Uncovering insensitive platitudes: a survey of people with metastatic breast cancer (MBC)

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Background

People with metastatic breast cancer (PWMBC) are often frustrated and hurt at the insensitive things people say to them (platitudes), which leaves them feeling unseen and misunderstood. PWMBC want others - including family, close friends, healthcare professionals, work colleagues and casual acquaintances - to understand their perspective and be more empathetic and considerate in their communication.

This survey was conducted to:

- Understand the most common and frustrating platitudes that are used with people with MBC
- Identify who is more likely to use the most frustrating platitudes
- Explore the impact of the most frustrating platitudes on people with MBC
- Identify and prioritise which words and actions people with MBC would find more supportive

Conclusions

This survey shows that PWMBC are exposed to insensitive platitudes in their daily life. It can be difficult for them to respond directly to inappropriate comments. PWMBC would prefer offers of practical support that make their life easier and for people to be more empathetic and encouraging in what they say and do. PWMBC do not want to be excluded from social activities because of their condition and would prefer for people to say nothing when there is nothing to say. The differences in the findings between the English and German-speaking respondents may point to some cultural differences between the English- and German-speaking worlds or between younger and older PWMBC.

The survey findings demonstrate a strong need to raise awareness about hurtful MBC platitudes and to foster an understanding of how health professionals, family members, friends, work colleagues and society can communicate in a more sensitive way with PWMBC.

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After Breast Cancer Diagnosis

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Methods

The survey questionnaire was developed based on desk research and interviews with PWMBC to identify commonly used platitudes about MBC. A market research company drafted the questionnaire, which included a mixture of closed-ended and open-ended questions. The face validity of the English version of the questionnaire was tested by two PWMBC and then translated into German. The link to the English version of the online survey was distributed by the patient organisations: abcdiagnosis and METUPUK via online patient communities for PWMBC. The German version was distributed by Mamma Mia!. A screening question was used to exclude people who were not affected by MBC. The quantitative data were analysed using descriptive statistics. A thematic analysis was conducted to identify common themes in the qualitative data.

Results

Perceptions of MBC platitudes

The most negatively ranked MBC platitudes were trite comments about the person's appearance, the value of MBC treatments or that the MBC was caused by certain lifestyle choices. Commonplace sayings that downplayed the seriousness of MBC were also viewed as negative. PWMBC also disliked when others claimed to know what they were going through. Respondents' feedback on different types of MBC platitudes are outlined in figures 1-4.

Perceptions about how PWMBC are labelled

Respondents were asked to provide feedback on the words that people often use to describe PWMBC. None of the words that were tested had positive connotations for the respondents, and most were viewed quite negatively, with words like "sufferer", "warrior" and "fighter" being least appreciated (see figure 5). Overall, the Germanspeaking respondents had more positive perceptions of different words than their English-speaking counterparts.

Figure 1: PWMBC's perceptions about platitudes about their lifestyle (n=249)

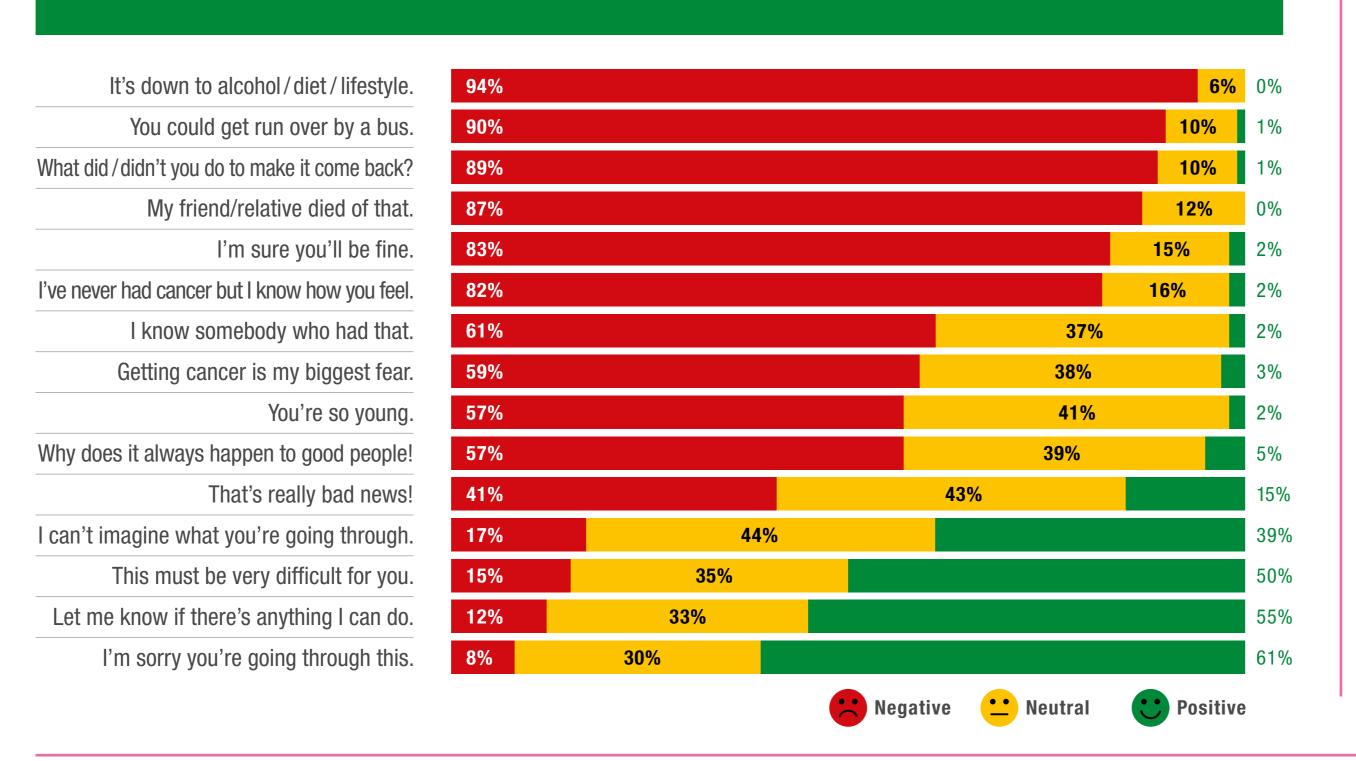


Figure 6: Ranking of people who most often say or write inappropriate

Casual acquaintances

Work colleagues

Close friends

Other health professionals

My family doctor/GP

My psychologist

My breast cancer nurse

My oncologist

Other people with breast cancer

Rank (the lower the average rank, the more often the group shows the most inappropriate behaviour)

My family

or insensitive things to PWMBC (n=249)

Respondents

There were 249 responses, 167 in English and 82 in German. One German-speaking respondent answered the English questionnaire. The respondents who answered the English questionnaire were living in the following countries: UK (87%); Ireland (5%); Switzerland (1%); USA (2%); France (1%); Spain (2%); Other (1%). The German questionnaire was completed by respondents living in Germany (90%); Switzerland (5%); France (1%); Austria (2%) and other (1%). An overview of the characteristics of the respondents can be found in table 1

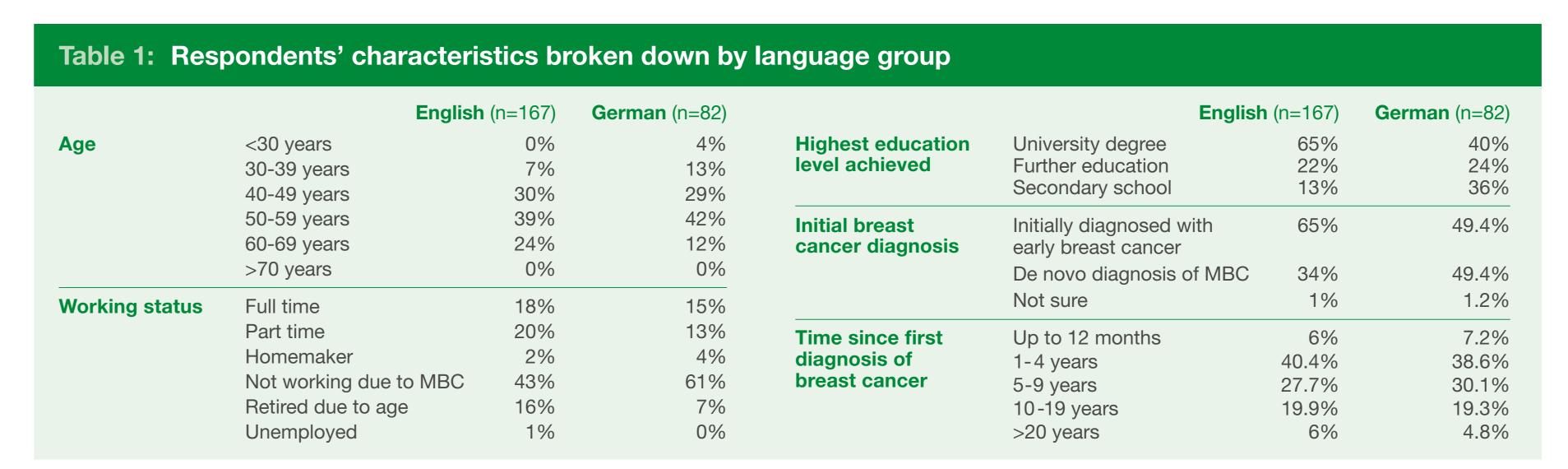
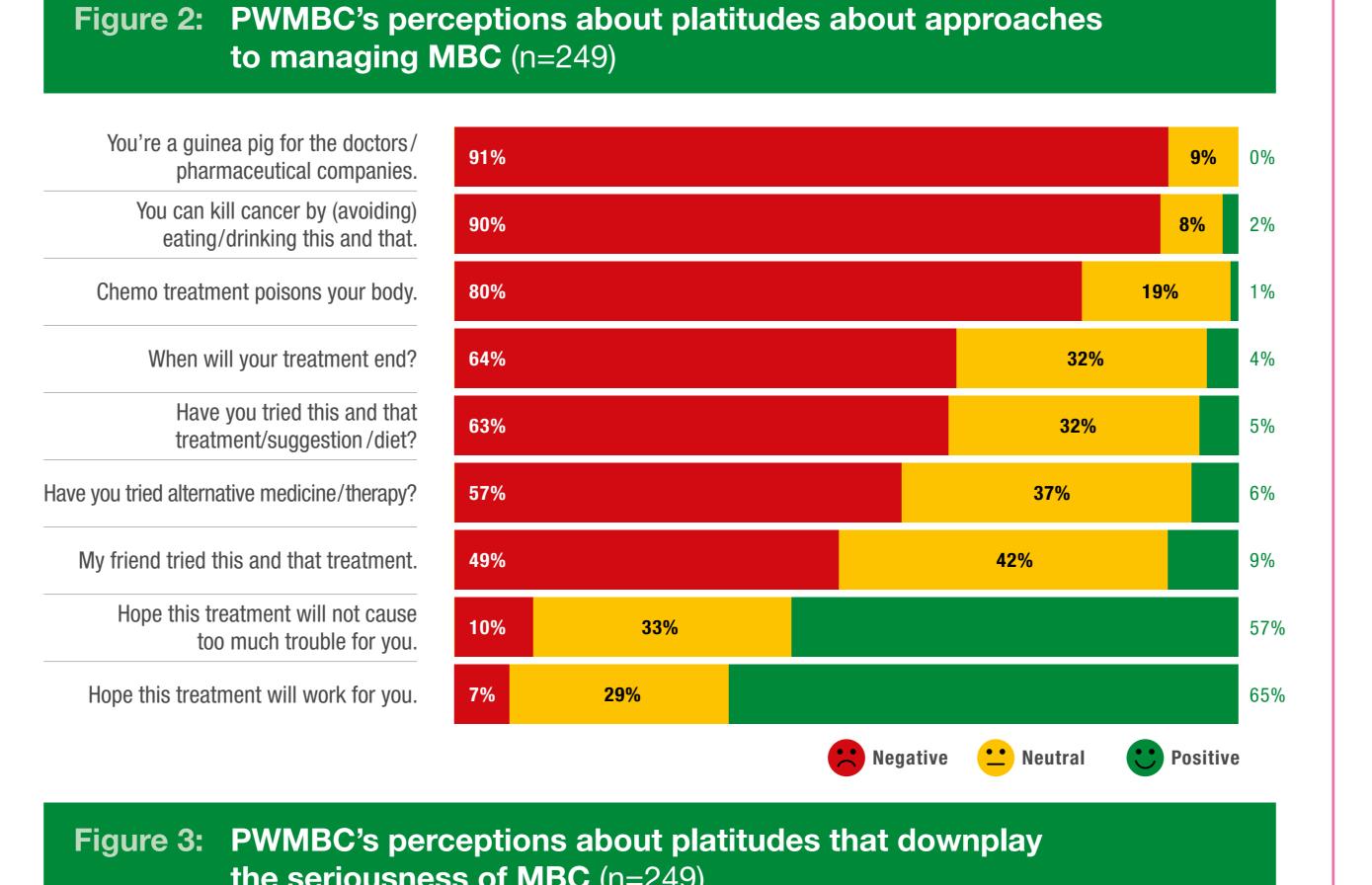
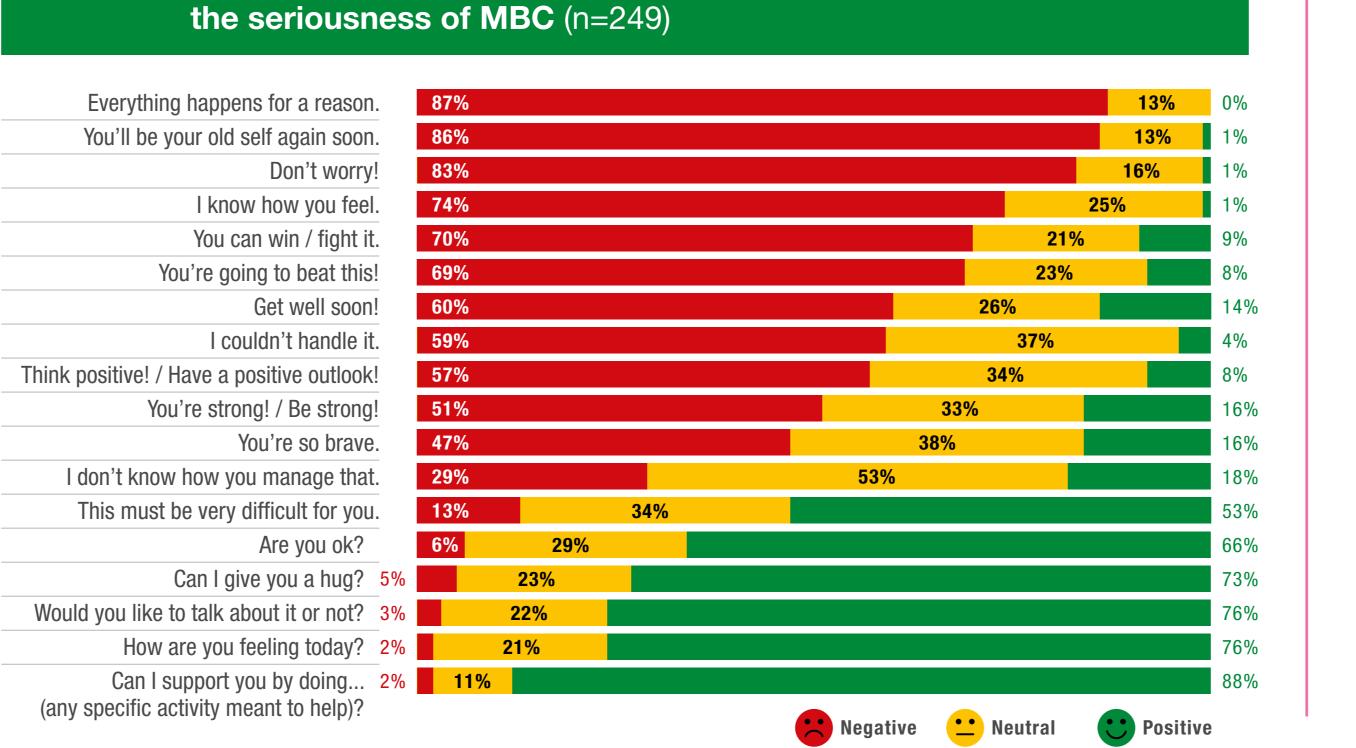
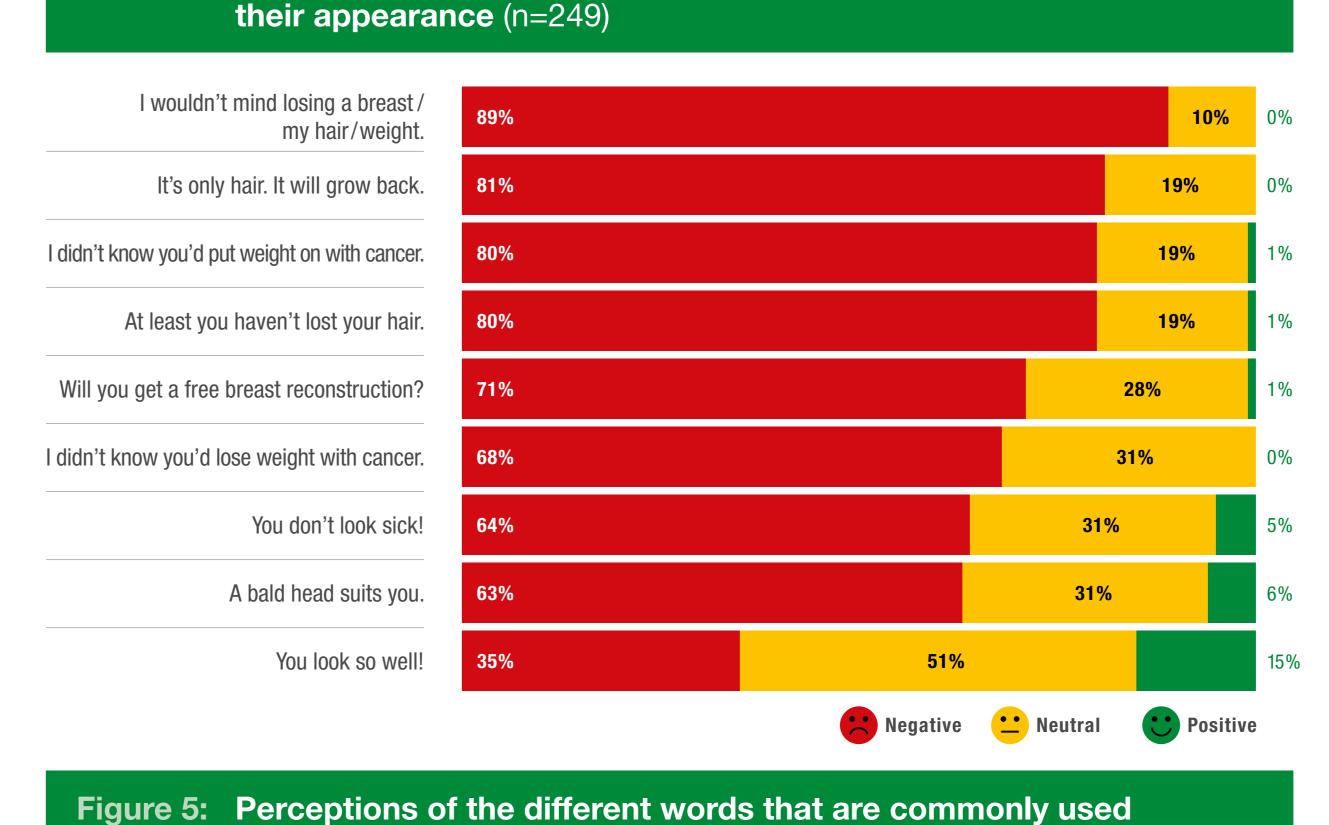
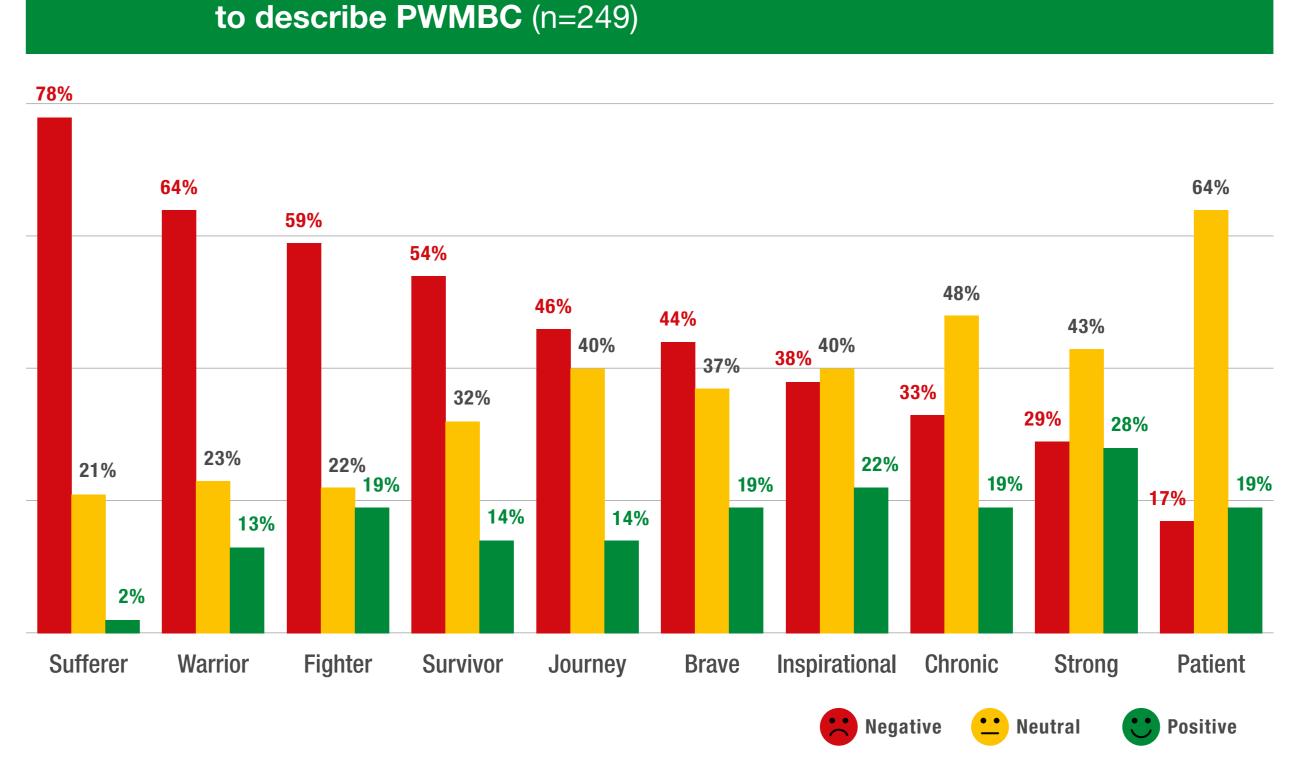


Figure 4: PWMBC's perceptions about platitudes about









Data from the German respondent who answered the English questionnaire included in the German-speaking responses)

Those who say or write the most insensitive things

Respondents indicated that their oncologist and others with breast cancer were least likely to say something inappropriate to them, whereas casual acquaintances and work colleagues were most likely to say something that was insensitive. (see figure 6)

(Rank 1.9

(Rank 2.8

(Rank 4.3)

(Rank 4.9

(Rank 5.

(Rank 5.5

(Rank 6.2)

(Rank 6.3)

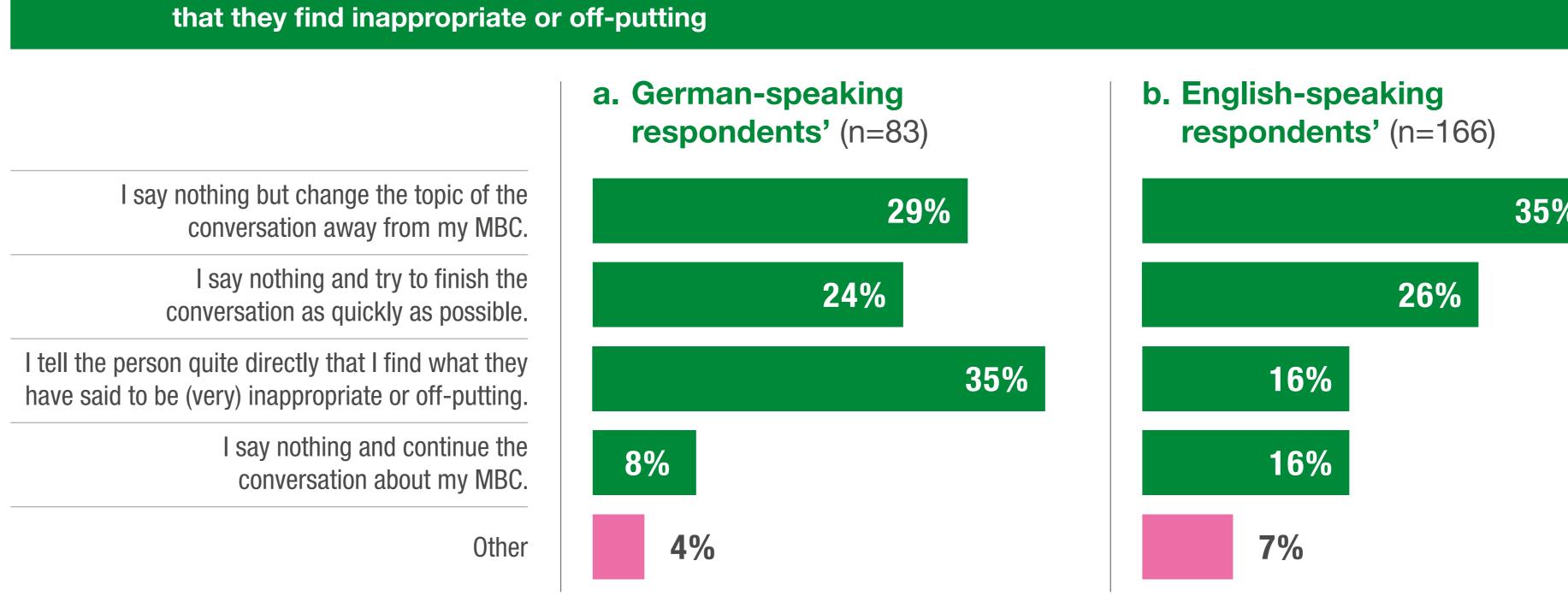
(Rank 6.7

(Rank 7.

PWMBC's approach to dealing with inappropriate or insensitive words

Only a quarter of respondents told people directly when they had been insensitive. German-speaking respondents were more likely to do this (see figure 7a), whereas English-speaking respondents were more likely to say nothing and continue the conversation. (see figure 7b)

Figure 7: Respondents' approach to dealing with words, phrases or questions in everyday life



Words and actions that are most appreciated by PWMBC

Respondents were asked to identify the nicest words or responses that they received from people in connection with their MBC. Their responses were analysed to identify common themes, which are outlined in table 2. Respondents indicated they most appreciated practical support. They also liked to receive caring words and gestures, encouragement and authentic communication that leaves space for difficult conversations, to be treated as normal and for people to simply say nothing.



Common themes	Frequency theme was mentioned	Description of theme
Practical support	103	Be genuine and concrete in offers of support that will make the person's life easier. Be present with the person when and where they need it.
Caring words and gestures	86	Use empathetic words and actions that make the person feel loved and cared for.
Encouragement	56	Encourage, praise and compliment the person about how they are coping with the reality of living with MBC.
Authentic communication	56	Genuinely enquire as to how the person is feeling or coping, and be ready to discuss, whatever their answer. Rather than actively avoiding painful and difficult conversations, leave space for them to speak about topics such as death and dying.
To be treated as normal	27	Treat the person as you normally would, remembering they are a person before being a patient. Offer to do normal things together, while being flexible enough to cancel or postpone if needed.
Nothing	18	Know when it is right to say nothing at all, rather than filling the silence with an insensitive 'platitude'.

Results of the thematic analysis of the 249 responses to the question (combined English and German results). Multiple answers were possible (total >100%)

Examples of the nicest things that PWMBC heard from others when speaking about their MBC:

⁶⁶ Can I do (insert chore) for you, please? [Rather than just: 'is there anything you need, let me know' or 'if anything happens, get in touch']"

"Actual offers of practical help, i.e., I can come with you/take you to your appointments/I can do some shopping/walk the dog/come sit with you - if that will help"

"They will sit with me and hold my hand. Sometimes you don't need words, just for someone to be there to help in whatever way"

"A message that says: 'I am thinking of you, no need to reply"

Your illness is a part of you, but you're much more than that..."

I admire how you deal with it - for staying positive despite everything you're going through"

"I wish the fact that I am terminally ill was not constantly actively denied or 'forgotten'"

"I understand you might not feel up to committing to something, but we will include/invite you as we want to see you and spend time with you"

When people treat you like they did BC (before cancer), not always having to mention it, talking about other things. I'm not just my cancer diagnosis"

> **People who listen and try to understand that this is forever. I'm not going to be cured and I will always be on treatment"

"I don't want you to die.' In that moment there was both love and acknowledgement of [the] eventual outcome. It was open, honest, heartfelt and enabled further conversation"

[£]Encouragement from those who see the struggle for what it is and acknowledge with no expectation to reply"

Survey limitations

There are several limitations to this survey which means that care should be taken when interpreting the data and generalising its findings to everyone with MBC. A convenience sample was used, respondents were recruited via online patient communities, and the questionnaire was only available in English and German. Respondents tended to be younger women, well-educated women who had been living with breast cancer for over 5 years. 39% of them had been diagnosed with de novo MBC. This means that the experiences and opinions of everyone affected by MBC may be under-represented in the survey findings.