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ORIGINAL ARTICLE

A prospective and population-based inquiry on the use and acceptability of peer support for women newly diagnosed with breast cancer

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Abstract
The degree to which peer support is used and accepted as a supportive care approach by women with breast cancer is unclear. We examine peer support use across three major modalities (i.e. support groups, online platforms, one-on-one) and identify enablers and barriers to peer support using the beliefs framework of the theory of planned behaviour. A population-based sample of women newly diagnosed with breast cancer ($n = 3105$) who were on average 54.08 weeks since diagnosis completed mailed surveys at baseline measuring beliefs about peer support and intention. Peer support use was measured via telephone interview at baseline and prospectively at 12-month follow-up ($n = 2780$). In all, 37% of women had used at least one peer support service since diagnosis (support group = 20%, online = 18%, one-on-one = 10%). A path analysis examined what beliefs enabled or acted as barriers to peer support use at follow-up adjusting for past behaviour (i.e. baseline use), sociodemographic characteristics, and treatment. In order of relative strength, enablers included beliefs that peer support is an outlet for honest expression of feelings ($\beta = .35$), a source of empathy ($\beta = .30$), approved by doctors ($\beta = .07$), and approved by family/partner ($\beta = .04$). Barriers were beliefs that it encourages dwelling about breast cancer ($\beta = -.06$) and involves exposure to negative stories about this disease ($\beta = -.04$). Strategies which communicate the potential emotional support benefits of a shared illness experience and social approval by others, particularly the medical profession, may help to promote acceptance of peer support and encourage service uptake in breast cancer.

Keywords Breast cancer · Peer support · Psychosocial care

Background

In response to the psychosocial sequelae of breast cancer [1–3], women may choose to seek support from a variety of peer support services in the community. By contrast to professional support, the key premise of peer support is mutual support based upon shared illness experience [4]. The process of sharing experiences can provide insight into effective coping, decrease social isolation, and promote hope for the future. Peer support was initiated in breast cancer care by Terese Lasser, who herself had undergone mastectomy, with the Reach to Recovery one-on-one support program in North America in

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1952. Peer support has since been adopted globally as a model of psychosocial support, and modalities have diversified from one-on-one to support groups and online discussion platforms [4, 5]. Intervention studies have also reported that this form of support can be beneficial to women with breast cancer [6, 7].

Despite the variety in modalities and proposed benefit, peer support may be underutilised amongst women with breast cancer. The reported rate of uptake in past research ranges from 11 to 36% [8–11]. Studies report uptake of one specific modality only, and the degree to which peer support, overall, is used and accepted by women is unclear. Problematically, almost all research that has examined the predictors of peer support in breast cancer has been cross-sectional with retrospective measurement of behaviour [8–14]. Reported predictors include higher education, rural residence, receipt of mastectomy, encouragement from family, lower spiritual well-being, optimism, and poorer mental health. Findings are inconsistent where some studies have reported these predictors as nonsignificant. For example, one study identified poorer mental health as a predictor of use in women with breast cancer [13] whereas two other studies reported findings different to this [12, 14]. Numerous distress-related variables were measured but all yielded nonsignificant effects on peer support use including psychological distress (e.g. anxiety and/or depression, negative mood, emotional wellbeing) and mental health-related quality of life [12, 14]. As such, it is unclear what encourages or deters women with breast cancer from using peer support.

Women's perspectives about peer support have been well described in the qualitative literature which could provide insight into perceptions that influence this behaviour prospectively. Service users consistently describe the benefit of emotional support based upon shared experience with emphasis on heightened empathy and honest expression of feelings about breast cancer [15–23]. In contrast, non-users have described potentially negative consequences such as hearing negative stories or dwelling about cancer in these settings [13]. Other concerns regard the difficulty in accessing peer support, such as a lack of information about where to find services and being too unwell or busy [13, 24].

The aim of the current study was to examine the use and acceptability of peer support for women with breast cancer. First, we examine overall use of peer support across the three major modalities (i.e. support groups, online discussion platforms, one-on-one) in a large cohort. Second, we applied the beliefs framework of the theory of planned behaviour (TPB) to examine whether perspectives commonly reported in the qualitative literature enable or act as barriers to overall peer support use [25, 26]. This framework examines how specific beliefs or expectations about seeking peer support influence behaviour via intention. Constructs from the TPB have been applied to the prediction of support group use in mixed cancer diagnosis samples [27, 28] and men with prostate cancer [29]. In the proposed model (Fig. 1), we prospectively examine whether peer support in breast cancer is enabled by beliefs about the benefits of emotional support based upon shared illness experience (i.e. positive behavioural beliefs) and approval from key social network members (i.e. normative beliefs). Potential barriers include beliefs about the negative consequences of peer support (i.e. negative behavioural beliefs) as well as difficulties in accessing services (i.e. control beliefs). From this, we identify targets for future research and practice in peer support programs for breast cancer [26].

Method

Participants and procedure

A population-based cohort of women newly diagnosed with breast cancer were recruited from a state cancer registry. Eligibility requirements were: first primary diagnosis of invasive breast cancer (histologically confirmed) 1 July 2010 to 30 June 2013; aged 20 to 79 years at time of recruitment; and resident of Queensland, Australia. Exclusion criteria were inability to speak or understand English and cognitive impairment. Human research ethics was approved by Griffith University.

Data from new hospital or pathology notifications were entered in the registry in advance to minimise time from diagnosis to recruitment. Contact details of eligible women and their treating doctors were then obtained from the registry, and 87% of treating doctors provided consent for the research team to mail patients a study invitation. Patients who consented (74%) completed a self-administered questionnaire at baseline and a computer-assisted telephone interview 12 months later to assess use of peer support services.

Measures

Beliefs about peer support Belief items were written according to the TPB framework [25] and based upon qualitative research on peer support in breast cancer and advice from consumer representatives. In the baseline mail questionnaire, women rated their agreement with these ten beliefs about seeking support from other women with breast cancer in the next 12 months on a scale of 1 (*strongly disagree*) to 7 (*strongly agree*).

Intention to seek peer support Two items measured women's intention to seek peer support in the next 12 months via the baseline mail questionnaire. For example, "I intend to get support by talking to other women with breast cancer in the next 12 months." Items were scored on a scale of 1 (*strongly disagree*) to 7 (*strongly agree*). The two items ($r = .83$, $p = <.001$) were constructed as average scores.

Peer support service use Behaviour was measured via computer-assisted telephone interviews and defined as accessing

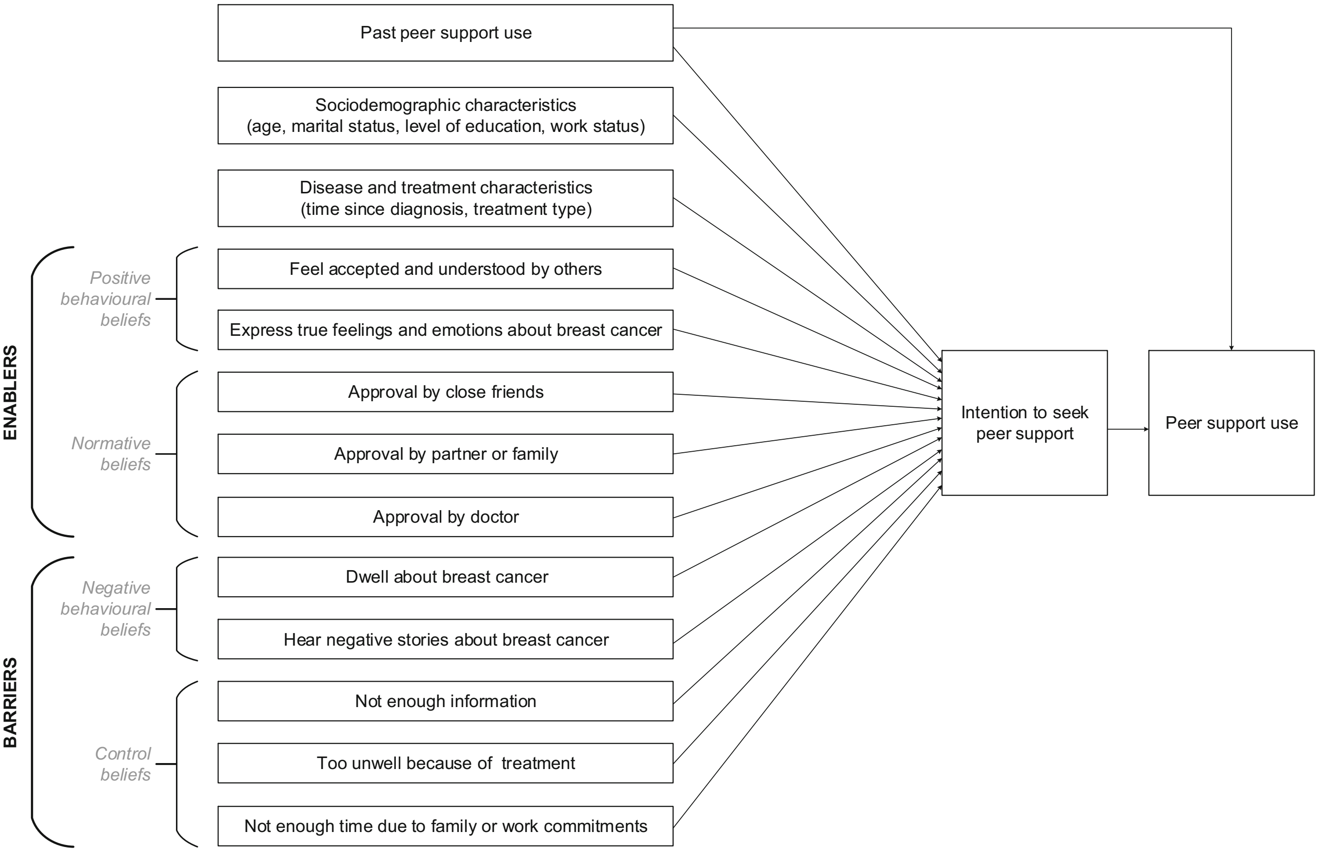

Fig. 1 Proposed model of peer support use adjusting for past use and sociodemographic, disease and treatment characteristics

a peer support service that provided women the opportunity to speak to other women diagnosed with breast cancer. At follow-up, women reported whether they had accessed three types of services (i.e. support group, online discussion platform, or one-on-one service) in the previous 12 months. For example, “Since your first interview on [date], did you get support from a support group where you spoke to other women with breast cancer?” Women who used at least one of these services were allocated a score of 1 and women who did not use any of these services received a score of 0. Interviewers were trained to identify and clarify services that met the study’s behavioural definition of peer support use. Service-specific criteria was provided for additional guidance.[1] At baseline, women reported their use of the three services since diagnosis as a measure of past behaviour and the same scoring system was applied.

Statistical analyses

The degree women endorsed the beliefs about peer support was reported as the percentage who disagreed (score 1–3) or agreed (score 5–7) with belief items. A path analysis was undertaken via Mplus (Version 6) [30] to examine the proposed model (Fig. 1). The model was estimated using a robust weighted least squares estimator as the main outcome of peer support use was binary. Adequate model fit was determined by the following fit indices: non-significant chi-square statistic, comparative fit index > 0.95, root mean square error of approximation < 0.06, and weighted root mean square residual for binary outcomes < 0.90. Unstandardised path estimates for the model are reported. In addition, standardised estimates were requested for paths to intention to determine the relative strength of belief predictors as enablers or barriers to peer support.

Results

Sample characteristics

Overall, 3105 women returned the baseline questionnaire and 2780 (90%) completed 12-month follow-up. Women who did not complete follow-up were deceased ($n = 76$), withdrew

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[1] For the present study, the criteria for a support group were (a) a formalised group of people who meet at a scheduled time on a regular basis and (b) the people in the group are connected in some way by cancer (e.g. currently undergoing or finished treatment for cancer or friend/relative/partner of someone with cancer). This included both professional- and peer-led groups. The criteria for an online peer support platform were (a) an online service where people can join to seek contact with other people (e.g. discussion boards, chat rooms, or interactive online mailing lists) and (b) all people who sign up to the online service are connected in some way by cancer. A one-on-one peer support service was defined as a service that organised women diagnosed with breast cancer to speak one-on-one with a breast cancer volunteer.

from the study ($n = 114$) or follow-up interview ($n = 47$), or were uncontactable ($n = 88$). The average age of women was 58.74 years (SD = 10.83). Most women were married (67%) and educated up to the levels of school (39%) or certificate/diploma (38%). Seventeen percent were undertaking full-time work and 24% were working part-time or casually. Women had been diagnosed with breast cancer at an average of 54.08 weeks (SD = 20.09) prior to the study and most were diagnosed with stage I (49%) or stages IIA/IIB (38%) breast cancer. Regarding treatment, 39% of women had mastectomy, 68% lumpectomy, 54% chemotherapy, 71% radiotherapy, 67% hormonal therapy, and 11% Herceptin.

Use of peer support services

At baseline assessment, 872 (29%) women had accessed at least one peer support service since diagnosis. Use was lower within the specific modalities of support. Specifically, 455 (15%) women had accessed a support group at least once since diagnosis, 327 (11%) an online platform, and 282 (9%) a one-on-one service. One hundred seventy-six (6%) had accessed more than one type of service at baseline assessment.

At 12-month follow-up, 720 (26%) women had used at least one peer support service in the past 12 months and of these, 257 (36%) were first-time users. Use within specific modalities was lower at follow-up: 413 (15%) women accessed a support group at least once in the past 12 months (40%, $n = 167$ first-time use), 383 (14%) an online platform (53%, $n = 204$ first-time use), and 44 (2%) used one-on-one support (34%, $n = 15$ first-time use). One hundred fourteen (4%) women had accessed more than one type of service in this time-period.

Across both assessments, 1139 (37%) had used at least one peer support service for breast cancer (15% retention across assessments, $n = 453$). Within specific modalities, 626 (20%) had accessed a support group at least once (8% retention, $n = 242$), 537 (18%) used an online platform (6% retention, $n = 173$), and 298 (10%) used one-on-one support (1% retention, $n = 28$). One hundred forty-one (5%) women had accessed more than one type of modality across both assessment periods.

Beliefs about peer support

For enabler belief statements, over half of women agreed that social network members would approve of peer support (61–67%; Table 1). Less than half agreed peer support would lead to personal benefits relating to emotional support (40–42%). More women agreed it would involve hearing negative stories about breast cancer (57%)—a potential barrier to use. Other barrier belief statements were not as strongly endorsed by women (13–29% agreement).

Path analysis

Descriptive statistics and intercorrelations between main analysis variables are presented in Tables 1 and 2. The proposed model was initially a poor fit to the data, $\chi^2(\text{df}) = 9.40(21)$, $p < .001$, CFI = .93, RMSEA = .04, WRMR = 1.48. Modification indices were examined to improve model fit. These were examined in a sequential fashion where suggested paths were added to the model one-by-one and model fit was reassessed. Suggested paths with the largest indices were added first if they made theoretical or practical sense. Newly added paths did not concern any belief variables. After inclusion of the three paths, the revised model was an acceptable fit to the data, $\chi^2(\text{df}) = 26.09(18)$, $p = .098$ CFI = .99, RMSEA = .01, WRMR = 0.74.

For clarity, unstandardised estimates for significant paths only are reported in the final model (Fig. 2). Beliefs that did not have a significant effect on intention and are omitted from

Table 1 Beliefs about peer support

Belief statement			Disagreement	Agreement	M (SD)
Enabler	Positive behavioural	Feel accepted and understood by others	38%	42%	3.96 (1.86)
		Express true feelings and emotions about breast cancer	38%	40%	3.92 (1.88)
	Normative	Approval by close friends	17%	67%	5.09 (1.75)
		Approval by partner or family	14%	69%	5.19 (1.64)
		Approval by doctor	12%	61%	5.02 (1.57)
Barrier	Negative behavioural	Dwell on breast cancer diagnosis	56%	29%	3.24 (1.91)
		Hear negative stories about breast cancer	25%	57%	4.57 (1.83)
	Control	Not enough information	60%	27%	3.09 (1.97)
		Too unwell because of treatment	74%	13%	2.52 (1.56)
		Not enough time due to work/family commitments	57%	27%	3.22 (1.86)

Disagreement and agreement with belief statements are indicated by a score of 1–3 and 5–7 on the measure, respectively. M (SD) for intention = 3.29 (1.77)

Table 2 Correlations between analysis variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
1. Past PSU																								
2. PSU	.45*																							
3. Intention	.32*	.34*																						
4. BB1	.27*	.29*	.59*																					
5. BB2	.26*	.29*	.60*	.62*																				
6. BB3	−.01	−.01	−.07*	−.03	.04^																			
7. BB4	.09*	.10*	.06*	.10*	.16*	.39*																		
8. NB1	.14*	.14*	.28*	.34*	.36*	.03	.20*																	
9. NB2	.13*	.14*	.30*	.32*	.36*	.01	.18*	.56*																
10. NB3	.10*	.11*	.29*	.29*	.32*	.04^	.15*	.49*	.56*															
11. CB1	.08*	.10*	.22*	.29*	.31*	.10*	.17*	.11*	.10*	.07*														
12. CB2	.01	.03	.11*	.11*	.16*	.21*	.15*	.02	−.01	.00	.34*													
13. CB3	.09*	.08*	.14*	.20*	.24*	.22*	.23*	.08*	.08	.08*	.27*	.28*												
14. Age	−.27*	−.27*	−.21*	−.19*	−.24*	−.14*	−.22*	−.23*	−.26*	−.17*	−.09*	−.04^	−.20*											
15. Married	.02	.04^	.02	.01	.05^	.00	.06^	.05^	.09*	.05^	.01	.00	.00	−.07*										
16. High education	.11*	.08*	.07*	.06*	.08*	.08*	.13*	.06*	.04^	.04	.05^	.02	.13*	−.23*	−.04^									
17. Full-time work	.04^	−.01	−.02	.01	.04^	.03	.04^	.10*	.11*	.03	−.01	−.04^	.12*	−.25*	−.07*	.11*								
18. Time since diagnosis	.03	−.09*	−.06^	.00	.02	.02	−.02	.01	.01	.00	.02	.00	.01	−.04^	−.03	.04^	.05^							
19. Mastectomy	.12*	.10*	.07*	.05^	.03	.03	.03	.02	.02	.04^	.02	.06*	.03	−.06*	.01	−.02	−.07*	.06*						
20. Lumpectomy	−.08*	−.09*	−.03	−.02	−.01	−.02	.01	.02	.00	.00	−.02	−.05^	−.01	.00	.01	.03	.06*	−.07*	−.73*					
21. Chemotherapy	.18*	.23*	.18*	.13*	.14*	.03	.11	.12*	.12*	.07*	.06*	.08*	.08*	−.39*	.04^	.08*	.00	.06*	.26*	−.16*				
22. Radiotherapy	−.07*	−.05^	−.01	.00	.00	−.02	−.01	.06*	.03	.00	−.04^	−.05^	−.03	−.04^	.02	.03	.05^	.01	−.56*	.48*	.04^			
23. Hormonal therapy	−.03	−.04^	.00	.03	.02	−.01	−.03	.03	.02	.02	.03	.00	−.02	.04^	−.02	−.02	.05^	.13*	−.02	.07*	−.07*	.14*		
24. Herceptin	.04^	.07*	.06*	.04^	.04^	.02	.05^	.03	.02	.00	.00	.05^	.03	−.13*	.03	.02	−.03	.04^	.11*	−.08*	.34*	−.01	−.13*	

PSU peer support use; BB1 = it would provide me with a place in which I would feel accepted and understood by others, BB2 = it would provide me with an outlet to express my true feelings and emotions about my diagnosis of breast cancer, BB3 = I might dwell on my breast cancer diagnosis, BB4 = I might hear negative stories about breast cancer; NB1 = close friends, NB2 = partner or family, NB3 = doctor; CB1 = If I do not have enough information about how to contact other women with breast cancer for support, CB2 = If I am unwell because of my breast cancer treatment, CB3 = If I had family or work commitments placing high demands on my time. *$p < .001$. ^$p < .05$

this figure include approval from close friends (− .02, $p = .343$), not having enough information about accessing peer support (.01, $p = .408$), and having too many demands on time (− .01, $p = .358$). Other variables that did not have significant effects on intention include age (− .003, $p = .297$), marital status (− .04, $p = .382$), and education (.06, $p = .270$).

Relative strength of belief predictors Standardised path estimates predicting intention were also requested to compare the strength of predictors and are outlined below in-text. Inspection of the standardised path estimates indicated that the strongest predictors of intention were beliefs that peer support is an outlet for honest feelings ($\beta = .35$) and a source of empathy ($\beta = .30$). The remaining significant predictors of intention were weaker. Positive predictors of intention were beliefs regarding approval from doctors ($\beta = .07$) and partner/family ($\beta = .04$). Negative predictors of intention were beliefs that peer support encourages dwelling ($\beta = -.06$) and involves exposure to negative stories ($\beta = -.04$). Contrary to expectations, control beliefs did not act as barriers. The belief that feeling too unwell from treatment had a positive relationship with intention but was the weakest predictor in the model ($\beta = .03$). Relative strength of other variables were past behaviour, $\beta = .13$; time since diagnosis, $\beta = -.07$; receipt of chemotherapy, $\beta = .06$; and currently in full-time work, $\beta = -.05$.

Discussion

Over one third of women in our breast cancer cohort accessed peer support following diagnosis. Use of support groups, online discussion platforms, and one-on-one services was consistent with previous estimates [8, 11]. While the use of specific service types may appear low, we demonstrate that a considerable proportion of women with breast cancer do seek peer support, as such, across different modalities. One-on-one use was more prevalent closer to diagnosis; use in this cohort dropped at 12-month follow-up. In contrast, retention was higher for group-based services including support groups and online discussion platforms. This finding raises questions about what factors might influence use of one-on-one versus group-based modalities over time. It is suggested future research examine and compare long-term trajectories of peer support use across different modalities.

Almost half of the cohort believed peer support would provide emotional support benefits such as an outlet for the honest expression of feelings and empathy. These positive behavioural beliefs were the strongest predictors of intention in our prospective model of peer support use. In past qualitative research, peer support users often emphasise that emotional support from others with breast cancer is beneficial [15–23, 31]. Our study extends this by demonstrating such perspectives strongly enable peer support use, prospectively, and are the most ideal targets for promoting acceptance and encouraging uptake of services within this population.

Women generally agreed their social network would approve of peer support and approval by doctors and partners or family members, specifically, were also enablers. Australian clinical practice guidelines in cancer include peer support as a referral option for support and encourage medical practitioners to know which services are available in their community, [32, 33] and clinicians generally report positive attitudes about peer support [34, 35]. Our findings reinforce that doctor referral should continue to be considered alongside support from partners or family members.

However, our study also suggests that a considerable proportion of women may be averse to peer support as they work to move beyond their breast cancer experiences. More than half of women believed peer support involves exposure to negative stories and a third agreed it leads one to dwell about this disease. Negative behavioural beliefs were significant barriers to peer support in our model, and this finding extends prior qualitative research on reasons for not using cancer support groups [36]. Not accessing peer support in this manner could be part of an avoidance coping strategy where situations that are likely to provoke negative emotions about the stressor are avoided [37]. Negative stories about breast cancer cannot be avoided altogether where women will likely be exposed to these through the media or events in their social networks. Nevertheless, it is critical that such concerns are recognised and managed in discourse alongside the potential benefits of emotional support. We recommend that peer support be presented as a unique opportunity to develop resilience and effective coping [38].

Beliefs about the difficulties of accessing peer support did not act as barriers to uptake. Contrary to expectations, those who believed it would be difficult to seek peer support if they were unwell had stronger intentions to do so, although this belief was the weakest predictor. When treatment is affecting women's overall health and quality of life (e.g. side effects from chemotherapy), talking to someone facing a similar situation may be a key source of advice and guidance [13, 36, 39] that is accessed despite these barriers. Other proposed difficulties did not influence intention and it may be that these relate to specific delivery formats (e.g. distance to travel to face-to-face support groups) [40] rather than peer support itself.

It is critical to acknowledge the above recommendations rest on an assumption that peer support is beneficial to women with breast cancer, based upon the current status of evidence. Women who choose to participate in such programs often report high satisfaction and describe numerous psychosocial benefits [15–23]. However, it is noted that evidence on the effectiveness of peer support is inconsistent from randomised controlled trials [7, 6, 41]. Randomised trials reporting significant benefits such as a reduction in depression or anxiety symptoms tend to be of average methodological quality or

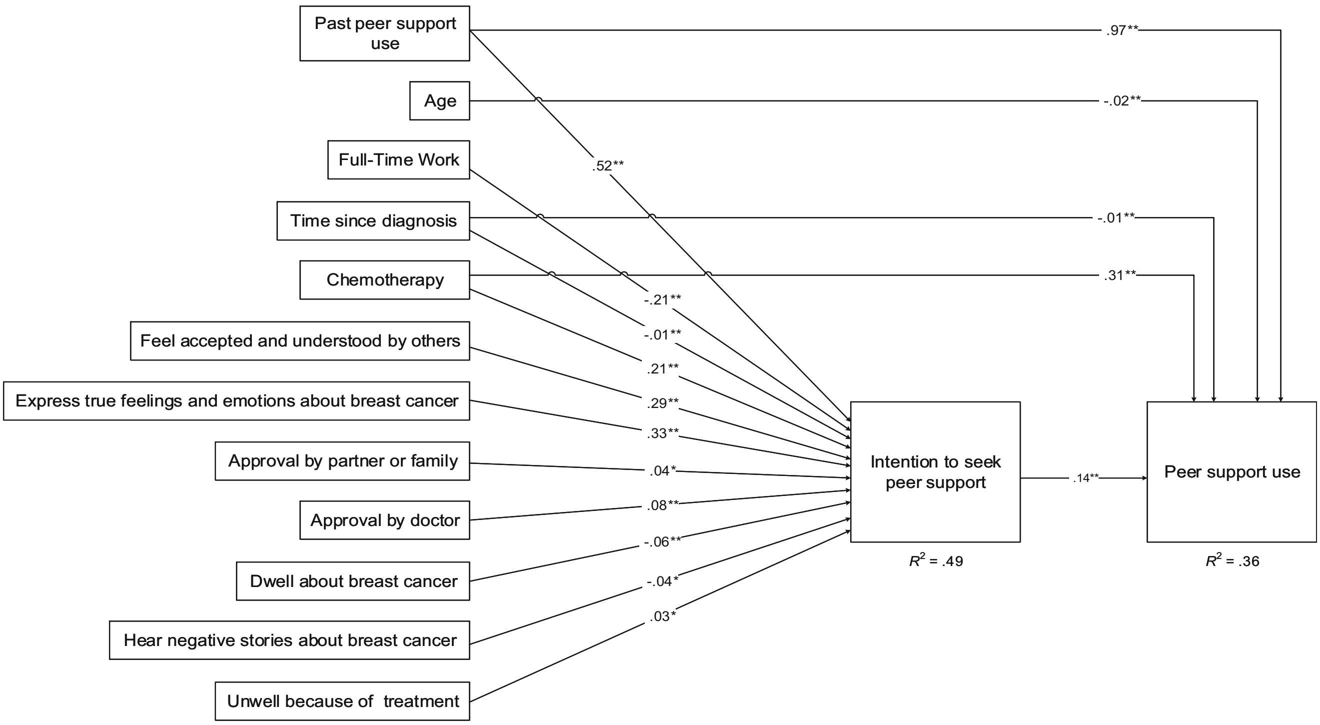

Fig. 2 Unstandardised path estimates for final model of peer support use. $^{**}p < .001$; $^{*}p < .05$. Standardised path estimates were requested for paths to intention only in order to examine the relative strength of belief predictors. These results are reported in-text

the effects are short-lived, with further research warranted [6, 41]. More trials which examine mediators of intervention effect will also improve understanding of how or why peer support may enhance wellbeing (e.g. improved life purpose [42]). Our recommendations for improving uptake of peer support programs based upon the findings of this study are thus contingent on the outcome of future trials which improve the level of evidence.

Study limitations and conclusion

The prospective design, theoretical basis, and large single-diagnosis cohort recruited from a population-based cancer registry are strengths of this study. However, the following limitations should be noted. First, peer support use at follow-up included a higher number of repeat users rather than first-time users. While we adjusted for past behaviour in analyses, the factors contributing to retention and first-time use could be explored in future research. For example, perceptions about past use may affect service retention in different ways depending on the modality (e.g. one-on-one versus group-based services) or composition of the service (e.g. mixed stage groups). Second, there may be other beliefs about peer support which enable or act as a barrier to service use. Our selection of beliefs was based upon a review of the qualitative literature on peer support for breast cancer and consultation with consumer representatives. A potential avenue for future research are beliefs not measured in the present study such as those that are highly relevant to specific peer support modalities. For example, uptake of one-on-one programs may be influenced by expectations about interacting with someone who has been diagnosed with cancer in the past but is now physically and emotionally well (e.g. beliefs that this type of support will inspire hope for one's own future or provide a role model for effective coping).

Last, potential avenues for future research include psychosocial predictors outside the scope of the theory of planned behaviour which were not addressed in the present study and could contribute to first-time service use or retention. Perceived social support and distress are commonly examined but their effects on peer support use are inconclusive. In breast cancer, almost all past research has been cross-sectional. Studies with stronger, prospective designs tend to produce different findings but have been conducted with mixed-diagnosis samples. For example, perceived social support from family and friends has yielded nonsignificant effects on peer support use for breast cancer [10, 13, 14]. In mixed-sample studies with prospective designs, this has produced both significant and non-significant findings [27, 43]. Distress has been reported as both a significant [13] and non-significant predictor in breast cancer [12, 14]. However, strong evidence has not emerged for the role of distress in mixed-diagnosis studies with both cross-sectional [28, 44, 45] and prospective study designs [27, 43]. These included numerous measures covering psychological distress (e.g. anxiety and/or depression, negative mood, emotional wellbeing), cancer-specific distress (e.g. fear of cancer recurrence), and mental health-related quality of life [12, 14, 27, 28, 43–45]. Future research in breast cancer is warranted in order to better understand the influence of these variables.

In conclusion, peer support appears to be moderately used and accepted by women newly diagnosed with breast cancer. More than a third of women accessed at least one of the three major modalities following diagnosis (i.e. support group, online platform, one-on-one service). The strongest enablers of peer support in the present study were beliefs about the benefits of emotional support based upon a shared illness experience. Less than half of the cohort endorsed these beliefs. On this basis, we recommend emphasising these potential benefits in discourse if seeking to encourage uptake of services targeted toward this population. Discourse stating that peer support is approved by others, particularly the medical profession, may also encourage uptake as these beliefs were identified as enablers. A considerable proportion of women believed peer support settings were potentially negative and, as these beliefs were identified as barriers, should be carefully managed in provider communication. For future research, we suggest that long-term trajectories of peer support use be examined and compared across different modalities.

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Compliance with ethical standards

The authors have full control of all primary data and agree to allow the journal to review data if requested.

Conflict of interest The authors declare that they have no conflict of interest.

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