SHORE-C
Sussex Health Outcomes Research & Education in Cancer

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MAKE 2NDS COUNT
Giving hope to those affected by secondary breast cancer.

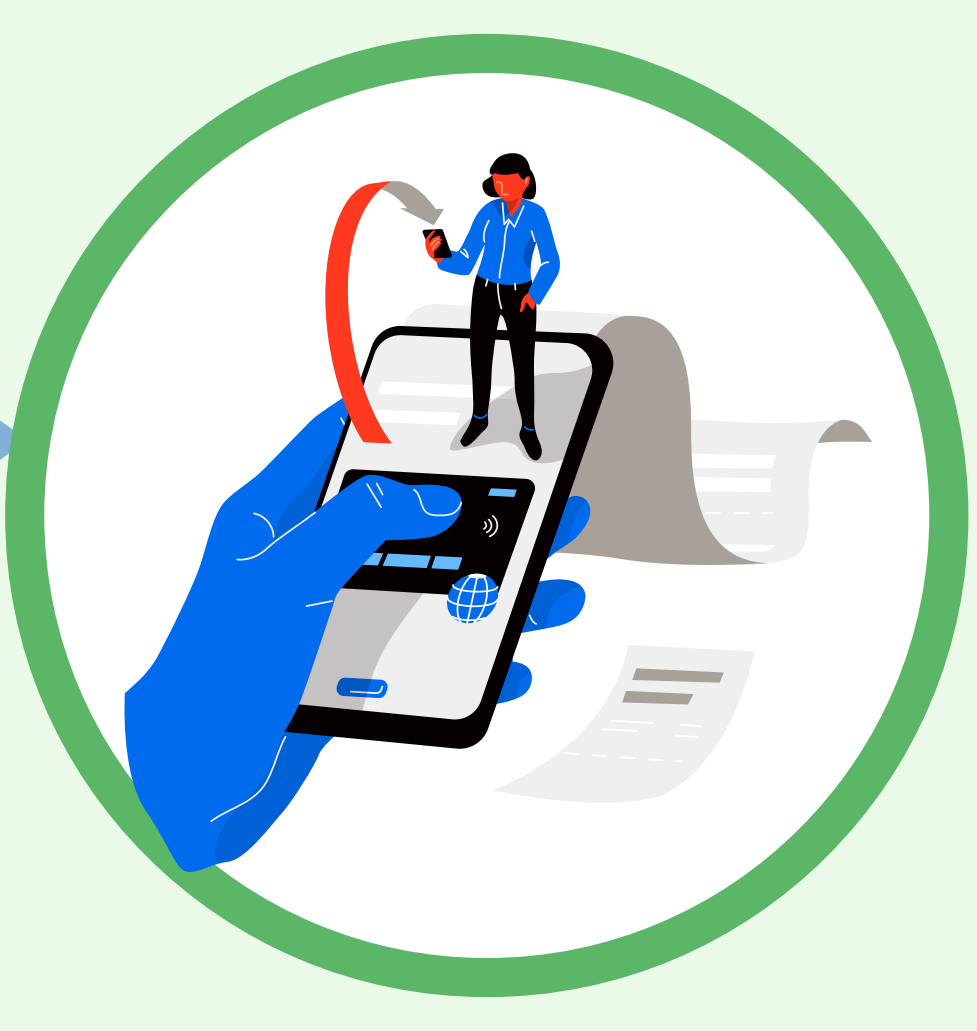
Key Results From The LIMBER Survey

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

LIMBER examined how living with MBC is negatively & positively affected by :

- information provided at diagnosis by doctors & nurses
- treatment & management issues that remain confusing
- supportive behaviours that doctors & nurses did or did not do
- helpful and unhelpful actions of friends & family

The survey also explored the varied caring roles of respondents & potential financial burden of living with MBC



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

1

About you

Average age 52yrs; age range 28-77yrs
90% white; 51% completed higher education
82% had a partner/married
70% nominated partner as main support
33% had a first diagnosis of MBC
33% employed (F/T, P/T self employed)
38% had been living with MBC for over 2yrs

2

Roles & responsibilites

MBC had a serious impact on people's social life and their caring abilities for their families

"It is very disappointing that there has been no attempt to consider the impact it (my illness) has had on, or support for my family."

3

Terms used to describe MBC

Term	Doctors used	Patients preferred
metastatic BC	60%	26%
secondary BC	57%	54%
incurable disease	55%	1%
stage IV BC	47%	11%

Doctors used various terms at different times but the most preferred by patients was Secondary BC

4

Communication of diagnosis

News delivered in person for 88%

Only 58% had someone with them

41% said prognosis was **NOT** discussed at diagnosis

56% had specialist nurse/key worker

71% wished they had known about MBC before diagnosis

"Just that it existed! I had never heard of it - ALL the focus in the media is on early breast cancer."

5

Treatment & management

60% on 1st line of treatment
11% on 4th line or more

57% on targeted therapy e.g. lapatinib
14% offered a trial

31% offered supportive care including pain management

47% still did not understand things about their illness

"How it started?" "Prognosis?"

"If it is hereditary?"

"How targeted therapy works?"

"What lifestyle changes really make a difference?"

6

Information needs

87% prefer verbal information
Get information from:-

- doctor/nurse 60%
- charity websites 61%
- online searches 64%
- support groups 66%

67% indicated dr/nurse did NOT address emotional needs

45% that dr/nurse did NOT consider their lifestyle/culture

""Unsure what I don't know as I am still learning".

"How can it not be seen on scans but be told I still have it?".

"Why am I de novo - why haven't I got a primary?"

Things family/friends did that did not help

"Being over protective" "Constantly asking for updates"

"Avoiding me" "Ignoring it, not talking about it"

"Saying I need to be positive instead of letting me be sad"

"Saying 'You look well' when I feel like s**t."

"Tried to take over/run my life rather than help"

"Telling me I'm brave!"

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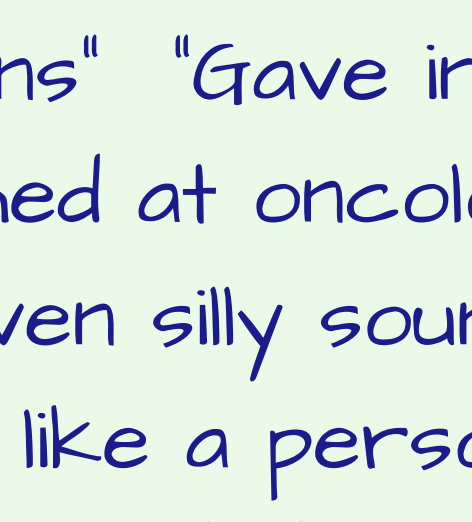


Final reflections

Things drs & nurses did that helped (n=101)

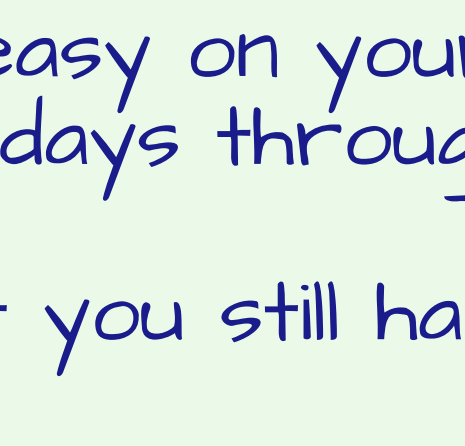
"Answer questions" "Gave information & choices"
"Never felt rushed at oncology appointments"
"Let's me ask even silly sounding questions"
"Making me feel like a person"
"Listened when I needed help"

Things drs & nurses did that **DID NOT** help (n=90)

"Asked me to sign DNR when I went for biopsy"

" Didn't ask how I was, no focus on holistic needs"
"Make assumptions that you know/understand"

"Told me to make a will and memory boxes on the same appointment I was told I had it"



Advice to new patients

"Have people around you who will support you"

"Breath, go easy on yourself, it's scary but you will have better days through the storm."

" Realise that you still have a life so enjoy it"

"Do not Google, and ask questions"

" Join a good support group"

Conclusion & Next Step

To examine further the LIMBER results for publications

Use results to guide the content of educational materials for patients, their carers, drs & nurses

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