

Comparing clinician and patient perspectives in the management of sexual difficulties in UK women after breast cancer treatment

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Introduction

An estimated 550 000 people live in the UK today having had a diagnosis of breast cancer and up to 70% experience sexual difficulties. Oestrogen replacement remains the most effective treatment for vulvo-vaginal atrophy and associated sexual arousal and pain difficulties. However, this is usually contraindicated in women with oestrogen-dependent breast cancer.

Increased endocrine therapy duration from 5 to 10 years has led to reduced recurrence and mortality. In younger women with higher risk breast cancer who receive endocrine therapy plus ovarian suppression further benefits are observed. But, also increased menopausal symptoms, depression, increased adverse sexual and musculoskeletal effects.

Any recurrence rate reduction must clearly be weighed against the adverse effects of oestrogen deprivation.

Background

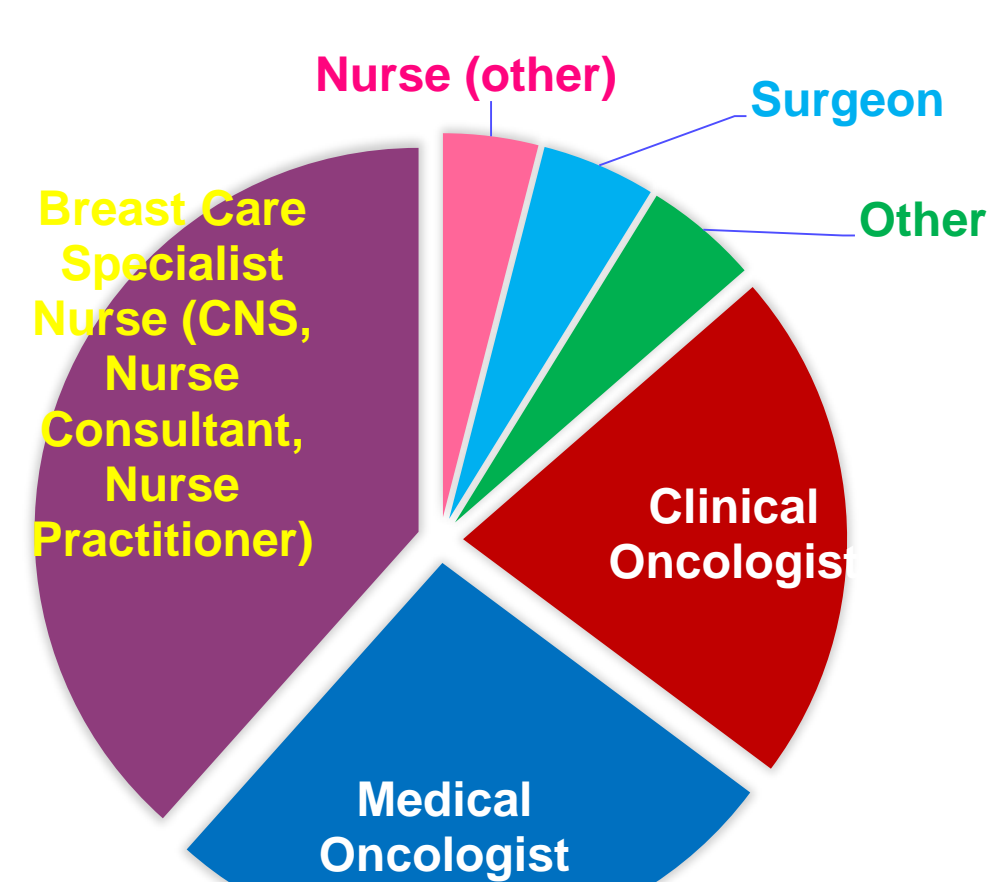
Patient members of the NCRI Breast CSG identified that there is limited research into the management of symptoms after breast cancer treatment. In response we established the Symptom Management Subgroup. Members of the group have a particular interest in the management of sexual difficulties and include patient advocates, clinical and academic partners, representing oncology, psychology, gynaecology, complementary therapies and the voluntary sector.

Patient and HCP Survey Details

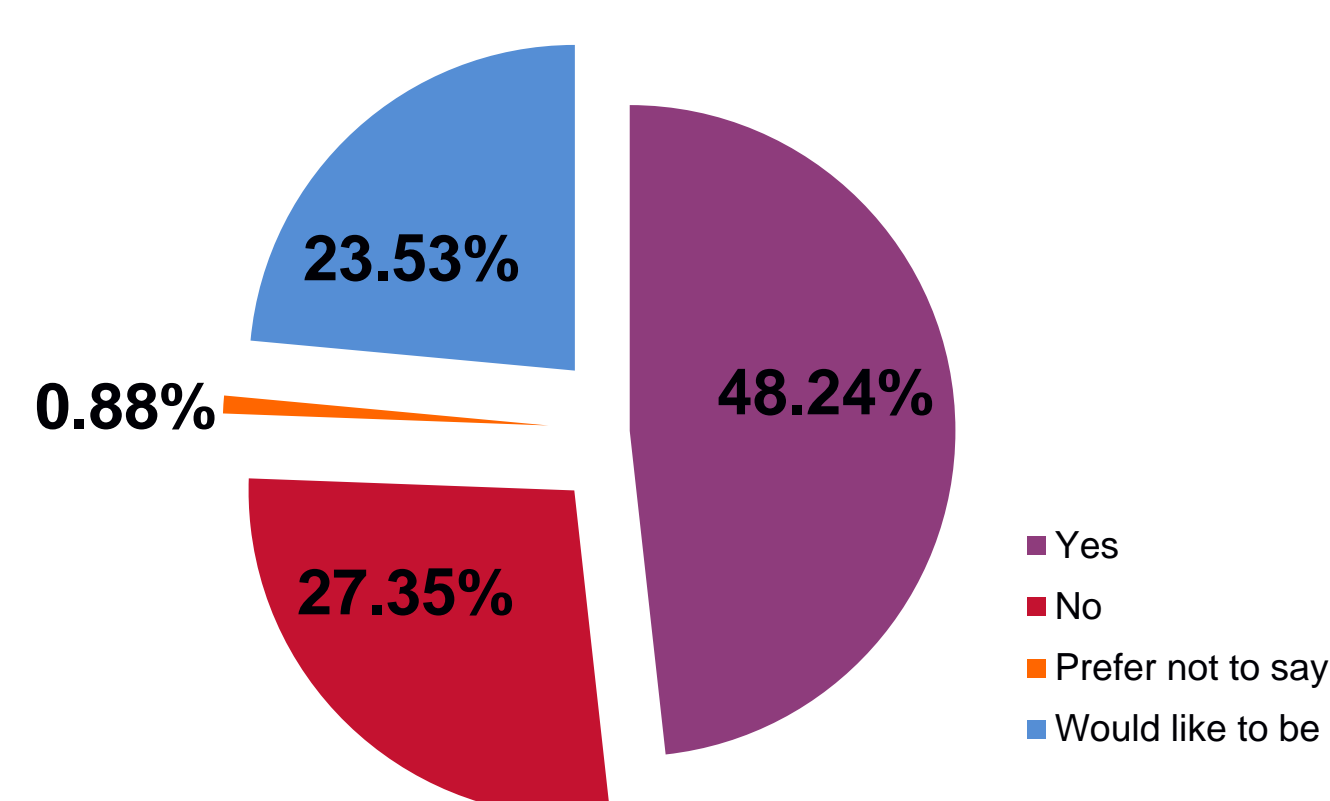
We surveyed 345 breast cancer patients and 126 health care professionals (HCPs)

99% (N=344) of the patients were female, 50% were aged 45-54 years at the time of their diagnosis, with approximately a third (33%) of women under 45 years of age and 17% ≥ 55

Discipline of 126 professional (HCP)

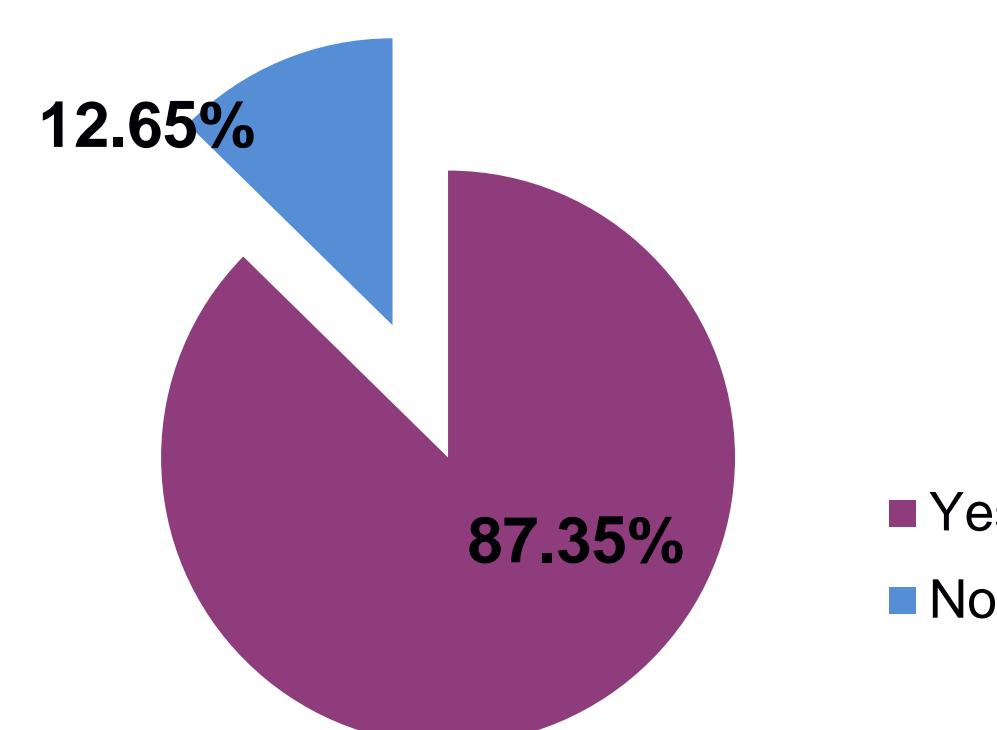


Are you sexually active?

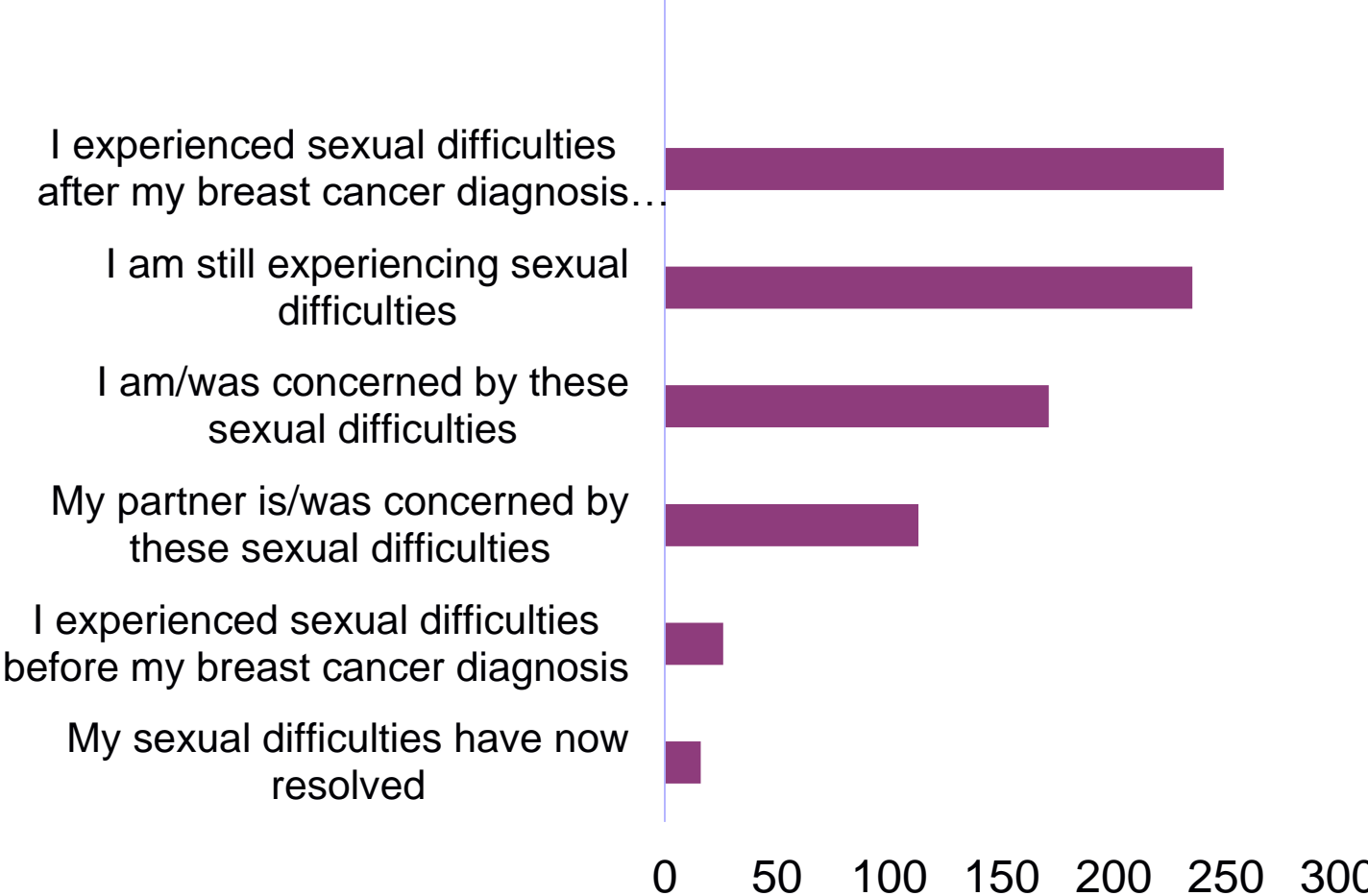


The majority of patients were pre-menopausal at the time of diagnosis (70.4%; n=243) More than half reported early menopause as a direct consequence of their breast cancer treatment (51.3%; n=177) and the majority of had never taken hormone replacement therapy (HRT) (79.7%; n=275)

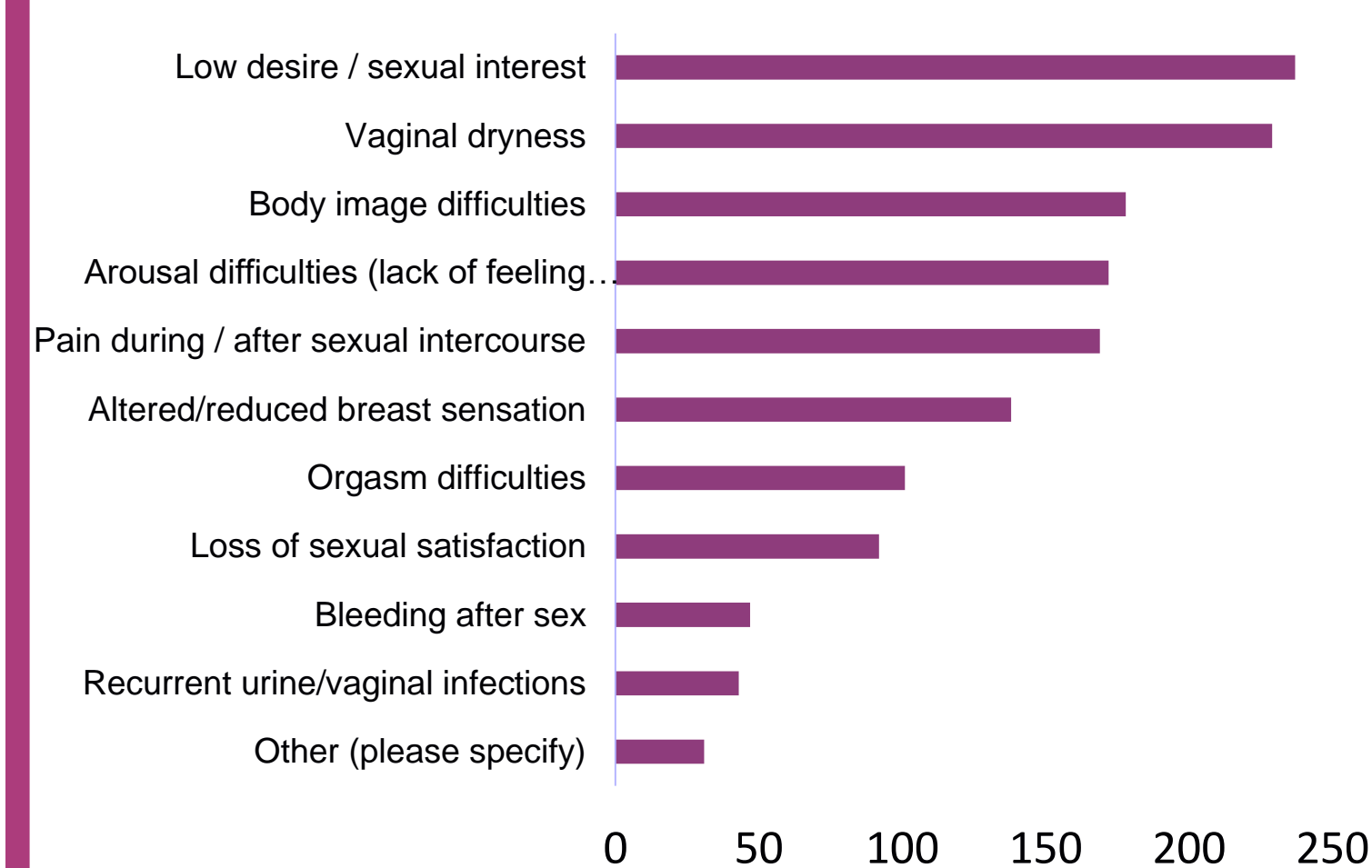
Have you experienced sexual difficulties?



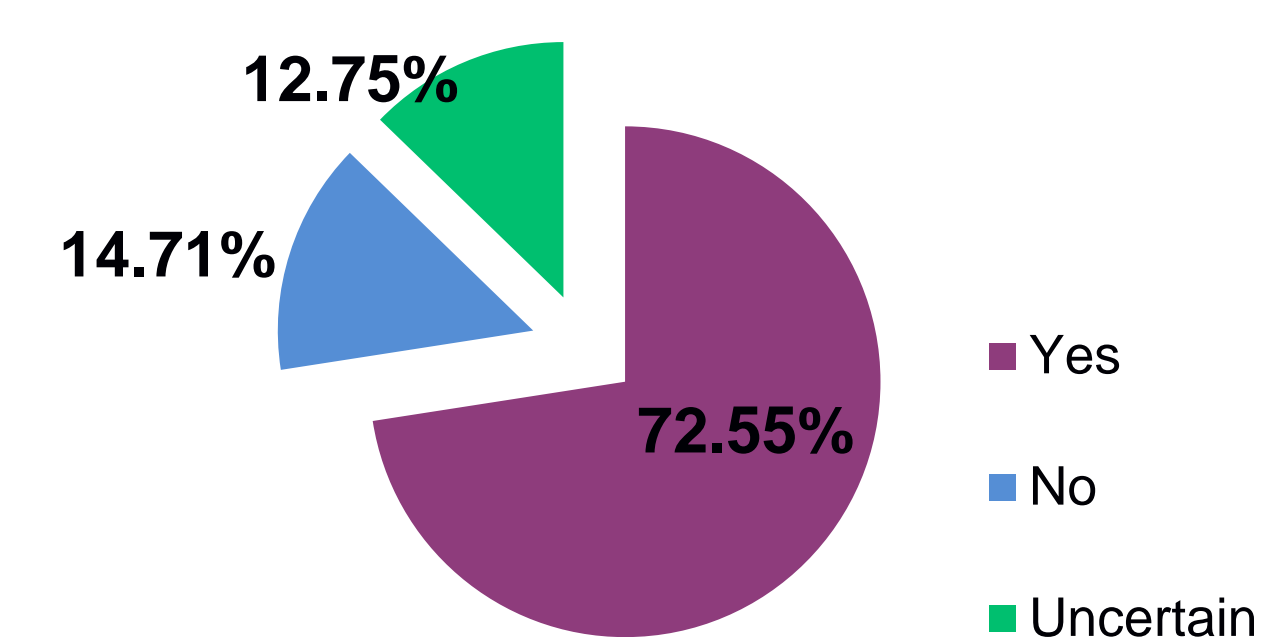
If you have had sexual difficulties, what have they been?



If you have had sexual difficulties, which of the following have you experienced?



If you are not sexually active, is it related to sexual consequences of your breast cancer treatment?



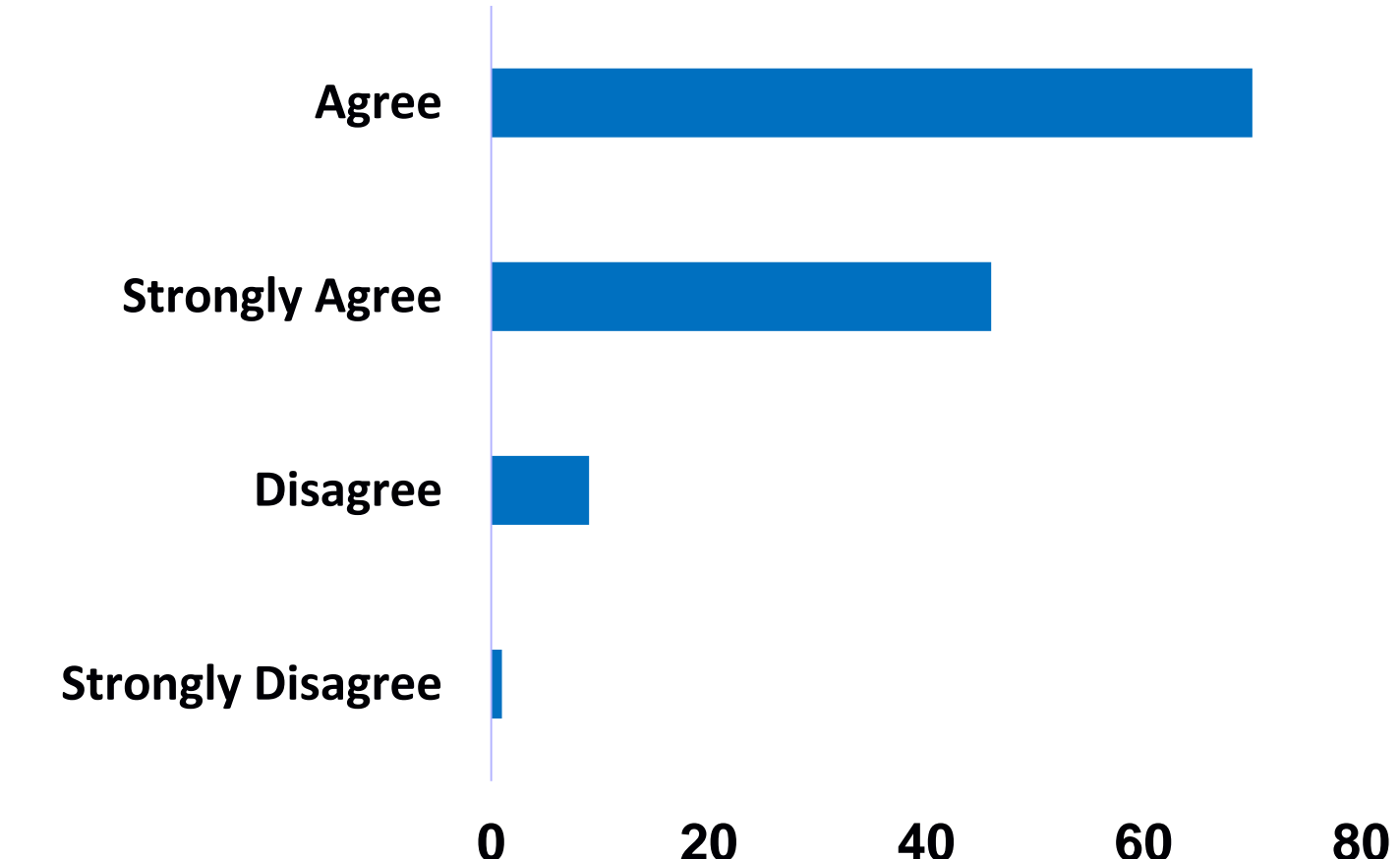
Lack of Information or Help offered for management of sexual difficulties

Fewer than 14% of HCPs thought that sexual difficulties were that frequent. 38% didn't know that their patients had any sexual problems, few asked patients about sexual problems, despite recognising an unmet need.

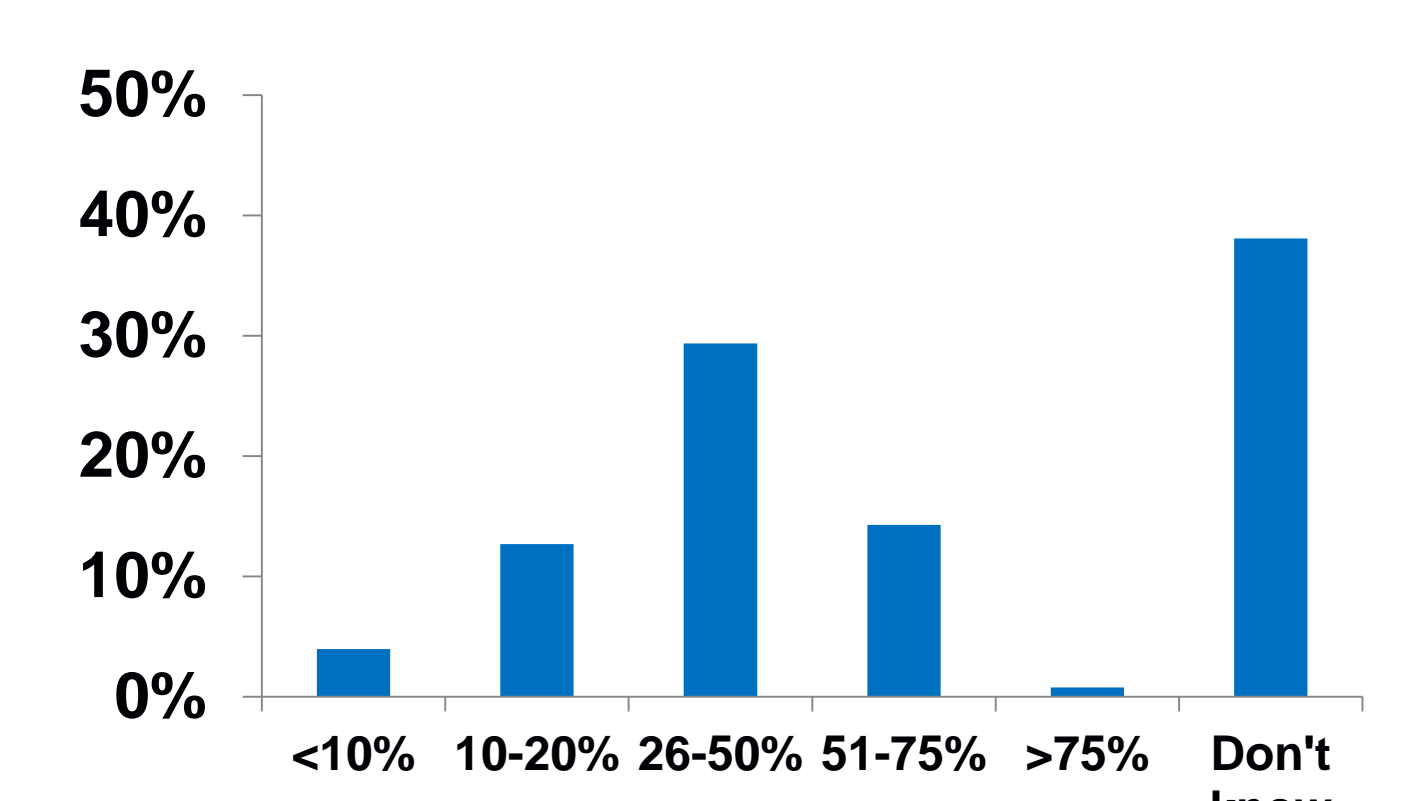
The majority of patients had not had any discussion with HCPs about the potential impact of breast cancer treatment on their sexual lives either prior to (85%) or following (82%) treatment.

61% if patients felt a discussion with their specialist nurse about sexual consequences of treatment would have been helpful.

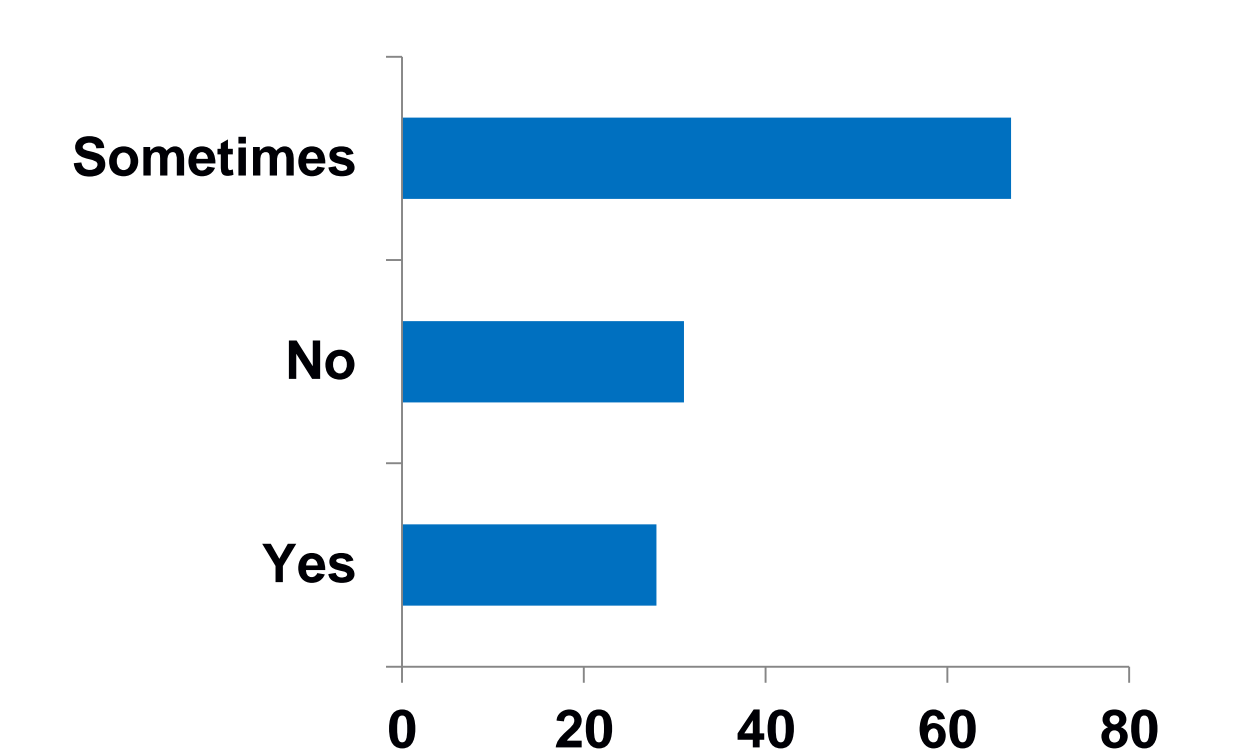
I believe that women's need for recognition and management of sexual difficulties arising from breast cancer treatment are largely unmet.



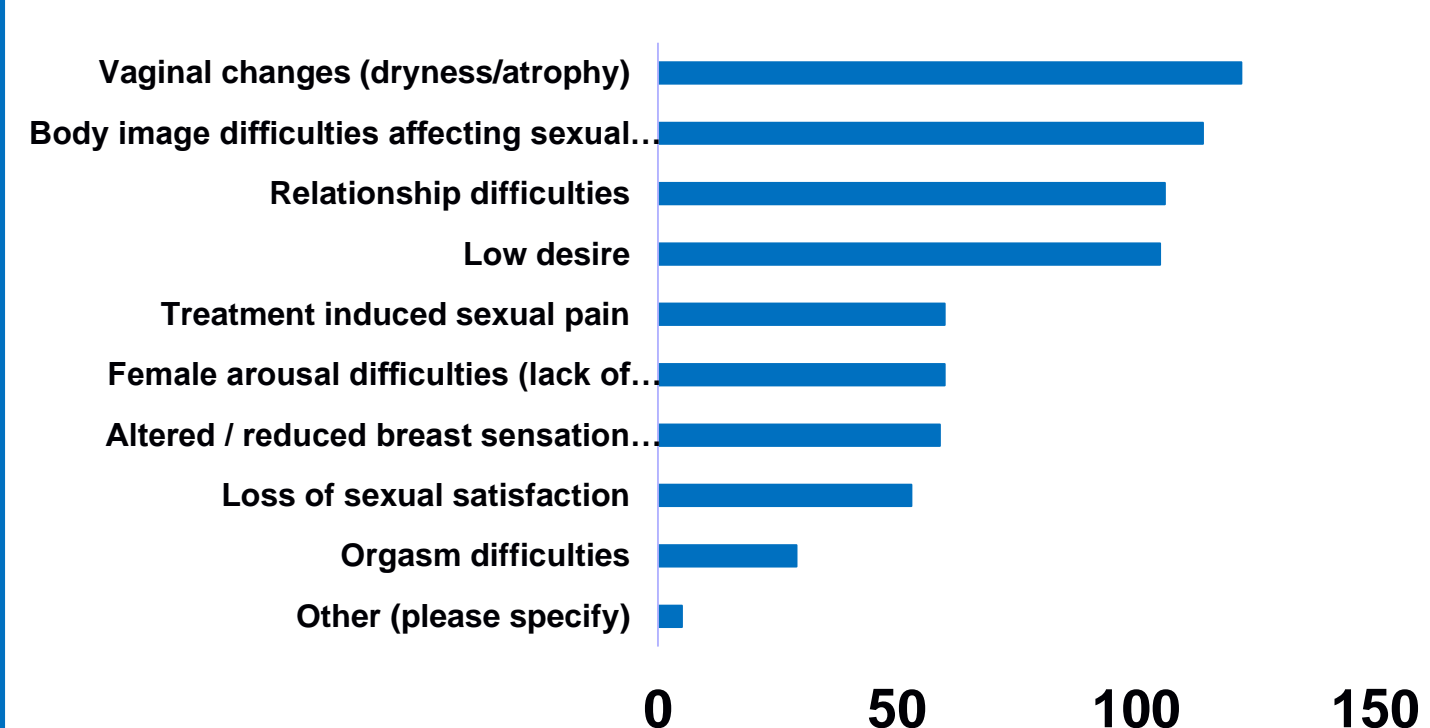
Roughly what percentage of women that you see with breast cancer have sexual difficulties arising from their disease and / or treatment?



Do you routinely ask women about the sexual consequences of breast cancer treatment?



Which sexual difficulties associated with breast cancer and its treatment do you encounter in your work with these women?



Lack of clinic time, No local referral route, Other priorities and Lack of Knowledge.

Despite over 90% of HCPs recognising that patients were suffering from severe treatment related issues of: Vaginal changes (dryness/atrophy), Body image difficulties affecting sexual expression, Relationship difficulties and Low desire, fewer than 20% routinely asked patients about these. HCPs stated the main reasons for lack of discussion of sexual concerns were lack of clinic time, no local referral route, other clinical priorities and lack of knowledge.

Conclusions of patients sexual problems

More than half of patients (55.7%; n=192) stated that they always experienced sexual difficulties, while a further 25.5% (n=88) reported that they experienced difficulties affecting more than 40% of sexual encounters.

Approximately half of patients (50.4%; n=174) stated that they experienced difficulty in becoming sexually aroused. Younger age and pre-menopausal status at time of cancer diagnosis was associated with a higher incidence of arousal difficulties compared to women who had completed menopause prior to their diagnosis (77% vs. 20.1%; X² (2, N = 345) = 7.37, p<0.025).

A statistically significant relationship was found between patients who were in receipt of endocrine treatment and the likelihood of experiencing sexual arousal difficulties X² (1, N = 345) = 8.68, p<0.003.

There was a statistically significant relationship between patients in receipt of endocrine treatment and experience of orgasm difficulties X² (1, N = 345) = 4.40, p<0.004 compared to women who had not had endocrine treatment.

In summary, women who had received endocrine treatment reported a greater incidence of sexual difficulties, X² (1, N = 345) = 8.63, p<0.003 overall, including increased incidence of low desire/sexual interest, arousal difficulties, vaginal dryness and pain during/after sex compared to women who did not receive endocrine treatment. Despite experiencing a range of treatment-associated sexual difficulties, most women did not stop taking their endocrine therapy 78%; n=262.

Six themes emerged from qualitative analysis of free text:

- 1) Impact on relationships and partner;
 - 2) Neglected area especially by HCP;
 - 3) Staying alive vs quality of life;
 - 4) Needing or wanting more information and or support;
 - 5) Unable or difficult to have sex post cancer – due to physical or psychological issues;
 - 6) Changes to body image and self-confidence
- 1) 'This problem can ruin your relationship and therefore also wreck your most important support system. It gets treated like an unfortunate side effect, like pain, or night sweats, but it's worse than that. When not intimate with my partner, I actually begin to like him less. We are certainly not as close, and partaking in it just to maintain the relationship doesn't work. It's destructive.'
- 2) 'I feel there is no help and no solution - and no-one seems to even acknowledge the problem of loss of libido and painful sex - particularly oncologists but other HCPs aren't much better.'
- 3) 'I feel that my symptom post treatment were dismissed as somewhat minor. eg...well you could be dead.'
- 4) 'Please tell doctors they must disclose the potential for sexual difficulties as a result of treatment. It is wrong not to let us know. Plus we need early help with coping with this.'
- 5) 'Sex is now painful and uncomfortable due to tightness and I think dryness. Not right for a 30 year old.'
- 6) 'Yes having one breast is a lonely isolating experience. 'No one can prepare you for the sense of loss of self-worth and confidence.'

In Conclusion

Our patient and HCP questionnaires highlight significant unmet needs in patients after breast cancer regarding HCP's provision of information and management support for treatment-associated sexual consequences.