

Background

Shared decision making requires patients with metastatic breast cancer and their care teams to make complicated choices between diverse and unfamiliar treatments. Patient input is vital to ensure productive discussion, but it is required at a time when the patient is emotionally vulnerable. Qualitative research provides the understanding of patient preferences which can help care-teams guide patients through difficult decisions. The findings of this research helped inform the design of a discrete choice experiment questionnaire.

Aims

To use a range of qualitative sources to identify the most relevant goals of treatment and relative importance of outcomes for metastatic breast cancer patients.

Methods

Three study designs were employed in parallel work packages (WP):

- (1) a systematic review of the qualitative literature in the area of metastatic cancer
- (2) a thematic analyses of 9 metastatic breast cancer patient interviews
- (3) secondary data from the Scottish Medicines Consortium.

Discussion

A broad portfolio of qualitative evidence can provide diverse perspectives and tell us why a treatment outcome such as overall survival is important, but quantitative evidence is required to understand relative importance to other treatment outcomes such as specific toxicities.

Results

We found strong evidence across all WPs that extending overall survival was a dominant goal of treatment. This preference only diminishes in special cases where there are either exceptional levels of pain, debilitating symptoms and side effects, or the condition is putting the patient and their family under severe financial strain. Secondly, specific symptoms and side effects, such as nausea, fatigue and diarrhoea, became concerning for patients when they began to interfere with the patient's daily living, for example when they limited the patient's ability to leave the house or complete basic tasks. Finally, the patient's concept of making the most of their final days did not involve grand new experiences but rather to continue living their life as they had before their incurable diagnosis.

Lay Summary

A variety of methods were used to identify the key issues for patients with metastatic breast cancer when engaging in discussions about their choice of treatments. Patients often have a high degree of trust in their care teams and don't always prefer to take an active role in treatment decision making - other patients appreciated the opportunity. The common goals of treatment, however, remain consistent. Patients wish to have manageable symptoms and side effects which will enable the closest approximation to a normal life while also extending their survival.

Results - Systematic Review

We have selected key findings from six aspects of treatment which featured prominently in the identified literature

Physical Functioning

- Physical limitations are a barrier to normal life and an ability to perform normal duties
- Physical limitations mean that patients are more dependent on loved ones and carers. This was a difficult transition to make
- Extreme loss of functioning, sense of burden and debilitating symptoms were potential reasons to want a hastened death

Survival

- Patients perceive a conflict in quality of life and quantity of life objectives
- Survival benefits of treatment may not always be worthwhile given severe side-effects
- Any hope of long-term survival prospects were extremely valued, patients wanted more time in future with their loved ones

Fatigue

- Fatigue was viewed as a burden and a life-limiting symptom of cancer and its associated treatments
- Fatigue was related to feelings of powerlessness and loss of independence
- Lack of energy made hospital visits more burdensome

Cognitive Functioning

- Daytime sleepiness was seen as a threat to patients 'usual self'
- Sedative side-effects of medication made some patients reluctant to take more of the drugs

Pain

- Pain is viewed as a component of treatment burden and is frequently identified as a highly distressing and disturbing
- Patients feared that increases pain signified progression of their disease
- Pain was a reason to desire an assisted death

Mode of administration

- Cyclical treatments helped patients to cope with side effects. Knowledge/hope that side effects would alleviate made the harsh treatment more bearable
- Patients tend to want to avoid travelling and multiple hospital visits
- Oral treatments are generally preferred to intravenous

Results - Interviews

We wanted to develop an understanding of how patients experienced shared decision making in practice. Consequently, part of the focus of discussion during interviews with metastatic cancer patients was choice. We have some important quotes below.

It was discussed with me but I am quite happy to go with what experts say, but it was my choice in a way to come off the Eribulin as I really struggled with that one.

They mainly make the decision and then they tell me what it's about and you know, unless it sounded horrific, you would- I'd take it, because you would take anything to keep going

My consultant guided me. And I like it to be that way. I know that patient choice is always given, but I have confidence in the team that's looking after me. And I'm more than happy to bow to the experts (laughs)

I always listen to ... whoever it is that I'm consulting with them, what they have to say, and what they think is the best choice. And despite, although it might bring back a bit worse side effects than the other one, I'm- I think I'm more prone to go with what they're gonna say.

I don't remember there being a lot of discussion. It was just like, you know: here's- here's the best drug for you.

He gave me a choice, and I went: I don't know. I says: but what I need- I need to be on something that's no going to make me feel no well, cause I'm working and I cannae really be off my work, mortgage [know] what I mean? So, so he suggested, well, he says: well there is

Results - Scottish Medicines Consortium

Six core theme were identified from the thematic analysis: symptoms and side effects, survival, psychological effects, ability to live a normal life, effects on close ones, and effect on routine. The most important themes were survival and ability to live a normal life. We identified these two features as the most important consideration for patients undergoing treatment for metastatic breast cancer. To learn more please see our poster titled *Patient and Clinician Engagement statements as a tool to explore patient preferences for metastatic breast cancer treatments in Scotland*.

