Key Results From The LIMBER Survey

143 women living with Metastatic Breast Cancer (MBC) completed the survey between Oct 21st-Jan 2022

LIMBER examined how living with MBC is negatively & positively affected by:
- Information provided at diagnosis by doctors & nurses
- Treatment & management choices
- Emotional support
- Information needs
- Communication of diagnosis
- Treatment & management
- Information needs

The Survey
LIMBER comprised 7 sections: -
1) About You
2) Your day-to-day roles & responsibilities
3) Terms used to describe metastatic breast cancer
4) Communication of diagnosis
5) Treatment & management
6) Information needs
7) Final reflections

About you
Average age 52yrs; mean 52.7 (SD 10.1)
96% white; 51% completed higher education
51% had children, 22% a partner

Roles & responsibilities
MBC had a serious impact on people's social life and drive other day-to-day activities for their families

“Telling me I’m brave!”
“Tried to take over/run my life rather than help”
“Saying ‘You look well’ when I feel like s**t.”
“Saying I need to be positive instead of letting me be sad”
“Avoiding me”
“Being over protective”
“Constantly asking for updates”

Terms used to describe MBC

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Information needs
37% prefer verbal information 40% digital/information from family 11% chat with others 67% Google/search 54% nurses 26% doctors 11% friends 45% family did NOT address emotional needs 65% family did NOT provide support for the future 72% family did NOT provide information on the future

Communication of diagnosis
News delivered in person for 88%
Only 58% had someone with them
41% of diagnosis was NOT a surprise but a diagnosis
56% had specialist nurse/key worker
11% said they had been given information about MBC before diagnosis

“Just that it existed!”
“Just that it existed, thank you for the info”
“Just to have it there”

Information delivery
87% provided supportive care
41% offered a trial
11% offered supportive care in pain management
41% did NOT understand
70% asked for information

“Don’t tell me I’m not ill!”
“Don’t tell me that I should be happy!”
“Don’t tell me I should be more positive”

Treatment & management
54% on 1st line of treatment
11% on 4th line or more
51% on targeted therapy/gp support
14% offered a trial

“Deny me in my illness”
“Don’t tell me I’m not ill!”

Final reflections
Things & doctors that did not help (n=103)
“Don’t tell me I’m not ill!”
“Don’t tell me I have cancer”
“Don’t tell me I should be happy”

References
Make2ndsCount & clinicians to make this happen
SHORE-C will work with patient representatives, Macmillan Cancer & charities to make this happen

Advice to new patients

“Do not Google, and ask questions”
“Realise that you still have a life so enjoy it”
“Breath, go easy on yourself, it’s scary but you will be okay”
“Have people around you who will support you”

Things & doctors that did not help (n=103)

Remember that people with MBC have had a tough time before
Don’t ask how I was, don’t ask questions, don’t assume that you understand me

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Conclusion & Next Step
To summarise, further the LIMBER results for publications

Use results to provide the context of current national & international policy, programmes, etc.

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