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ORIGINAL ARTICLE

What quality-of-life issues do women with ductal carcinoma in situ (DCIS) consider important when making treatment decisions?

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Abstract

Purpose To explore quality-of-life (QOL) issues considered important when deciding on treatment for ductal carcinoma in situ (DCIS).

Methods Breast Cancer Network of Australia members diagnosed with DCIS in the past 5 years (self-identified) participated in an online survey (Sep–Nov 2015). From a list of 74 QOL issues, participants selected all issues they experienced during DCIS diagnosis, treatment or recovery, then the issues they felt important to making a DCIS treatment decision, and completed the Health Literacy Questionnaire (HLQ). Associations between QOL issues and self-reported treatment received were assessed with χ^2 tests.

Results The primary analysis included 38 participants treated with breast-conserving surgery ($n = 15$), mastectomy ($n = 23$), and/or radiotherapy ($n = 14$). Fatigue-related symptoms (82%) and "fear of progression" (50%) were the most frequently-experienced issues. When deciding on DCIS treatment, the most important consideration was "fear of progression" (50%). A higher proportion of mastectomy (compared to non-mastectomy) patients considered "difficultly looking at yourself naked" ($p = 0.03$). Radiotherapy (compared to non-radiotherapy) patients were more likely to consider "feeling unwell" important ($p = 0.006$). Results were similar in a sensitivity analysis involving all 101 respondents (i.e., including 63 respondents who reported receiving chemotherapy, endocrine therapy, and/or Herceptin, suggesting that they may have been treated for invasive breast cancer). Health literacy was high across all nine HLQ scales.

Conclusion Fear of progression is a key consideration in DCIS treatment decision making for women with high health literacy. QOL treatment considerations differed by treatments received. Women diagnosed with DCIS may

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benefit from evidence about QOL to inform treatment decision making.

Keywords Ductal carcinoma in situ (DCIS) · Decision making · Quality of life · Patient-reported outcomes

Introduction

Ductal carcinoma in situ (DCIS) is defined as an abnormal proliferative condition of epithelial cells confined to the mammary ducts [1, 2]. DCIS is a non-invasive malignancy, and is treated to reduce the risk of progression to invasive breast cancer. Approximately 4.5–11.7% of DCIS patients are diagnosed with invasive breast cancer within 10 years of treatment [3, 4], but it is difficult to predict which DCIS cases are at the highest risk of progression [5]. DCIS treatments commonly offered include breast-conserving surgery, with or without radiotherapy; mastectomy with or without reconstruction; or endocrine therapy [6, 7]. Each treatment option may impact quality of life (QOL) in different ways. Women successfully treated for DCIS have a normal life expectancy, and so must consider likely long-term QOL outcomes when making a treatment decision. This is particularly important given concerns regarding over-diagnosis [8] and over-treatment of DCIS [9].

Our understanding of the QOL impact of different treatment options is limited by a lack of DCIS research involving patient-reported outcomes (PROs) [10]. Qualitative research indicates women who had a mastectomy reported physical concerns [11], although whether these concerns differed between women who received and did not receive a breast reconstruction is unclear, and quantitative data on the type and severity of such concerns are not available. Furthermore, a large number of women with DCIS experience psychosocial concerns, particularly anxiety about disease progression, which is likely related to the controversial and inconsistent use of the word 'cancer' when describing DCIS, and because treatments offered for DCIS are similar to those offered for invasive breast cancer [11, 12].

Little is known about what information women consider when deciding on DCIS treatment. Previous research has shown that women require access to DCIS-specific information and its associated risks to make informed treatment decisions, and to minimise decisional regret [12]. Many women are dissatisfied with information about progression risk following treatment [11, 12]. Much of the information women receive about DCIS treatment is likely to come from their clinician, yet clinicians also report a need for more evidence to inform treatment decision making [13, 14]. Due to a general paucity of DCIS-specific QOL evidence, clinicians may be forced to rely on QOL evidence from invasive breast cancer studies; however, the extent to which this information is appropriate for DCIS patients is unclear. Adding to these challenges is the conflicting QOL evidence available regarding various surgical options in breast cancer populations [15]. Comprehensive, DCIS-specific PRO evidence is needed to inform clinicians and future patients about likely QOL treatment outcomes.

The role of health literacy in treatment decision making cannot be ignored. Health literacy is defined as possessing the necessary cognitive and social skills to access, understand, and use information to promote and maintain good health [16]. Women with poor DCIS knowledge are more likely to worry about dying from the disease or developing breast cancer [12].

Women previously treated for DCIS understand the anxieties of their newly-diagnosed peers and are well-placed to communicate the QOL impact of their chosen treatment. The current study aimed to explore what QOL issues women with a past diagnosis of DCIS: (1) experienced throughout diagnosis, treatment and recovery from DCIS and (2) consider important when making a DCIS treatment decision. We also aimed to explore health literacy in our sample and to generate hypotheses for future research about the role of health literacy in DCIS treatment decision making.

Methods

Ethics

The University of Sydney Human Research and Ethics Committee approved this research 5 August 2015 (2014/533). Informed consent was implied if women submitted the survey.

Participants

Participants were recruited through the Breast Cancer Network of Australia (BCNA) Review and Survey Group. BCNA is the peak national organisation in Australia for people affected by breast cancer. In addition to providing support services and informational resources, BCNA has a database of volunteers willing to participate in research projects: the Review and Survey Group. BCNA divides its Review and Survey Group membership into 'early breast cancer' and 'secondary breast cancer' groups. The 'early breast cancer' group includes women with DCIS, lobular carcinoma in situ and early invasive cancer, whereas the 'secondary breast cancer' group includes women with invasive or metastatic breast cancer. All 886 members in the 'early breast cancer' group at the time of our survey received the survey invitation email (Appendix A). Women with a diagnosis of DCIS in the past 5 years (self-identified) were eligible to participate, and these criteria were made clear in the survey invitation and wording of the questionnaire. Based on BCNA records, it is unclear exactly how many members were eligible, however, based on evidence that DCIS accounts for 20% of screen-detected breast cancers [17], and we estimated that 177/886 women were eligible.

Survey

The web-based survey (Appendix B), administered through *Qualtrics*, was live 2 September–20 November 2015, and two email reminders were sent during this period. Our survey was completely anonymous; no identifying information was collected of participants. From a list of 74 potential QOL issues, participants selected: (1) all issues they *experienced* during diagnosis, treatment, or recovery; (2) *all issues* they felt were important to consider when making a treatment decision for DCIS; and based on their previous responses, (3) the *top 10* they felt were important to consider when making a treatment decision; and (4) *top 3* issues to consider. The list of 74 potential QOL issues was generated from the content of most commonly used QOL questionnaires in breast cancer populations, each of which was developed through a rigorous process of consultation with clinicians and patients: the European Organisation for the Research and Treatment of Cancer (EORTC) Quality-of-Life Questionnaire-Core 30 (QLQ-C30) [18], the breast cancer module (QLQ-BR23) [19], and emerging items from the breast reconstruction module, which is currently in development (QLQ-BRECON23) [20], as well as the Functional Assessment of Cancer Therapy-Breast cancer questionnaire (FACT-B) [21]. The issues listed address concerns that are important to women at diagnosis and during and post-treatment. We also consulted the research team, which included a consumer representative (JM), for any additional relevant issues.

Finally, participants completed the Health Literacy Questionnaire (HLQ) [22]. The 44 items of the HLQ cover nine conceptually distinct aspects of health literacy: (1) feeling understood and supported by healthcare providers; (2) having sufficient information to manage health; (3) actively managing health; (4) social support for health; (5) appraisal of health information; (6) ability to actively engage with healthcare providers; (7) navigating the healthcare system; (8) ability to find good health information; and (9) understanding health information well enough to know what to do. The HLQ has been validated and is appropriate for use in a range of populations [22].

Analysis

Prior to analysis, the research team observed that a high proportion of respondents received chemotherapy (23%) and/or Herceptin (4%), which are not typically administered for DCIS. In addition, a higher proportion of patients received endocrine therapy (54%) and post-mastectomy radiotherapy (13%) than would be expected for DCIS. This potentially indicated participation of some primary invasive cancer participants (i.e., not a pure DCIS sample), which was possible given that participants were self-identified; or that our sample was not representative of the DCIS population in terms of treatments received, or the proportion who progressed to invasive breast cancer; or a combination of all three factors. To acknowledge these possibilities, our primary analysis included only participants who *did not* report receiving chemotherapy, endocrine therapy, or Herceptin treatment (i.e., women received "surgery and/or radiotherapy only"). We then ran a sensitivity analysis using data from all 101 respondents to determine whether inclusion of women who may have had invasive cancer (either subsequent to their DCIS diagnosis or as their initial diagnosis) would have altered our findings.

Treatment and demographic questions were summarised with descriptive statistics. Definitions of recovery provided by participants (question 8) were analysed using content analysis, which enabled us to pool responses from all 101 participants at all stages of recovery, by assigning one of three definition categories: (1) side-effect-related (e.g., 'feeling as I did before treatment', 'I am still suffering from fatigue', 'I felt recovered when I stopped experiencing swelling when lifting heavy objects' or any other mention of physical or emotional side-effects of diagnosis and treatment); (2) treatment-related (e.g., 'I felt recovered when I completed radiotherapy', 'I don't feel recovered because I am still receiving treatment'); or (3) definition not provided (e.g., '3 months', 'I don't feel recovered' without providing a reason). QOL issues experienced and QOL treatment considerations were frequency-ranked in the primary and sensitivity analyses and for the five most common treatment subgroups (lumpectomy, simple mastectomy, double mastectomy, radiotherapy, and endocrine therapy). Because most participants received >1 treatment, participants were also coded for each of three treatment categories: (1) type of surgery: lumpectomy (without subsequent mastectomy), simple mastectomy or double mastectomy; (2) radiotherapy received (yes/no); and (3) endocrine therapy received (yes/no). We then conducted a series of exploratory Chi-square tests for differences within treatment categories in the proportion of endorsed QOL issues in response to question 2.3: 'the top 10 issues to consider when making a treatment decision' ("QOL treatment considerations" hereafter).

The HLQ was analysed according to the developers' instructions for all responders [22]. Exploratory *t* tests of all HLQ scales comparing participants who endorsed the concern: "feeling unsatisfied, regretful or unhappy with your treatment decision" to those who did not (Q2.1), using a Bonferroni adjusted alpha of 0.05/9 = 0.006. All analyses were performed using SPSS Version 21.0 (IBM, Armonk, 2012).

Results

Sample characteristics

The survey was completed by 101 participants (mean completion time: 30 min). Table 1 shows characteristics of the primary ($n = 38$) and sensitivity analysis samples ($n = 101$; i.e., 38 from the primary analysis plus 63 who received chemotherapy, endocrine therapy, or Herceptin). In the *primary analysis* group, 13 (93%) of 14 participants who received radiotherapy also received lumpectomy and 1 (7%) of the 14 also received a mastectomy. In the *sensitivity analysis*, 42 (75%) of the 56 participants who had radiotherapy also had a lumpectomy and 13 (23%) also had a mastectomy. Three participants who did not attempt the HLQ were excluded from the health literacy analysis.

Time to recovery-qualitative content analysis

Most (58%) participants defined "recovery" in terms of their side-effects, for example, feeling and functioning (including psychologically) as they had before DCIS, While 28% reported a treatment-related definition, for instance, the DCIS being "removed", treatment being completed; and 15% did not provide a definition of recovery. 41% believed that they were still recovering from DCIS. The remaining 59% felt fully recovered between 3 months and 2.5 year post-treatment.

Issues experienced as a result of DCIS

The ten most frequent QOL issues *experienced at any stage during diagnosis, treatment, and recovery* in the primary analysis: Patients who received radiotherapy and/or surgery, without endocrine therapy, chemotherapy or Herceptin ($n = 38$) were: feeling tired ($n = 31$, 82%), needing to rest ($n = 24$, 63%), trouble sleeping ($n = 23$, 61%), fear of progression ($n = 19$, 50%), feeling weak ($n = 18$, 47%), feeling sad ($n = 18$, 47%), feeling physically less attractive ($n = 17$, 45%), feeling satisfied with your health ($n = 16$, 42%), difficulty doing strenuous activities ($n = 16$, 42%), and loss of sensation at your donor site (reconstruction patients only) ($n = 16$, 42%).

The ten most frequently endorsed QOL issues *experienced* for the Sensitivity analysis, whole sample ($n = 101$) were very similar: feeling tired ($n = 90$, 89%), needing to rest (76%), trouble sleeping (68%), fear of progression (60%), feeling weak (60%), difficulty remembering things (56%), difficulty doing strenuous activities (56%), feeling sad (53%), feeling physically less attractive (51%), and hot flushes (50%).

Twelve participants reported experiencing "other" QOL issues, in addition to the list of 74 options: "aching joints", "dry vagina", "communicating with friends or family about diagnosis/DCIS", "having to be one's own advocate in treatment", "axillary web syndrome" (cording), "access to DCIS-specific information and support services" (including online), "muscle failure to maintain grip", "nerve damage in hands and feet", "facial rash", "ability to care for children", "psychosocial experience of loved ones", and "lymphedema".

QOL treatment considerations

When asked to select the top 10 issues to consider when making a DCIS treatment decision, or "*Top 10 QOL treatment considerations*", fear of progression was the top-ranked issue in both primary and sensitivity analyses, endorsed by 50 and 59% of respondents in each analysis, respectively (Table 2). Results from the sensitivity analysis were similar to the primary analysis; however, "worry about dying" was the second-most endorsed QOL treatment concern for women in the sensitivity analysis (whole sample, 37%), whereas this was ranked 12th ($n = 9$, 24%) in the primary analysis.

QOL treatment considerations–treatment subgroups

The top 10 QOL issues to consider when making a treatment decision are reported separately for each treatment category below.

Differences by type of surgery

Appendix C shows results of between-surgical-groups χ^2 tests for differences in the proportion of women endorsing each QOL treatment consideration. In the primary and sensitivity analyses, a significantly higher proportion of women who received a mastectomy and breast reconstruction (compared to women who did not) considered "difficulty looking at yourself naked" ($p < 0.04$), "stiffness/tightness at donor site" ($p < 0.05$), "loss of sensation at donor site" ($p < 0.015$), and "feeling satisfied with

Table 1 Sample characteristics

	PRIMARY ANALYSIS Surgery and/or radiotherapy only group		SENSITIVITY ANALYSIS Whole sample	
	$N = 38$	%	$N = 101$	%
Demographics				
Mean age	59.5		56.7	
Time since DCIS diagnosis				
6 months—1 year	0	0	3	3
1–2 years	4	11	15	15
2–5 years	33	87	82	81
> 5 years	1	3	1	1
Time since completion of treatment				
< 6 months	0	0	12	12
6 months—1 year	1	3	7	7
1–2 years	12	32	25	25
2–5 years	25	66	57	56
Treatment received[a]				
Lumpectomy without mastectomy	15	39.5	46	45.5
Simple mastectomy				
Total	18	47.4	35	34.7
No breast reconstruction	6	15.8	14	13.9
Immediate breast reconstruction	8	21.1	9	8.9
Delayed breast reconstruction	4	10.5	12	11.9
Double mastectomy				
Total	5	13.2	20	19.8
No breast reconstruction	0	0.0	8	7.9
Immediate breast reconstruction	2	5.3	5	5.0
Delayed breast reconstruction	3	7.9	7	6.9
Radiotherapy	14[d]	36.8	56[e]	55.4
Endocrine therapy[b]	0	0.0	54	53.5
Other treatments[c]				
Other (total)	3	7.9	32	31.7
Other (Herceptin)	0	0.0	4	4.0
Other (chemotherapy)	0	0.0	23	22.8

[a] Most participants received more than one treatment option; therefore, rows may not sum to the total number of patients ($n = 38$ or $n = 101$)

[b] Endocrine therapy includes tamoxifen, aromatase inhibitors

[c] Responses for "Other treatments received" were re-coded at analysis

[d] 13/14 participants who received radiotherapy also had lumpectomy, and 1/14 also had mastectomy in addition to radiotherapy

[e] 42/56 radiotherapy participants also received lumpectomy, and 13/56 also received mastectomy

donor site appearance after recovery from treatment" ($p < 0.04$) important.

In the primary analysis, a significantly higher proportion of patients who received mastectomy (compared to lumpectomy) considered "worry about dying" important ($p = 0.045$), but this was not significant for the whole sample.

In the sensitivity analysis (all respondents), but not for the primary analysis, a significantly lower proportion of simple mastectomy patients, compared to women who did not receive mastectomy or who received double mastectomy, felt it was important to consider "feeling content with QOL" ($p = 0.04$); a higher proportion of lumpectomy patients felt that it was important to consider "family accepting your condition" ($p = 0.01$) compared to women who received mastectomy; and a higher proportion of double mastectomy patients compared to simple mastectomy and lumpectomy patients felt that it was important to consider "ability to have sex" ($p = 0.046$), "arm or shoulder pain" ($p = 0.016$), and "reduced appetite"($p = 0.016$).

Table 2 Quality-of-life (QOL) issues most frequently to consider when making a treatment decision, from a list of 74 QOL issues

Rank	PRIMARY ANALYSIS Surgery and/or radiotherapy only group Issue	$N = 38$ N	%	Rank	SENSITIVITY ANALYSIS Whole sample Issue	$N = 101$ N	%
When participants were able to endorse an unlimited number of important QOL issues							
1	Ability to enjoy life	23	61	1	Fear of progression	70	69
1	Fear of progression	23	61	2	Worry about dying	53	53
3	Feeling tired	19	50	3	Feeling satisfied with your health	51	50
3	Feeling satisfied with how your breast/s would look and feel after treatment	19	50	3	Receiving emotional support from your family or friends	51	50
5	Needing to rest	18	47	5	Your ability to enjoy life	48	48
5	Feeling satisfied with your health	18	47	6	Needing to rest	47	47
6	Emotional support from family or friends	17	45	7	Feeling tired	45	45
7	Family accepting your condition	16	42	8	Financial difficulties caused by physical condition or medical treatment	43	43
8	Difficulty looking at yourself naked	15	40	8	Feeling content with your quality of life	43	43
8	Feeling content with your quality of life	15	40	10	And worry about the effect of stress on your illness	42	42
8	Worry about the effect of stress on your illness	15	40				
8	Feeling satisfied with how your donor site would look after you had fully recovered from treatment (mastectomy + reconstruction participants only)	15	40				
8	Feeling close to your partner (or main support person)	15	40				

Rank	PRIMARY ANALYSIS Surgery and/or radiotherapy only group Issue	$N = 38$ N	%	Rank	SENSITIVITY ANALYSIS Whole sample Issue	$N = 101$ N	%
When participants were able to endorse their "Top 10" QOL issues							
1	Fear of progression	19	50	1	Fear of progression	60	59
2	Feeling tired	13	34	2	Worry about dying	38	37
2	Ability to enjoy life	13	34	3	Receiving emotional support from your family or friends	37	36
2	Receiving emotional support from family or friends	13	34	3	Financial difficulties caused by your physical condition or medical treatment	36	36
5	Needing to rest	12	32	5	Feeling satisfied with your health	33	33
5	Feeling satisfied with how your breast/s would look and feel after treatment	12	32	6	Your ability to enjoy life	31	31
7	Difficulty looking at yourself naked	11	29	7	Feeling tired	27	27
7	Feeling close to your partner (or main support person)	11	29	7	Feeling content with your quality of life	27	27
7	Financial difficulties caused by your physical condition or medical treatment	11	29	9	Feeling satisfied with how your breast/s would look and feel after treatment	26	26
10	Feeling satisfied with your health	10	26	10	Needing to rest	25	25
				10	Worry about the effect of stress on your illness	25	25
				10	Feeling close to your partner (or main support person)	25	25

Differences by whether radiotherapy was received

Appendix D shows comparisons in QOL treatment considerations between patients who received (versus did not receive) radiotherapy. The proportion of women who received a mastectomy and breast reconstruction was significantly higher in the non-radiotherapy group (compared to radiotherapy group) in both primary ($X^2 = 12.67$, $p < 0.001$) and sensitivity analyses ($X^2 = 23.25$, $p < 0.001$). In both the primary and sensitivity analyses, radiotherapy patients were significantly less likely to consider "difficulty looking at yourself naked" ($p < 0.004$), "feeling satisfied with donor site would look" ($p < 0.003$), and "loss of sensation at donor site" ($p < 0.04$). Women

Table 3 Health Literacy Questionnaire results

HLQ scale	Scale name	Surgery &/or RT only: $n = 36$ Full sample: $n = 97$	Mean score	SD
Scale 1 (HPS)	Feeling understood and supported by healthcare providers (HPS)	Surgery &/or RT only	3.22	0.27
		Full sample	3.24	0.26
Scale 2 (HSI)	Having sufficient information to manage my health (HSI)	Surgery &/or RT only	3.09	0.37
		Full sample	3.17	0.37
Scale 3 (AMH)	Actively managing my health (AMH)	Surgery &/or RT only	3.14	0.28
		Full sample	3.17	0.32
Scale 4 (SS)	Social support for health (SS)	Surgery &/or RT only	3.03	0.46
		Full sample	3.14	0.51
Scale 5 (CA)	Appraisal of health information (CA)	Surgery &/or RT only	3.07	0.40
		Full sample	3.10	0.44
Scale 6 (AE)	Ability to actively engage with healthcare providers (AE)	Surgery &/or RT only	3.83	0.31
		Full sample	3.92	0.41
Scale 7 (NHS)	Navigating the healthcare system (NHS)	Surgery &/or RT only	3.74	0.40
		Full sample	3.82	0.35
Scale 8 (FHI)	Ability to find good health information (FHI)	Surgery &/or RT only	3.95	0.37
		Full sample	3.97	0.37
Scale 9 (UHI)	Understand health information well enough to know what to do (UHI)	Surgery &/or RT only	4.17	0.35
		Full sample	4.21	0.36

36 participants completed the HLQ from the Surgery and/or RT only group, and 98 participants completed the HLQ in total (from the full sample). There was no item-level missing data. Interpretation: Scales 1–5 each have four levels (i.e., 1–4); therefore, scores >3 are considered 'high'. Scales 6–9 have five levels (i.e., 1–5). Scores ≥ 3.5 are considered 'high'

who received radiotherapy were significantly more likely to consider "feeling unwell" ($p < 0.006$) important.

In the primary analysis, a significantly higher proportion of women who received radiotherapy reported "breast skin problems (itchy, dry, flaky)" ($p = 0.018$), compared to women who did not receive radiotherapy. This finding was no longer significant in the sensitivity analysis.

In the sensitivity analysis, but not in the primary analysis, radiotherapy participants (compared to women who did not have radiotherapy) were significantly less likely to report "feeling satisfied with how donor site would look after recovery from treatment" ($p = 0.006$), "stiffness or tightness at donor site" ($p = 0.008$), or "feeling physically less attractive" ($p = 0.01$); and significantly more likely to consider "hot flushes" ($p = 0.04$) and "ability to have sex" ($p = 0.04$) important.

Differences by whether endocrine therapy was received

All 101 respondents were included in QOL treatment considerations comparisons between patients who received ($n = 54$) versus did not receive ($n = 47$) endocrine therapy (Appendix E). A significantly higher proportion of endocrine therapy patients compared to women who did not receive endocrine therapy felt that it was important to consider "hot flushes" ($p = 0.03$) and "hair loss" ($p = 0.05$). A significantly lower proportion of endocrine therapy patients compared to women who did not receive endocrine therapy felt that it was important to consider "feeling sad" ($p = 0.04$).

Health literacy

Participants had high health literacy scores across all nine scales, with the highest literacy found for the "understanding health information well enough to know what to do" scale in both the primary and sensitivity analyses (Table 3).

Thirteen participants endorsed "feeling unsatisfied, regretful or unhappy with your treatment decision" in the "issues you experienced question". When compared to the 85 participants who did not feel unsatisfied, regretful or unhappy with their treatment decision, there were no significant differences for any of the nine HLQ scales (data not shown).

Discussion

This study explored what QOL issues women with a past DCIS diagnosis experienced and which issues they considered important for making a DCIS treatment decision.

Participants felt that women diagnosed in the future should consider fear of progression above all other QOL treatment considerations, and fear of progression was among the top five most common issues experienced by the sample. This suggests that the main driver of treatment decision making may be perceptions about risk, and associated anxiety or fear. It is well documented that women with DCIS often over-estimate their risk of developing invasive breast cancer [12, 23, 24]. This inflated fear may reflect inadequate communication about risk or confusion about their DCIS diagnosis, given the similarities in treatment to invasive breast cancer and the inconsistencies in language to describe DCIS [25]. Our findings reinforce the recognised need for improved patient information and communication about individualised risk of disease progression or recurrence to mitigate potentially unwarranted anxiety. Four exciting new trials will add to knowledge about risks: the LORIS trial (A Phase III Trial of Surgery versus Active Monitoring for LOw RISk DCIS: ISRCTN27544579), in which women are randomised to either surgery or active monitoring and surveillance for 10 years [26]; the COMET trial (Comparison of Operative versus Medical Endocrine Therapy for Low Risk DCIS) [27]; a Randomised Phase III Study of Radiation Doses and Fractionation Schedules in Non-low Risk DCIS (NCT00470236) [28]; and the LORD study ("LOw Risk DCIS", BOOG2014-04/ EORTC-BCG1401) [29].

Fatigue, trouble sleeping, feeling sad, feeling less physically attractive, and difficulty doing strenuous activities were also considered important QOL treatment considerations by most of the sample. These are key QOL concerns that need to be communicated to newly-diagnosed patients to facilitate their adequate preparation for DCIS treatment and recovery.

Although QOL treatment considerations were similar across treatment groups, there were some key between-treatment-group differences. Most of these differences can be explained by common treatment side effects. For example, in the surgical group comparisons, women who had mastectomy were more likely to report difficulty looking at themselves naked as compared to women who had breast-conserving surgery, and women who had a mastectomy and breast reconstruction were more likely to report symptoms related to their donor site as compared to breast-conserving surgery patients. These results were significant in both the primary and sensitivity analyses.

We observed some differences between the primary and sensitivity analyses comparing QOL treatment considerations between treatment groups. For example, radiotherapy (compared to non-radiotherapy) patients were more likely to consider skin problems around the breast important in the primary analysis ($p = 0.018$), but surprisingly, this was not significant in the sensitivity analysis ($p = 0.115$). In the primary analysis only, a significantly higher proportion of women who had a double mastectomy considered 'worry about dying' important to making a treatment decision as compared to women who had a single mastectomy or breast-conserving surgery. Other significant differences appeared only in the sensitivity analysis. For instance, women who had a double mastectomy (60% of whom had a reconstruction) were more likely to consider 'your ability to have sex' important to making a treatment decision than lumpectomy or simple mastectomy patients. Rowland [30] found that breast cancer survivors who received mastectomy and breast reconstruction reported a negative impact on sexual functioning, compared to women who received mastectomy alone or lumpectomy [30]. Similarly, Winters [31] found that women who received immediate autologous extended latissimus dorsi breast reconstructions reported better sexual functioning 3 years post-surgery compared to those receiving implant-based latissimus dorsi flaps [31]. Similarities between these invasive breast cancer studies and our full-sample sensitivity analysis align with our assumption that some women with invasive cancer participated in this study, and support the need for DCIS-specific QOL research, as it demonstrates potential differences in post-surgical experiences of women with DCIS compared to invasive breast cancer. Alternatively, our sensitivity analysis may have had greater power to detect effects due to the larger sample size.

Participants in this sample were highly health literate across all nine HLQ dimensions. Unlike the past studies [12], treatment decisional regret did not appear related to health literacy in this sample; however, we observed a strong ceiling effect, limiting the extent to which trends could be examined. It is possible that other factors, such as QOL outcomes, may be the cause of regret in these women. However, we did not use a validated decisional regret tool, which may explain why we did not observe a difference.

Our results suggest that women newly diagnosed with DCIS would benefit from receiving DCIS-specific information about the possible QOL outcomes of treatment options available. More prospective research on QOL treatment outcomes is needed in DCIS specifically, as it is unclear how generalizable QOL data from invasive breast cancer samples is to this population. Notwithstanding differences in treatments offered, women with invasive cancer have higher mortality risk than DCIS patients. The need for DCIS-specific information is further evident by differences observed in our primary and sensitivity analyses.

Strengths

Our results highlight key QOL issues by treatment group, which may form a basis for selecting PRO endpoints in future DCIS research. Important QOL treatment considerations were identified by women with a past diagnosis of DCIS, who understand the difficult decision ahead of their newly-diagnosed peers and have experienced the impact of their chosen treatment on daily life. Thus, our sample was uniquely placed to identify issues that should be considered by future DCIS patients when making treatment decisions. Participants varied in terms of how they defined "feeling fully recovered from treatment" and in terms of how "recovered" they felt at the time of survey completion, which may have added diversity to the issues they considered important in treatment decision making as captured in the survey. Our survey was administered online to eligible members of the *BCNA Review and Survey Group*, which has a large, national membership and includes women from rural and remote areas.

Limitations

Our recruitment strategy meant that participants self-identified as having a history of DCIS. It was not possible to screen participants for eligibility, and consequently, some women with invasive breast cancer may have participated as suggested by the self-reported treatment profile of some participants. Some women would be expected to develop invasive cancer post-DCIS [4]; therefore, these women form an important part of our sample in terms of inclusiveness and representativeness to the "real world" DCIS population. However, we felt that the proportion (63%) was disproportionately large, and so utilised this data in a sensitivity analyses to overcome potential generalisability issues and to facilitate transparent interpretation of our results. This decision resulted in a primary analysis sample of $n = 38$, which limited the power of our analyses. The uncertainties apparent here highlight that women may often be unclear about their diagnoses, which reinforces the need for clearer communication and education about the differences between DCIS and invasive breast cancer.

The BCNA Review and Survey Group participants may not be representative of the greater DCIS population, particularly in terms of health literacy. We anticipate that our sample was more health literate than the general and DCIS populations; however, no HLQ normative data were available at the time of this analysis; therefore, this hypothesis could not be tested. We also did not test knowledge of DCIS, which may be a limitation of our study, as it is possible that participants' perceptions about health literacy may be discordant from their actual knowledge of DCIS. We did not directly ask participants if they were satisfied with their treatment outcome; however, it is possible that treatment satisfaction impacted survey responses or even participants' decision to take part in the survey.

Practice implications

DCIS-specific QOL information would allow women to make more informed treatment decisions, to prepare for these potential QOL issues post-treatment, and may even alleviate some psychosocial concerns associated with uncertainty. There is scope for QOL information to inform treatment decision making, along with information about DCIS pathology and patient preferences. Furthermore, clinicians and other DCIS health professionals also need to be informed about the QOL issues that women with DCIS perceive important for patient-centred care and improved communication.

Conclusion

Participants' fear of their DCIS returning or progressing to invasive breast cancer is likely to be the strongest factor considered by DCIS patients when making a treatment decision. Other key concerns across treatment groups included fatigue-related symptoms, desire to enjoy life and need for emotional support from loved ones. There were several differences in QOL concerns by treatment received, which were most likely reflective of differences in treatment side effects. These differences highlight that women newly diagnosed with DCIS may benefit from information about QOL impact of available treatments for DCIS to make informed treatment decisions.

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Compliance with ethical standards

Conflicts of interest None to declare.

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