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Factors involved in treatment decision making for women diagnosed with ductal carcinoma in situ: A qualitative study

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ABSTRACT

Whilst some of the diversity in management of women with ductal carcinoma in situ (DCIS) may be explained by tumour characteristics, the role of patient preference and the factors underlying those preferences have been less frequently examined. We have used a descriptive qualitative study to explore treatment decisions for a group of Australian women diagnosed with DCIS through mammographic screening. Semi-structured telephone interviews were performed with 16 women diagnosed with DCIS between January 2012 and December 2018, recruited through the LifePool dataset (a subset of BreastScreen participants who have agreed to participate in research). Content analysis using deductive coding identified three themes: participants did not have a clear understanding of their diagnosis or prognosis; reported involvement in decision making about management varied; specific factors including the psychosexual impact of mastectomy and perceptions of radiotherapy, could act as barriers or facilitators to specific decisions about treatment.

The treatment the women received was not simply determined by the characteristics of their disease. Interaction with the managing clinician was pivotal, however many other factors played a part in individual decisions. Recognising that decisions are not purely a function of disease characteristics is important for both women with DCIS and the clinicians who care for them.
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1. Introduction

The vast majority of new cases of ductal carcinoma in situ (DCIS) are found on screening mammography so it is not surprising that the incidence of DCIS has increased in line with the widespread implementation of population-based screening mammography [1]. In Australia in 2018, 5640 women aged 50–74 were diagnosed with invasive breast cancer (IBC) through the national mammographic screening program (BreastScreen Australia) which is a rate of 58.1/10,000 women. In the same year, 1384 women aged 50–74 years were diagnosed with DCIS, equivalent to a rate of 14.2/10,000 [2]. This shows that DCIS makes up nearly 20% of neoplastic conditions identified through the national mammographic screening program in Australia [2], although DCIS will also be identified through

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mammography occurring outside of the national screening program.

DCIS is a pre-invasive condition but is a risk factor for developing IBC [3]. Women who have been diagnosed and treated for DCIS have a higher risk of dying of breast cancer, with a standardised mortality ratio of 1.8 (95%CI 1.7–1.9) and an absolute risk of death from IBC at 10 years of 1.1% and at 20 years of 3.3%, although these figures are heavily influenced by the age of the woman at diagnosis and the characteristics of the DCIS [4,5].

Treatment guidelines have been produced for the management of DCIS[6]6). Currently the most common surgical treatment of DCIS is breast conserving surgery (BCS) [7] with most recommended to undergo post-operative radiotherapy. The type of surgery recommended (BCS or mastectomy) is dependent on the extent of the disease, including the size of the lesion (compared with breast volume), and whether the disease is multi-focal. The risk of DCIS recurrence and/or development of IBC is lower with mastectomy than for BCS [4,5,8,9], although the addition of radiotherapy to BCS reduces the risk of ipsilateral recurrence of DCIS/IBC [10,11]. Despite the reduced risk of disease recurrence with mastectomy, there is no evidence of reduced breast cancer-specific mortality for mastectomy compared with BCS (with or without radiotherapy) [5,12]. Women who have a mastectomy for DCIS may choose to have a contralateral mastectomy to reduce their risk of contralateral DCIS or IBC [13], although evidence that this reduces their breast cancer specific mortality is lacking. Despite this evidence, the rates of mastectomy for DCIS are variable and rates of bilateral mastectomy for DCIS are increasing [13], which suggests that factors other than the tumour characteristics are influencing management. The diversity of treatment regimens for DCIS is a feature of the prospective study of large numbers of women diagnosed with DCIS in the Sloane project in the United Kingdom [8].

In 2018 a scoping review that evaluated communication experiences in women with DCIS and their physicians [14] identified a range of issues including for the women, lack of knowledge and for the physicians, difficulty explaining the concept of DCIS. The review concluded that there was a concerning lack of research on how to improve communication between patients with DCIS and their health-care providers. However, the development of strategies for improving communication is contingent upon a clear understanding of the perspective of women diagnosed with DCIS.

Our study aimed to investigate the experience of women previously diagnosed with DCIS and report on the factors they identified as important in their management.

2. Methods

A qualitative descriptive study was conducted to address the study aim. The methods are reported according to the Standards for Reporting Qualitative Research (SRQR) [15] and the SRQR checklist is included as Supplementary Table 1.

3. Participants

The participants were recruited from “LifePool” (http://www.lifepool.org/). LifePool is an initiative of the National Breast Cancer Foundation (Australia) and funded by the National Breast Cancer Foundation and Cancer Australia. Participants of Lifepool are women who have had a mammogram with BreastScreen, the national breast screening service in Australia, and who opted to be contacted for future research. The LifePool dataset contains data from BreastScreen, State Cancer Registries, and relevant pathology reports. All participants in this study were from the southern Australian state of Victoria.

Eligibility criteria for our study included a history of DCIS diagnosed between January 2012 and December 2018 but no subsequent or previous diagnosis of invasive breast cancer, and the ability to understand spoken and written English. For the purpose of this study, the LifePool organisation contacted eligible participants from the state of Victoria via email on behalf of the researchers. An Explanatory Statement was provided and the women were asked to contact the research group at Monash University if they were interested in participating. No incentive was offered to women for participating in the study.

We required participants to be aged at least 50 years of age at the time of diagnosis and quota sampling was used in relation to geographical area of residence and age to ensure a broad range of patient experiences were captured. (see Table S1).

4. Interviews

Participants were interviewed about their DCIS diagnosis, treatment and decision making processes. Questions were developed based on our study aim and the work of Bromley [16] (Supplementary Table 2). At the beginning of each interview the participant confirmed verbal consent to the interview. The researcher conducting the interview (AH) was located in a private room at Monash University. The interviews lasted on average 45 min (range: 23–65 min). Recordings of the interviews were transcribed verbatim and the transcripts de-identified using numbers in order to protect participant privacy. Transcripts were sent back to participants for review, although this process did not result in any changes to the transcripts.

5. Analysis

Descriptive statistics were generated to provide information about the characteristics of the study sample, using the Statistical Package for the Social Sciences (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.)

Content analysis via deductive coding by two members of the research team using NVivo 12.0. Analysis was guided by the following questions:

1. What did participants understand of their diagnosis and prognosis?
2. How were treatment decisions made?
3. What were the barriers and enablers to specific treatment decisions and management?

Coding issues were resolved by discussion between members of the research team. Analysis was carried out during data collection and recruitment stopped once data saturation had been reached. Themes and sub-themes were identified and direct quotes from the transcripts are provided to illustrate the themes.

Ethics approval was obtained from Monash University Human Research Ethics Committee (Project 18,601).

6. Results

There were 217 women from Lifepool who fitted the criteria for the study. A total of ninety email invitations were sent out in batches over three weeks and resulted in the recruitment of 16 participants before recruitment was stopped. As analysis was occurring while data collection was underway, we did not need to approach all 217 potential participants in order to attain our sample. The demographic characteristics of the participants, along with the characteristics of their disease and treatment, extracted from the LifePool data base are shown in Table 1.

All women were aged over 50 years at the time of diagnosis and

their diagnosis of DCIS had occurred through the national BreastScreen program on average 5 years before the time of their interview. The women resided in a range of settings including rural areas and regional towns as well as the state capital city, Melbourne. None of the participants were BRCA1 or BRCA2 mutation carriers. Nine of 16 women had been diagnosed with high-grade DCIS (grade 3) and the size of the lesions ranged from 2 to 62 mm. Three of the 16 (18.8%) lesions were <1 cm and 9/16 (56.3%) were <2 cm in diameter. All 16 women underwent a surgical procedure, with the majority (11/16) having breast conserving surgery (BCS). Of these, all but one also had radiotherapy. Nine had oestrogen receptor positive disease but only two women received endocrine therapy. Lymph node biopsy status was unknown in one woman, but of the other 15, three had a sentinel lymph node biopsy and all nodes were clear of disease. Two of these three women had a unilateral mastectomy, one for a 10 mm grade 3 lesion and the other for a 10 mm grade 1 lesion. The third woman had BCS and radiotherapy for a 2 mm intermediate grade lesion.

The association between treatment and both disease grade and demographic characteristics are shown in Table 2. The majority of women had high grade disease and most of these women had a local excision with radiotherapy although two had a unilateral mastectomy. Of the six women with intermediate grade disease, four had a local excision, one had a unilateral mastectomy (of a tumour measuring 62 mm and this was the only woman reported to have multifocal disease) and one had a bilateral mastectomy (tumour measured 33 mm). Only one woman had low grade disease and she had a mastectomy with a 10 mm tumour. There were few women in individual categories when the data was stratified by age and location of residence, however there was no clear pattern of management being associated with either of these variables.

7. Themes

Three themes were identified from the content analysis (see Table 3 for quotes from the participants).

7.1. Theme 1 participants did not have a clear understanding of their diagnosis or prognosis

When asked to define DCIS, women had one of two responses, either *"pre-cancer"* or *"cancer"*. Seven women fell into the "*pre-cancer*" category and explained that DCIS was "*pre-invasive*", "*pre-cancer"* or "*not yet cancer*". There was also one woman who believed that DCIS was *"the same as a blocked milk duct"*. Eight women were of the understanding that DCIS was cancer and that DCIS "*contained cancer cells*"', was "*the least invasive cancer*" or "*the best cancer you can have*". There were three women who referred to the term "*carcinoma*" within the DCIS acronym, two from the "*cancer*" group, with one from the "*pre-cancer*" group. The two women in the "*cancer*" group said that this term had caused them anxiety and a third woman noted that the term "*carcinoma*" was confusing.

Six women reported that, without surgical intervention, DCIS in all cases would progress to IBC. Of the 7 women who considered they had pre-cancer, 2 said their condition was likely to progress to IBC, compared with 4 of the 8 women who described their

Table 1
Demographic characteristics, tumour characteristics and treatment modalities.

Study participants (n = 16)		
Characteristic	Mean (SD)	Range
Age at diagnosis (years)	63 (4.5)	51–77
Age at time of interview (years)	68 (4.3)	58–81
Time from diagnosis (years)	5 (1.2)	2–8
Size of main lesion (millimetres)	21 (17.4) mm	2–62 mm
	Proportion	
Geographical Location[a]		
Metropolitan	6/16	
Regional town	7/16	
Rural	3/16	
DCIS Grade		
1 (low)	1/16	
2 (intermediate)	6/16	
3 (high)	9/16	
DCIS hormone status		
+ve Oestrogen Receptor (ER)/Progesterone Receptor (PR)	6/16	
+ve (ER only)	2/16	
+ve (HER2)	1/16	
-ve	7/16	
Unifocal/Multifocal nature of lesion		
Unifocal	14/16	
Multifocal	1/16	
Unknown	1/16	
Treatment		
Monitoring	0/16	Size of lesion range (mm)
Breast Conserving Surgery (categorised below)	11/16	2–44 mm
Local excision + radiotherapy	8/11	5–44 mm
Local excision + radiotherapy + endocrine therapy	2/11	5–20 mm
Local excision alone	1/11	2 mm
Unilateral mastectomy	4/16	10–62 mm
Bilateral mastectomy	1/16	33 mm
Lymph node biopsy		
Yes[Y]	3/16	
No	12/16	
Unknown	1/16	

[Y] Of the participants who had a lymph node biopsy 2 had mastectomies and 1 had a local excision.
[a] Categorisation of participants to geographical location is based on Rural, Remote and Metropolitan Area classification.

Table 2
Treatment in relation to tumour size and grade as well as age and geographical location of residence.

Treatment		Age (years)		Geographical location			Size in mm range	DCIS Grade		
Treatment option	Total (n)	<65	≥65	Rural	Regional	Metro		1	2	3
Monitoring	**0**									
Local excision alone	**1**		1	1			2		1	
Local excision + radiotherapy	**8**	6	2	1	4	3	5–44		2	6
Local excision + radiotherapy + endocrine therapy	**2**	2			1	1	5–20		1	1
Mastectomy	**4**	3	1	1	1	2[a]	10–62	1	1	2
Bilateral mastectomy	**1**		1		1		33		1	
TOTAL	**16**	11	5	3	7	6	2–62	1	6	9

[a] There was only one woman with multi-focal disease. She was aged 77 years at diagnosis, lived in a metropolitan area, her lesion measured 62 mm and was classified as intermediate disease.

condition as cancer. Nine women said that the natural history of DCIS was unpredictable. The unpredictable nature of the prognosis was reported by 5/7 women who described their DCIS as pre-cancer and 4/8 women who described DCIS as cancer. A specific question about 'watch and wait' was included for all participants. All study participants reported that this concept was mentioned, although it was not clear if this was because it was considered as a treatment option or just mentioned for immediate exclusion. No participants were supportive of this approach.

7.2. Theme 2 participants reported involvement in decision making about management varied

There was an even split between women who reported shared decision making and those who did not. Amongst those who described shared decision making, six women described treatment options being presented to them by their clinician along with the clinicians' advice regarding the options. The final decision was explicitly placed on the participant. These women reported that they were able to "*verbalise what they wanted*". The group that experienced a more directive style from their clinician (n = 8) reported that not all treatment options were discussed with them, nor did they take an active role in the treatment decision making processes. Women who described this approach in a positive light trusted expert opinion and reported a strong rapport with the treatment team. These women felt that the clinicians "*know more about it than I do*" so were happy to proceed "*with whatever I was told to do*". However, two participants described this approach in a negative light and described a lack of autonomy. One of these women felt that the speed of the process was too fast (although we do not have the details of the timeframe involved) and expressed a "*wish I had have done a bit more research myself*".

7.3. Theme 3 there were factors that could act as barriers or facilitators to specific decisions about management

Factors identified by some women as a barrier, for other women acted as a facilitator: psychosexual l impact of mastectomy.

Some older women said that, given their age, their breasts were no longer functional and losing a breast would not have a large psychological impact. Other younger women felt that their breasts defined them and that a mastectomy would impact them psychologically. Women who did have a mastectomy reported that this option gave them '*peace of mind*', however, one woman believed that mastectomy was her only treatment option. We do not have information about what was discussed with the women about breast reconstruction.

Women recounted the experience of family or friends who had experienced surgery and or radiotherapy for breast cancer and these experiences could act as a facilitator or barrier in terms of what they wanted for themselves. Women also reported that people in their immediate social circle treated their diagnosis ("*the word cancer*" [participant 15], "*the C word*" [participant 3], the "*big C*" [participant 10] as catastrophic, in contrast with the information the women themselves were being provided by their treating team. Feeling different from women diagnosed with IBC provoked varied responses ranging from feeling *"lucky*" through to feeling "'*left out*'" of the so-called "*breast cancer club*".

7.4. Facilitator: radiotherapy after BCS

Of the women who had BCS, only one of 11 did not also have radiotherapy. Women who had BCS with adjuvant radiation saw the radiation as "*an extra layer of protection*", "*safety*" and "*peace of mind*".

7.5. Facilitator: gender of the treating clinician

The treating clinicians' preferences, either overtly or covertly, influenced decision making and that clinician preference might have been gendered. Three women said that they believed having a female clinician meant that they felt their clinician had a personal affinity with them which they felt led to being advised to choose mastectomy over BCS.

7.6. Barrier

Geographical location affecting proximity to treatment was identified as a factor in the decision to opt for mastectomy rather than BCS. One participant reported that the travel required for radiotherapy following BCS was the basis for her decision to proceed with a mastectomy.

8. Discussion

The decisions made about management of DCIS for the women in this study were complex and unique for each participant however, some clear themes arose from the 16 interviews. Interaction with the managing clinician was pivotal, with the experience of women ranging from a feeling of control over their own management through to being the passive recipient of a decision made by their surgeon, which was perceived by some as appropriate but offered others less than their preferred degree of autonomy. Clearly the treatment they received was not simply determined by the nature of their disease such as the grade or the size of the DCIS lesion nor just by the woman's understanding of her disease.

There was a diverse range of management options observed in our study ranging from BCS with no radiotherapy to bilateral mastectomy in the context that of nearly all women had uni-focal grade 2 or 3 disease and the majority had lesions <2 cm in

Table 3
Participant quotations.

Theme	subtheme		Participant quote
Theme 1			
Understanding of diagnosis and prognosis	*understanding of diagnosis:*	*Pre-cancer*	*"It's not really breast cancer, but it changes in the cells of your breasts in the milk ducts" [participant 6]*
			"It's just an unusual growth of cells that's changing and it's in the milk duct and at this stage it hasn't morphed any further, it's there and it needs to come out because we don't know how it will develop." [participant 5]
	understanding of diagnosis:	*Cancer*	*"So my understanding I think of what it was, was very clear actually because they said if you're going to get one of these cancers you've got the best you can get because it hasn't escaped from the cells yet, you've got a cancer more or less that is still contained, it's when it has gone through the cell wall that it's you know, that the treatment is much more major."[participant 12]*
	understanding of diagnosis:	*Issue with the word carcinoma*	*"The word cancer was front in my mind and she said it wasn't invasive. It was a ductal carcinoma in-situ so it was not escaped to the extent that they could see. [participant 10]*
			"If they say early stage cancer then you know what that is, but DCIS they don't know, so I think it ought to be called pre-cancer." [participant 8]
	understanding of prognosis	*likely to progress*	*"I was quite happy to yep, get it dealt with, particularly before it left the duct and became more widespread … he said how it starts and how it is in the ducts and you should get it while it's there and before it spreads."[participant 15]*
	understanding of prognosis	*Not predictable*	*"There isn't a lot of information about it because everyone has it removed and so that they don't know is it one fifth that move, is it one tenth, you know." [participant 11]*
			"… everything that I read said that they don't really understand the connection between DCIS and full-blown breast cancer they don't really understand how one can go to the other … I don't know what the outcome is if you leave it for years and years and years and don't do anything about it, you know it could be bad, but you know I didn't do that, for that reason."[participant 9]
	Watch and wait not acceptable		*"… there is no way in the world if I had the option to have 1 million pounds and not doing anything about it and have it done, then I would have had it done." [participant 14]*
Theme 2			
Participants reported involvement in decision making about management varied	*Involved*		*"I am forever grateful that I was guided, I wasn't told, I made the decision myself … she [the surgeon] guided me and gave me the options." [participant 10]*
			"I guess I am mostly clinician led, umm in what they would recommend, I never felt that I was being overridden or pushed into anything, everyone made sure that the patient was the person to verbalise what they wanted." [participant 15]
	Directed	*positive*	*"I don't think I made any decisions myself because I had no idea about it, and my view on life is if there's an expert telling you what to do then you know you might as well go along with what they say because they know more about it than I do, so I pretty much went along with whatever I was told to do." [participant 4]*
	Directed	*negative*	*"I wish I had have taken more control in my own hands it's actually the only part that sticks with me, I think I took their word and just sort of let them guide me, which is fine, I just wish I had have done a bit more research myself." [participant 2]*
Theme 3			
There were factors that could act as barriers or facilitators to specific decisions about management	*psychosexual effect of mastectomy*	*facilitator*	*"I said well I lean towards the complete mastectomy of that breast and she said why? And I said well I am 60 plus years old so nobody is looking at my breasts anyway and for many years I haven't found them of use …" [participant 8]*
			"… as far as I was concerned, I just want to have a mastectomy, if you are diagnosed with it [DCIS] then that's what you do." [participant 1]
			"… it's just incidental reading that I've done around, some people seem to be suggesting that it [mastectomy] may be hitting an acorn with a sledgehammer, but I have absolutely never regretted it, I know there's a lot of debate about it, but for me, it was the right choice." [participant 10]
	psychosexual effect of mastectomy	*barrier*	*"… like I did say that I prefer lumpectomy rather than a mastectomy, she said yes that's actually my preference as well, because there must be some sort of psychological influence of a woman losing their breast and she doesn't know how I would deal with it." [participant 13]*
			"The decision I made was to have a lumpectomy and radiotherapy the factors that influenced me, I was somewhat younger, I guess sex with my husband I mean they are part of your sexual relationship aren't they." [participant 6]
	Experience of Family and friends	*facilitator*	*"I physically made a pros and cons list and it took me months to decide … my mother was 62 when she got cancer and I thought I don't want to put myself through lymphoedema and other cancers, if I'm happy to lose a boob I've got no reason to have a boob anymore …" [participant 16]*
			"My grandmother had breast cancer when she died but she didn't die from breast cancer, I think in a twisted way I thought it was just there but I was gonna live with it." [participant 6]
			"You know that's one of the greatest criticisms of mammograms, that we go into overkill on things that aren't going to do anything anyway, but I think I've had enough friends, people who I've been directly in contact with … who have had problems with breast cancer … "[participant 3]
			"So as far as I was concerned and my husband was concerned I think because maybe we had already talked about the possibility of breast cancer, my immediate response was whatever it is I will have a mastectomy anyway, so it was always my choice to do that because I didn't want to have to worry, I would much rather have it not there." [participant 1]

(*continued on next page*)

Table 3 (*continued*)

Theme	subtheme		Participant quote
	Experience of Family and friends	*barrier*	*"… well basically they just explained to me what could happen if I had the radiation and I know people that have had radiation and it knocked them terribly" [participant 16]* *"I think at the time that I went through it there was loads of talk about breast cancer in the community so there was a bit of a scare element there for me, had it been today that it was diagnosed, I would definitely take my time to consider my options."[participant 2]*
	Radiation	*facilitator*	*"I chose to take the safest option that was to go ahead with the radiation." [participant 12]*
	Clinician characteristics	*facilitator*	*"both those doctors … are women and oh I did have an opportunity to see a male breast surgeon and he was, less than supportive, he wasn't unpleasant but he was 'oh so you decided to have the radical surgery', so I took from that, that maybe there is a gender issue with treatment" [participant 9]*
	Geographical location	*barrier*	*[discussing BCS and radiotherapy versus mastectomy] "… she outlined what that would involve and we live in regional Victoria, about 35 min from Geelong so it would be, you know, a pretty long [drive] on a regular basis, so we opted for a total mastectomy." [participant 10]*

diameter. Notably the woman who had a bilateral mastectomy did not have the most extensive disease and the only woman with grade 1 disease (size 10 mm) still elected to have a mastectomy. The final management of each woman is affected by all the other factors we identified as being important in decision making for individual women including psychosexual factors, the experience of family or friends with IBC and the advice of the clinician.

Previous studies have reported that women experience decisional conflict around the management of DCIS [17,18]. Although it has been reported that some women experience confusion when offered mastectomy as they associate this with the management of IBC, this was not supported by our study participants who had a mastectomy [17,19]. Most women in our study reported feeling satisfied with their level of participation in the decision making process regardless of their reported level of involvement. Our participants acknowledged that family and friends may have assumed the diagnosis was IBC and so expected more extensive treatment. The psychological impact of mastectomy has been well studied [20] and our participants who acknowledged the psychosexual implications of a mastectomy were more likely to choose lumpectomy. Although some studies have failed to find an association between decision making about surgery and geographical access to radiotherapy [21,22], at least one of our participants confirmed that this was issue for her [23,24]. Other researchers have reported that female surgeons are more likely to recommend mastectomy over BCS [25] and are also more likely than male surgeons to recommend contralateral prophylactic mastectomy ([26].

Lack of understanding of DCIS as a pre-cancerous condition was common although there was not a close association between lack of understanding of the diagnosis and belief about likely progression. The overall excellent outlook for women with DCIS, irrespective of the surgical management they receive has been used to argue that some women will experience over-treatment [27] and has also been the basis for the establishment of trials of active surveillance for low/intermediate grade DCIS[28–30]. None of our participants were supportive of this option. Other studies, one involving women with DCIS and another using a hypothetical scenario about DCIS, have reported a more positive attitude towards watchful waiting amongst Australian women [16,31]. . A recent study of Australasian health care professionals involved in the management of women with DCIS found that they were uncomfortable about this approach to care (watchful waiting), even for low risk DCIS, which they considered to be outside the scope of current standard DCIS care [32].

A study strength is that the participants were likely to have provided us with a comprehensive picture of factors associated with the management of DCIS in Australia. No research that requires people to volunteer is free from bias, and it is possible that women with DCIS recruited to our study from the LifePool database were better informed and more engaged with their diagnosis than other women with DCIS. All our participants were diagnosed through the national BreastScreen program (so none were diagnosed outside of this program), which also presents another potential source of selection bias.As all the women interviewed were diagnosed between 2012 and 2018 and none have subsequently developed IBC, our participants may not be fully representative of all women diagnosed with DCIS. Despite this, characteristics of DCIS experienced by our participants were similar to those seen in a population-based study of DCIS from another Australian state, New South Wales [33] in which 83% of women had intermediate or high grade disease and 61.5% had lesions <2 cm in diameter. Other strengths of our study were that the information about each woman's cancer and her treatment were derived from external sources so did not rely on individual recall and that the research team was multi-disciplinary including cancer surgeons and oncologists as well as psychologists and public health practitioners. A potential limitation of all qualitative analysis is bias which may be introduced because the researcher is the primary analysis tool. We aimed to limit this problem by using two independent coders for a sub-set of the interviews and regular review of coding by the study team. As none of our participants had experienced a recurrence of their DCIS or the development of IBC, they may have been less likely to report decisional conflict with their original management than women who did experience recurrence of DCIS or IBC.

The findings of our study suggest that women with DCIS continue to experience confusion about their condition. One suggestion aimed at reducing confusion for women and their families, but still not formally implemented, was removing the word carcinoma from the term DCIS [34]. Studies aimed at improving communication between clinicians and women with DCIS started 10 years ago [35] and moved to an online format more recently [36]. However, in 2018 a content analysis of information about DCIS available on the internet found that few DCIS information tools met the desired quality criteria for consumer health information [37], so clearly there is more work to do in this area.

9. Conclusion

Not all women with DCIS have a clear understanding of their condition and the nomenclature of DCIS likely contributes to the confusion. Strategies to help women diagnosed with DCIS to communicate with their family and friends about their condition would be helpful. Despite a number of decision aids being available, the quality of such aids remains a problem for consumers. Our study has confirmed the complexity of factors affecting decision making about the management of DCIS. Recognising that decisions are not purely a function of disease characteristics is important for

both women with DCIS and the clinicians who care for them. The opportunity to be actively engaged in treatment decision making should be available to all women diagnosed with DCIS.

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Declaration of competing interest

The following authors report that they have no interests to declare: Amy Hatton, Natalie Heriot, Darshini Ayton, Jill Evans, David Roder, Boon H Chua, Jolyn Hersch, Jocelyn Lippey, Jane Fox, Christobel Saunders, Bruce Mann, Jane Synnot and Robin J Bell.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.breast.2021.09.007.

Data statement

In the interests of confidentiality, the research data for this study is not available.

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