/friends the most helpful; followed by inner strength
- Majority grew closer to partner and children
- 40% felt isolated and outcast by friends and public

Fig 15. Ability to Cope

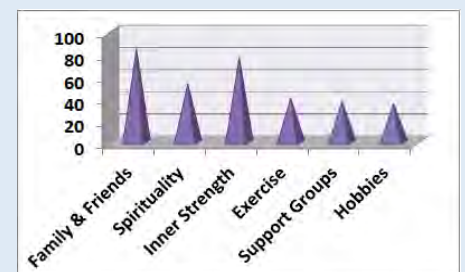
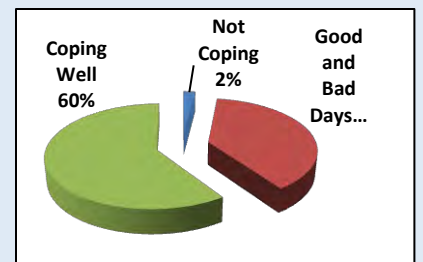


Fig 16. Best Sources of Support

Support

- Majority preferred non-hospital support programs
- Interaction with other MBC patients very popular
- Online discussion boards considered the most useful

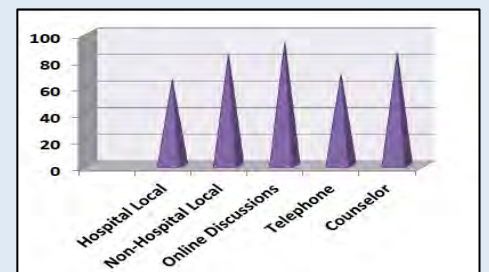


Fig 17. Popularity of Support Programs

Conclusion

- Critical patient support and lifestyle needs for these predominantly USA MBC patients are:
- No-delay disability and health insurance
 - A standardized means to inform patients of available rights and resources at the time of their diagnosis
 - National hotlines for financial assistance
 - Public media campaigns on the realities of stage IV
 - Wide availability of in-person support programs