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IMPLEMENTATION AND INITIAL RESULTS OF PATIENT RELATED OUTCOME IN THE SWEDISH NATIONAL QUALITY REGISTRY FOR BREAST CANCER

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Key points

- Breast conservation yields higher satisfaction in all ages
- Younger women < 50 score lower in all PRO parameters
- National implementation is resource demanding but
- Patients are willing to participate

Introduction

The Swedish National Quality Registry for Breast Cancer*, in function since 2008 assembles patient related outcome data (PRO) since 2020. Validated PRO and HRQoL instruments associated to the type of treatment (surgery and adjuvant) are linked to registry data. Patients receive baseline forms at diagnosis and at 6,12 and 36 months.

Materials and methods

Swedish data were collected for OECD international benchmarking. Pre and post treatment data were collected electronically from 2020-10-02 to 2022-09-29 in aggregated form. A total of 1072 (15%) were ever smokers, 893 (12%) had a BMI>30, 5185 (70%) received postoperative radiotherapy. Of all cases, 1485 (24%) responded to baseline and 7452 (59%) responded to 12month PROs. Response rates varied by type of surgery (breast conserving) surgery 62%, mastectomy 50%, immediate reconstruction 55%). Answers were presented in descriptive statistics and transformed to a 1-100 scale (100 = highest degree of satisfaction/wellbeing).

Results

Postoperative satisfaction with the breast was higher after BCS than after mastectomy and immediate reconstruction, postoperative body image was impaired regardless of surgical procedure, worse after mastectomy + immediate reconstruction. Social function and global health were perceived worse in women with mastectomy only. Younger women (<50) versus women >50 had worse postoperative satisfaction with the breast, worse emotional and social function, worse global health, and substantially higher degree of impaired body image.

Conclusion

Implementation of National PRO has been slower than expected as shown in low baseline compliance. However, at 12 months response rates increased. Type of surgery affects satisfaction, body image, social function, and global health but not emotional function. Younger women scored lower in all measured items. Its use in real time for clinical practice is warranted. 75% feel moderately or much involved in the decision regarding care and treatment