Background

For patients deciding between mastectomy and breast conserving therapy (BCT, lumpectomy), the incorporation of expected post-operative patient reported outcomes (PROs) may aid in shared decision making. This study aims to understand how patients interpret different PRO displays and use them to understand predicted PROs regarding breast satisfaction as well as physical, psychosocial, and sexual well-being after surgery.

Methods

We collaborated with Inworks, an innovation initiative at the University of Colorado School of Engineering, Design and Computing to develop six visual displays demonstrating PRO data in the BREAST-Q domains of breast satisfaction and psychosocial, physical, and sexual well-being. Patients ranked PRO displays based on most to least liked and provided open-ended comments explaining first and last choices. Demographic and disease-related variables were extracted through a review of the electronic health record. Display rankings were compared using means, standard deviations, and one-way ANOVA. Differences in rankings by demographic and cancer variables were assessed by generalized linear models with interaction between display option and variable of interest. Thematic analysis was conducted on open-ended responses.

Results

Survey emails were sent to eligible patients diagnosed with Stage 0-IV breast cancer seen in surgical consultation from June 2019-June 2022. Of 388 patients contacted, 70 completed the survey (18% response rate). Participants had a mean age of 53.6 years (SD 12.8). One-way ANOVA revealed statistically significant differences in first choice rank among the six displays with $p < 0.0001$. Displays 2, 4, and 5 had higher mean ranks; 1 and 6 had lower mean ranks. Display 6 received the greatest number of first ranking and last ranking among all options. No differences were found between ranks choice and measured demographic and disease-related, including race, ethnicity, education, income, or surgery type. From qualitative analysis of open-ended comments, patients favored display simplicity, reading ease, and the inclusion of longitudinal PRO data. Patients disliked displays that either had too little or too much information.

Conclusions

Displays that prioritize clarity and PRO evolution over time were strongly preferred by patients, while displays with abundant information may be overwhelming and counterproductive. Presenting data with context, such as a time point, allowed patients to better interpret the PRO findings and envision how their own experience may occur. Given that several displays were ranked highly, the use of multiple figures may be a helpful approach in pre-surgical consultation. Using a variety of visuals during pre-operative shared decision making that clearly display PRO changes over time may improve shared decision making, enable patients to better elucidate personal values and goals for treatment, and set reasonable expectations for treatment outcomes.