'I feel cancer patients have been neglected.': Exploring experiences of breast cancer survivors during the COVID-19 pandemic and lockdown in the UK using a mixed-methods approach

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Abstract

Purpose

This study aimed to explore the experience of the COVID-19 pandemic including Government-enforced restrictions, on women diagnosed with oestrogen receptor positive breast cancer in the UK using a mixed-methods approach.

Methods

Depression (PHQ-2), anxiety (GAD-7), optimism (LOT-R) and perceived risk of recurrence (IPQ-BCS) were measured pre-COVID-19 outbreak and perceived vulnerability, severity and impact of COVID-19 were measured during the UK lockdown period of 23rd March-13th May 2020. Free text responses provided qualitative data. Descriptive statistics regarding COVID-19-specific behaviours and correlations between pre-COVID-19 psychosocial factors and COVID-19 outcomes were conducted. Thematic analysis was conducted on qualitative responses. Quantitative and qualitative data are presented together.

Results

253 responses were received during the UK lockdown period. Twenty-six percent of the sample were shielding and 15% felt at higher risk of contracting COVID-19. Higher pre-COVID-19 depression and anxiety and lower optimism were associated with higher perceived vulnerability to and severity of COVID-19 and lower confidence in protecting oneself. There were positive and negative effects of lockdown on exercise and relationships and 42% reported negative impacts on anxiety. Participants reported fear of COVID-19, difficulties with adapting to isolation and using technology, and anxiety about the impact of delayed cancer treatment on their cancer recovery and recurrence.

Conclusions

Negative effects of lockdown, particularly for delayed cancer treatment should be considered to manage ongoing anxiety. Screening of state depression and anxiety is suggested for intervention prioritisation, but more longitudinal research is needed to understand the long-term effects of the COVID-19 pandemic on breast cancer survivors.

Keywords:

Breast cancer; COVID-19; depression; anxiety; isolation; qualitative

Introduction

A global pandemic of COVID-19 disease was declared by the World Health Organisation (WHO) in March 2020 [1]. As of July 2020, the UK had the third highest number of COVID-19 deaths worldwide [2], and had implemented government-enforced measures including enhanced hygiene practices, social distancing, travel restrictions, closure of public spaces and orders to stay-at-home to control the spread of the virus [3].

COVID-19 has resulted in social, economic, physical and psychological challenges globally. Many countries instituted stay-at-home orders whereby the public were required to quarantine regardless of COVID-19 symptoms. Increased depression, anxiety, financial worries and loneliness as a result of COVID-19 quarantine have been reported in the US [4] and China [5], with 25.4% of a general population sample in Hong Kong reporting that their mental health had deteriorated during the pandemic [6]; mirroring similar infectious outbreaks [7]. It has been suggested that the psychosocial impact may be heightened in cancer survivors, who already report unmet needs around anxiety, depression and fear of recurrence [8]. This is particularly concerning as depression [9] and loneliness [10] are associated with mortality in this group.

Hospital services have been severely overloaded during COVID-19 [11] with disruption to routine medical care due to redeployment of staff and resources and the need to limit hospital contacts for vulnerable groups [12-13]. Although data on the risk and outcomes of COVID-19 in breast cancer is currently lacking, advancing age, comorbidities and chemotherapy-induced immunosuppression present particular challenges [13]. Widespread measures have been implemented to reduce infection including postponement of surgery and routine follow-up, and switching to oral therapies where possible [14-15] which may have resulted in short-term mental health and longer-term oncological implications [12, 16] requiring further investigation.

It may be assumed that cancer survivors will experience higher psychological distress during the COVID-19 pandemic due to perceived vulnerability [15] and concerns around disruption of follow-up care [8], however the limited available empirical evidence is mixed [17-18]. There is therefore a need to understand the short- and long-term impact of the COVID-19 pandemic in this group and to identify factors associated with heightened distress to formulate effective interventions [19]. Although data are starting to emerge [18], these are

limited to quantitative surveys. Qualitative analysis allows a deeper exploration of the lived experience which is particularly important during novel situations such as the COVID-19 pandemic [20]. This study therefore aims to address this gap by using a mixed-methods design to explore the experience of the COVID-19 pandemic and stay-at-home orders in a cohort sample of breast cancer survivors to address four areas;

- (a) Impact of COVID-19 on breast cancer follow-up care in the UK
- (b) Psychological impact of the COVID-19 pandemic
- (c) Psychological impact of stay-at-home orders
- (d) Factors associated with perceived susceptibility and severity of contracting COVID-19 in breast cancer survivors

Methods

Study design

This mixed-methods study forms part of a longitudinal observational study (e-PATH study) [21]. The current analysis includes quantitative and qualitative data collected as part of six- or twelve-month follow-up that coincided with the UK lockdown in response to the COVID-19 pandemic.

Setting

On 23rd March 2020, stay-at-home orders were issued in the UK in response to the global COVID-19 pandemic. The general public were only allowed to leave their home for limited reasons: shopping for basic necessities; one instance of daily exercise; obtain or provide medical care; travelling to and from work where this cannot be done from home. On 13th May 2020, restrictions started to ease with unlimited outdoor exercise and travel for work permitted if necessary. The current data pertain to the period 23rd March to 13th May 2020 which is henceforth referred to as ‘lockdown’ [3].

Participants and procedure

Participants were recruited from outpatient breast cancer clinics across NHS Trusts in England and Wales. 2010 participants were recruited between January and December 2019 and were followed-up at 6 and 12 months. Eligibility criteria included; being female; aged

over 18; a diagnosis of primary breast cancer and; prescribed hormone therapy within the last three years. Participants were excluded if they had secondary breast cancer, were identified as being unsuitable to participate by their clinician, or were not fluent in verbal and written English.

Eligible participants were approached by a member of their clinical care team or a researcher and provided written and verbal information about the e-PATH study. Once written informed consent was obtained, participants completed a baseline questionnaire either on paper or via a secure online survey platform (Online Surveys). Follow-up questionnaires were sent six and twelve months after baseline via post or email. If responses were not received after two weeks, a reminder was sent. After a further two weeks, non-responders received a telephone reminder. An amendment to the e-PATH study protocol was approved by the Research Ethics Committee (18/LO/1674) on 23rd April 2020 to add questions to the follow-up questionnaire about the impact of COVID-19.

Materials

At baseline, clinical and demographic characteristics were self-reported by participants including age, ethnicity, time of cancer diagnosis, stage of cancer at diagnosis, primary cancer treatment and current adjuvant treatment. Additional psychosocial variables were measured. The following are included in the current analysis;

Depression

The PHQ-2 is a two-item measure to screen for depression [22]. Items are scored 0-3 from *not at all* to *nearly every day*. Total scores range 0-6 with higher scores indicating worse depression. The PHQ-2 demonstrates good internal consistency ($\alpha=0.83$) [22].

Anxiety

The Generalised Anxiety Disorder Screener (GAD-7) is a validated seven-item scale to measure generalised anxiety [23]. Items are scored from 0 (not at all) to 3 (nearly every day). Total scores range 0-21 with higher scores indicating worse anxiety. The GAD-7 shows good internal consistency ($\alpha=0.89$) [23].

Optimism

The Life Orientation Test-Revised (LOT-R) is a six-item scale measuring state optimism [24]. Items are scored 0-4, with higher scores indicating more optimism.

Risk of cancer recurrence

Perceived risk of cancer recurrence was measured using the risk of recurrence subscale of the Illness Perception Questionnaire for Breast Cancer Survivors (IPQ-BCS) [25]. The subscale contains four items scored 1-5 from *strongly disagree* to *strongly agree*. Scores range 4-20, with higher scores indicating a higher perceived risk of recurrence. The subscale has shown excellent internal consistency ($\alpha=0.9$) [25].

COVID-19 questions completed during follow-up

Participants were asked questions to assess whether they have had COVID-19 and to indicate if they were following government guidelines to social distance, shield, or self-isolate. Public Health England [26] definitions for these terms are as follows:

Social distancing: staying at least 2 metres away from people outside of the household and minimising time outside of the home.

Shielding: staying at home and avoiding any face-to-face contact for at least 12 weeks, irrespective of COVID-19 symptoms

Self-isolating: staying at home and avoiding any face-to-face contact for a period of 7 or 14 days as a result of COVID-19 symptoms.

To assess psychological perceptions of COVID-19, participants were asked about their perceived risk of contracting COVID-19, perceived severity of symptoms, and how confident they feel to protect themselves from COVID-19. Each was scored on a scale 1-7. Participants selected from a list which, if any, disruptions they had faced because of the lockdown. Finally, they indicated if the lockdown had a positive, negative or no impact on their mood, anxiety, exercise and relationships with friends and family. Two free-text boxes were provided to elaborate on any of the previous answers, or to add any additional impact.

Analysis

Statistical analyses were conducted using IBM SPSS (v25) with an alpha level of 0.05.

Bivariate analyses (*t*-tests/Pearson's correlations) explored the relationship between psychological perceptions around COVID-19 and relevant clinical-demographic variables (age, time since diagnosis, previous treatment, breast cancer stage), and shielding behaviour and pre-COVID-19 psychosocial variables (depression, anxiety, optimism, perceived risk of

cancer recurrence). Descriptive statistics (mean, frequency, percentage) of the impact of COVID-19 are presented.

Free text responses were subjected to inductive thematic analysis, a commonly used qualitative method which is not coupled to any predetermined theoretical framework [27]. This ensures the analysis is rigorous, data-driven and free from influence by the researchers' own assumptions and preconceptions [28]. Thematic analysis was carried out separately from the quantitative analysis and performed using a multi-stage coding process [29]. Two coders (MZ and VB) independently identified codes and then collaboratively developed a preliminary set of themes. Interpretation of the data was discussed by the research team to develop a coherent set of themes and subthemes.

Results

427 questionnaires were sent during this period and 340 were returned (80%). Of these, 87 were completed outside of the lockdown period and were removed from the analysis. The final sample included 253 participants. There were no statistically significant clinical or demographic differences between responders and non-responders. The mean age of participants was 60 ($SD=12$, range 28-95) and 23% were over 70. Participants were mostly White British (96%), married (64%) and had Stage 1 (42%) or Stage II (43%) cancer (Table 1). 18% ($n=46$) had at least one COVID-19 high risk comorbidity.

Table 1. Demographic characteristics

Age (<i>mean, SD</i>)	60 (12.0)
	Range 28-95
Ethnic group (<i>N, %</i>)	
White British	240 (96%)
White Irish	4 (2%)
Any other	5 (2%)
Current Employment Status (<i>N, %</i>)	
Employed (working from home)	63 (25%)
Employed (going out to work)	29 (11%)
Unemployed / Retired / Homemaker	128 (51%)
No longer working as a result of COVID-19	9 (4%)
Furloughed as a result of COVID-19	20 (8%)
Relationship Status (<i>N, %</i>)	
Co-habiting	22 (9%)
Married/in a civil partnership	158 (64%)
Separated/Divorced	30 (12%)
Single	17 (7%)
Widowed	20 (8%)
Stage at diagnosis (<i>N, %</i>)	
Stage 1	104 (42%)
Stage 2	106 (43%)
Stage 3	25 (10%)
Unsure	11 (5%)
Months since diagnosis (<i>mean, SD</i>)	29 (11.3)
Previous Treatment (<i>N, %</i>)	
Lumpectomy	175 (70%)
Single Mastectomy	71 (29%)
Double Mastectomy	11 (4%)
Chemotherapy	81 (33%)
Radiotherapy	174 (70%)
Current treatment (<i>N, %</i>)	
Tamoxifen	74 (31%)

Anastrozole	62 (26%)
Letrozole	89 (37%)
Exemestane	18 (7%)
Menopausal status at diagnosis (N, %)	
Pre- or peri-menopausal	68 (28%)
Post-menopausal	161 (66%)
Unsure	14 (6%)
Comorbidities (N, %)	
0	115 (46%)
1	70 (28%)
2	37 (15%)
3+	27 (11%)
Comorbidities associated with higher risk for COVID-19 ¹ (N, %)	
None	206 (82%)
One or more	46 (18%)

Note. ¹ Comorbidities associated with higher risk of COVID-19 from NHS guidance [30]. These include; have had an organ transplant; are having chemotherapy or antibody treatment for cancer, including immunotherapy; are having radical radiotherapy for lung cancer; are having targeted cancer treatments that can affect the immune system; have blood or bone marrow cancer; have had a bone marrow or stem cell transplant in the past 6 months, or are still taking immunosuppressant medicine; severe lung condition (e.g. cystic fibrosis, severe asthma or severe COPD), have a condition that means they have a very high risk of getting infections (such as SCID or sickle cell), are taking medicine that makes them much more likely to get infections (such as high doses of steroids or immunosuppressant medicine), have a series heart condition and are pregnant; have a lung condition; have heart disease; have diabetes; have chronic kidney disease; have liver disease; have a condition affecting the brain or nerves.

Qualitative Themes

Forty-five participants provided free-text responses (see Online Resource 1). The qualitative analysis revealed four major themes: the impact of COVID-19 on cancer treatment; psychological consequences of isolation; fears about COVID-19; uncertainty around lifting lockdown (Figure 1). These themes and corresponding subthemes will be discussed in following sections with supporting quotations in Table 2.

Figure 1. Themes and subthemes identified in the data

Table 2. Participant quotes to support themes and subthemes

Theme/Subtheme	Participant quotations
Impact of COVID-19 on cancer treatment	<i>“Not able to have first follow up appointment and mammogram since surgery. Up to now I have not had any visible proof that the tumour has been successfully removed” P011, 64 , shielding</i> <i>“Cancelled mammogram and smear test which has been very stressful, I worry that I will not get the reassurance I need for a long time. I also need to monitor my gums due to medication and I can’t attend the dentist.” P012, 45 , distancing</i> <i>“Self isolation brings back memories of chemo.” P013, 52 , distancing</i> <i>“I feel anxious about getting Covid 19 and being ill as being ill reminds of having breast cancer and my treatment. Also being inside a lot of the time and not going out also reminds me of when I had breast cancer and I feel depressed about that sometimes.” P014, 50, distancing</i> <i>“Frustration in not being able to attend hospital appointments. I know this might be selfish considering the people who have lost their lives. Having a mammogram stops me worrying.” P015, 64, shielding</i>

Psychological
consequences of
isolation

“Some days I feel really low and stress/anxiety cause mood swings. Some hyper anxious feeling, feeling 'fluttery', bit wobbly.” P016, 59, distancing

“Feel trapped. Very little to get up for. Lack motivation, even just watching tv is a bore” P017, 75, shielding

“Very depressed not being able to see family and complete lack of interest or energy” P018, 59, distancing

“I’m seeing and hearing very little from friends which is isolating. I’m missing me first months of my new grandsons life which is upsetting as he won’t know who I am when we meet up again. I live in a flat with no garden so can’t exercise properly, I find this very worrying and it affects my mood.” P019, 60, shielding

“Isolation is stressful, not seeing family, constant headaches (stress I think) extremely emotional, boredom, weight gain” P020, 60, shielding

“This time has made you really appreciate the simple things in life such as sitting around the dining table eating meals as a family each day ... You appreciate going for family walks in the clean air and blue skies listening to the sounds of nature” P021, 49, distancing

“My moods and anxiety levels have been most affected - some days I feel positive and hopeful, on others I feel very sad. I cry on a daily basis when I see the news” P022, 55, distancing

“I am enjoying the slower pace of life, although still working, it’s far less and I enjoy more quality because I have the time. Less rushed, busy and stressed.” P023, 51, distancing

“Really miss my brothers extra support with mum but discussed at start of lockdown that best they stay away. This way if I 'go down' at least one should be able to stand in. All of which has affected my mood - 3am thoughts are horrible!” P024, 55 , distancing

*Family as a source of
comfort and/or stress*

“The support from my family means that I do not go out (except in the garden), My daughter who lives with us at the moment shops for us and encourages me to bake, paint and do exercise by walking or fitness classes on line. These have all had a very positive impact on my well being.” P025, 65 distancing

“Stressful conversations with offspring (who should be at university) due to political differences mainly, so always trying to keep the peace. Therefore anxiety levels more” P026, 53, distancing

“I just find it hard dealing with home schooling which leads to arguments within the family, but that is the only issue that has arisen.” P027, 44, distancing

“Husband is on furlough... so now understands better how my life works as well as being more aware of my trigger points or fatigue.” P028, 53 , distancing

“I feel Bereft at not seeing my Grandchildren, we have tried to do FaceTime but they cry as use to seeing me 5-6 days a week, and just ask to come to “Nanny’s House”” P031, 51, shielding

<i>Attitude towards increased use of technology</i>	<i>“Online catch ups/phone calls with family and friends are again no substitute for being able to touch someone!” P0324, 61years old, distancing</i>
	<i>“Feeling very inadequate doing these things and not being very good with computer” P033, 65 , distancing</i>
	<i>“We keep in touch as much as possible by phone and have even had extended family games nights (e.g. a murder mystery game via zoom!)” P034, 57, distancing</i>
	<i>“Family relationships improved through more online contact.” P035, 68, shielding</i>
<i>Uncertainty around lifting lockdown</i>	<i>“I feel safe at home & enjoy having my family at home. I worry about when things start to get back to normal and leaving my home.” P036, 54,</i>
	<i>“Stress as teaching assistant so not sure if will need to go back to work soon with children who don't social distance.” P037, 54, distancing</i>
<i>Fears about COVID-19</i>	
<i>Fear of infection</i>	<i>“I feel very anxious about picking up the virus and passing it on to my partner or mother. I feel if they contracted it and died, I would be responsible for their deaths.” P038, 55, distancing</i>
	<i>“My partner is shielding and I am very worried if I catch it the consequences for him could be devastating so I am always very anxious about going shopping” P039, 28 , distancing</i>

“Being a carer for my partner who is in the extremely vulnerable category and had surgery has been difficult - we share a small flat and cannot stay apart as per government guidelines. So I have chosen not to leave my flat at all so most our life indoors can be as normal as possible.” P04014, 60, shielding

“I also have controlled asthma and the way it appears to attack the lungs has worried me a lot.” P041, 65, distancing

“I also have COPD so been difficult for me, slight wheeze, cough, sneeze ect creates, Concern, anxiety, worry, stress, fear of is it Covid or is it my illness??”P042, 60 , shielding

Health vulnerability

“I feel that I am coping ok with the Cancer rehabilitation and now I could die from a virus.” P043, 58, shielding

“Increased anxiety levels of getting it - anxiety already a bit high over fear of cancer recurrence.” P044, 100 , distancing

“My anxiety has increased, due to several factors. Worry for my family's wellbeing, also mine & my husband's health. I have Parkinson's & (type 2 diabetes - newly diagnosed) My husband has COPD” P045, 67 , distancing

Experience of COVID-19 and lockdown

Twenty-two people (9%) believed that they may have had COVID-19, but only one person had tested positive (0.4%). 71% reported that they were social distancing, 26% were shielding, 2% were in self-isolation and 0.4% reported not following any Government guidance. Women who reported shielding were older ($M=66$, $SD=13.4$) than those social distancing ($M=58$, $SD=10.7$, $t(235)=4.69$, $p<.001$), and more likely to have comorbidities related to COVID-19 ($\chi^2=5.89$, $p=.015$).

The most common disruption reported during the lockdown was cancellation of routine follow-up appointments or mammograms (Table 3). This was reported more frequently in those shielding than social distancing ($\chi^2=7.80$, $p=.008$). Most participants reported no issues with availability of or access to medications.

Table 3. Reported disruption as a result of the pandemic and lockdown

	Full sample (n=253)	Social distancing (n=177)	Shielding (n=64)
Routine appointments / mammograms cancelled	86 (34%)	53 (30%)	31 (48%)**
Worsened financial status	42 (17%)	34 (19%)	8 (13%)
Looking after / home-schooling children	37 (15%)	32 (18%)	5 (8%)
Worsening of ET side effects	21 (8%)	12 (7%)	8 (13%)
Improved financial status	18 (7%)	12 (7%)	6 (9%)
Difficulty accessing medication due to difficulty getting to GP / pharmacy	17 (7%)	9 (5%)	8 (13%)
Difficulty accessing medication due to availability of medication	11 (4%)	7 (4%)	4 (6%)
Improvement in ET side effects	8 (3%)	5 (3%)	3 (5%)
Loss of employment	3 (1%)	3 (2%)	0

Note., **indicates a significant effect at $p<.01$. ET=Endocrine Therapy

This was supported by the theme ‘*Impact of COVID-19 on Cancer Treatment*’ (Table 2). Many participants expressed concern that COVID-19 was taking resources away from mammograms, surgeries and ongoing monitoring, further impacting their recovery and potential recurrence of cancer. While for a few, isolation prompted memories of their cancer treatment.

“My breast feels different and I would like to see a doctor but was told there is nothing to worry about which is impossible to say unless I have been examined. I know my own body. I feel cancer patients have been neglected.” P001, 63, shielding

Impacts of the COVID-19 pandemic & lockdown

Figure 2 shows the reported impact of COVID-19 on mood, anxiety, exercise and relationships with friends and family. Whilst 50% ($n=118$) of participants reported no impact on their mood, 13% ($n=30$) reported a positive impact and 38% ($n=89$) reported a negative impact. Similarly, for anxiety, 47% ($n=110$) reported no impact, 11% ($n=26$) reported a positive impact and 42% ($n=99$) reported a negative impact. The impact on exercise and relationships was mixed.

Figure 2. Impact of COVID-19 on mood, anxiety, exercise levels and relationships.

These mixed results were also highlighted in the theme '*Psychological Consequences of Isolation*'. For many, lack of connection with loved ones, exercise frustrations, adapting to new work routines, and excessive introspection were sources of distress.

"Feeling anxious about the future - work/money/travel. Health has declined due to not being able to exercise as much, more aches and pains. Eaten more and consumed more alcohol than usual. Feeling isolated and missing family, especially grandchildren." P002, 58, distancing

For others, more time for walks and fewer daily distractions were identified as positive impacts of lockdown.

"Feel safe at home during lockdown, my anxiety is better, life seems more calm." P003, 55, distancing

Several subthemes were identified. The subtheme '*Family as a source of comfort and/or stress*', supports the mixed impact of lockdown on relationships (Figure 2). Some participants discussed their family as a source of comfort and help, whereas for others, being in close quarters exacerbated tensions and increased care responsibilities, creating additional stress.

"My family and I are enjoying the time we are spending together, and we make every effort to get fresh air and exercise daily." P004, 44, distancing

"Difficulty being 24/7 in house with daughter with anorexia/anxiety issues and a 22 year old in final uni year, used to living her own life." P005, 82, distancing

Another subtheme was '*Attitude towards increased use of technology*'. For many, online platforms provoked anxiety and feelings of inadequacy regarding their ability to adapt to the technological demands. Participants also expressed a preference for face-to-face contact. Conversely, others welcomed these new platforms as ways to connect with people they would otherwise be separated from.

"...Becoming invisible. Not as accomplished with technology as youngsters(!)-phones and computers not enough." P007, distancing

"Brought family closer even though we do not see them, only by telephone or internet." P008, 65, distancing

The qualitative data also highlighted the struggle associated with ‘*Uncertainty around lifting lockdown*’, with participants discussing concerns around the process of lifting lockdown and getting back to a sense of normality. Some were concerned about the compliance of others to guidelines while for many, the uncertainty itself and coping with the unknown were added sources of distress.

“I am quite concerned about not wanting to go out once I am allowed.” P009, 68, shielding

Perceptions of COVID-19

The majority of participants (63%) felt that they were as likely as the average person to contract COVID-19 with 22% feeling less likely and 15% feeling more at risk. Feeling more at risk was not associated with any clinical variables (Table 4). There was a small correlation between risk perception and age, with older women feeling less at risk than younger women ($r=.20$). There was no difference in perceived risk between those who were shielding and social distancing. Feeling more at risk of contracting COVID-19 was associated with higher levels of anxiety ($r=.14$) and depression ($r=.14$), and lower levels of optimism ($r=.13$) pre-COVID-19.

On a scale of 1-7, the average perceived symptom severity from COVID-19 was 4.3 ($SD=1.1$). Perceiving worse symptom severity was not associated with age, or clinical variables (Table 4). However, women who had high COVID-19-risk comorbidities had higher perceived symptom severity than women who did not ($t(199)=3.8, p<.001$), and women who were shielding perceived higher symptom severity than those social distancing ($t(71.2)=4.6, p<.001$). Perceiving worse symptom severity correlated with higher pre-COVID-19 anxiety ($r=.23$) and depression ($r=.27$).

On a scale of 1-7, the average confidence in protecting oneself against COVID-19 was 4.7 ($SD=1.3$). Confidence was not associated with age, time since cancer diagnosis, or comorbidities (Table 4). However, women who were previously treated with chemotherapy felt less confident than women who have not had chemotherapy ($t(241)=2.0, p=.044$), and those with Stage 3 cancer felt less confident than those with Stage 1 or 2 cancer ($t(227)=3.3, p=.001$). Confidence was associated with higher optimism ($r=.27$), lower anxiety ($r=-.25$), depression ($r=-.27$) and perceived risk of recurrence ($r=-.25$) pre-COVID-19.

Table 4. Relationships between perceptions of COVID-19 and clinical and psychological variables.

	Risk of getting COVID-19	Perceived symptom severity	Confidence in protecting self from COVID-19
Mean (SD)			
Range 1 – 7	3.9 (0.8)	4.3 (1.1)	4.7 (1.3)
Age	$r=.20^{**}$	$r=.07$	$r=.11$
Time since cancer diagnosis	$r=-.03$	$r=-.01$	$r=-.03$
Stage at cancer diagnosis			
Stage 1 or 2	3.90 (0.78)	4.25 (1.05)	4.78 (1.3) ^{**}
Stage 3	3.88 (0.97)	4.32 (0.95)	3.92 (1.4) ^{**}
Comorbidities related to COVID-19			
Yes	4.07 (1.01)	4.89 (1.10) ^{***}	4.89 (1.40)
No	3.86 (0.74)	4.17 (1.00) ^{***}	4.60 (1.28)
Radiotherapy			
Yes	3.85 (0.85)	4.23 (0.97)	4.59 (1.44)
No	4.00 (0.86)	4.39 (1.18)	4.77 (1.23)
Chemotherapy			
Yes	3.92 (0.71)	4.26 (1.03) ^{***}	4.41 (1.35) [*]
No	3.88 (0.83)	4.28 (1.03) ^{***}	4.76 (1.3) [*]
Shielding	3.82 (1.00)	4.91 (1.24) ^{***}	4.84 (1.27)
Distancing	3.93 (0.70)	4.05 (0.85) ^{***}	4.55 (1.28)
Pre-COVID-19 anxiety (GAD)	$r=.14^{*}$	$r=.23^{**}$	$r=-.25^{**}$
Pre-COVID-19 depression (PHQ)	$r=.14^{*}$	$r=.27^{**}$	$r=-.27^{**}$
Pre-COVID-19 optimism	$r=-.13^{*}$	$r=-.13$	$r=.27^{**}$
Pre-COVID-19 risk of recurrence perceptions	$r=.13$	$r=.13$	$r=-.25^{**}$

These data are supported by the theme ‘*Fears about COVID-19*’, which relates to fears about infection and the health vulnerability of this cohort. The subtheme ‘*Fear of infection*’ reflects widespread worry about themselves or loved ones contracting the virus. There was a general fear of exposure to the outside world and concern that the consequences of COVID-19 could be particularly severe for them. The subtheme ‘*Health vulnerability*’ encapsulates feelings of distress as a result of the vulnerability due to breast cancer or other pre-existing conditions.

“I feel anxious in case I catch the COVID virus. I have health conditions that put me at high risk...I felt very alone and vulnerable going through radiotherapy...it feels like it was all for nothing and I may never see my daughter and granddaughter again.” P010, 73

Discussion

This mixed-methods study provides insight into the impact of the COVID-19 pandemic and lockdown in a cohort sample of UK breast cancer survivors. Areas for potential intervention to provide support during potential ongoing outbreaks and as a result of long-term physical and psychological consequences were identified.

Twenty-six percent of this sample reported shielding which is expected given the average age and comorbidities reported. In line with previous cancer research [18], only 15% reported feeling more at risk of contracting COVID-19. Perceived risk and severity of COVID-19 were not related to clinical-demographic factors, but confidence in protecting oneself was related to cancer stage and having had chemotherapy. All COVID-19 perceptions were associated with pre-COVID-19 depression, anxiety and optimism, which was supported by the qualitative data. Despite concerns of heightened COVID-19-related anxiety in the cancer population [15, 18], these results suggest that women do not feel they are at high risk of COVID-19 illness.

Half of the sample reported no impact on mood or anxiety, although 42% reported worse anxiety which is in line with studies from Hong Kong [6, 18]. Qualitative data revealed worries about financial implications and declining health due to lockdown which may be fuelling anxiety. There was a mixed impact on relationships and exercise with some people finding lockdown beneficial while others struggled. Factors such as perceived self-efficacy [31-32] and preference for problem-focused coping [18] may influence success in adapting

health behaviours during lockdown and it would be beneficial to investigate this further to identify potential targets for intervention.

Cancelled routine follow-up appointments and screening were frequently reported and disproportionately impacted those who were shielding, possibly due to these women being unable to attend the hospital. As reported elsewhere, participants expressed stress, anxiety, and frustration about the impact on cancer prognosis [17], and reminders of isolation during chemotherapy/radiotherapy [8]. Tailored clinical decisions considering risk of COVID-19 infection and cancer prognosis are recommended [13, 15] which postpones routine follow-up in the absence of symptoms. However, high COVID-19-related anxiety is associated with reporting more somatic symptoms [33], and so women with high cancer-related anxiety due to missed screening may report more symptoms, leading to unnecessary healthcare contacts and exposure to COVID-19. Similarly, the recommendation to defer surgery in favour of hormone therapy (HT) [13-14] could have negative effects beyond cancer-related anxiety as a small proportion of this sample reported worsening HT side-effects and difficulty accessing medication which can adversely affect adherence [34-35]. The current sample had been prescribed HT for more than two years on average and the impact may be stronger in those newly prescribed [36]. The uncertainty [12] highlights the need for clear communication about the necessity and potential impact of postponed treatment, reiteration of the symptoms to access imaging if necessary, and behavioural intervention to support HT adherence.

The move to telehealth [12, 15] is likely to be maintained due to continued social distancing, and as a result of the investment in technological infrastructure. Although telehealth satisfaction is generally high [37], feedback has identified frustration with equipment problems and slow responses [38]. Notwithstanding the potential benefits of technology for breast cancer survivors who are employed or have caring responsibilities, participants reported barriers including lacking skill and confidence when using technology. It is important to recognize that the current crisis may pose further challenges to communities that have previously faced barriers to healthcare, such as those in rural environments, with low-income, uninsured or underinsured, racial/ethnic minorities, and sexual minorities [8].

Brief, home-based interventions have been suggested to support mental health during lockdown [6, 8], however strained healthcare resources and budget deficits for charities [39] reinforce the need to prioritise support for those that would most benefit. A growing body of evidence from this study and others [18, 40] suggests state anxiety and depression may be

related to heightened distress during the pandemic, providing an opportunity to easily screen for intervention. Perceived vulnerability, confidence in managing COVID-19, exposure to COVID-19 news [41] and problem-focused coping [18] are emerging as potential mediators to target for intervention [19] during the primary COVID-19 period, although further prospective, longitudinal research is required to assess the secondary impacts of delayed treatment on mental health and oncological outcomes.

This study benefitted from being drawn from a cohort of UK breast cancer survivors with a high response rate, however diagnosis was two years ago on average and so the results may not be generalisable to newly diagnosed women who are experiencing immune-suppressing primary treatment and/or require more hospital contacts. Data were restricted solely to the UK lockdown period of March-May 2020 to provide an accurate representation of this period. The mixed-methods design allowed for in-depth understanding of the experience of the COVID-19 pandemic and lockdown to identify areas for future intervention, however it should be noted that semi-structured interviews were not conducted, meaning some areas of importance to participants may not have been identified.

In conclusion, this study highlighted the negative impact of lockdown and delayed cancer treatment for breast cancer survivors, but also found positive effects on relationships and exercise. Higher pre-COVID-19 depression, anxiety and lower optimism appear to be related to heightened distress during the pandemic, offering opportunities to screen for intervention. More research is needed on the long-term effects of the COVID-19 pandemic in breast cancer survivors.

Data Availability

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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Author contributions

Material preparation, data collection and analysis were performed by Zoe Moon, Mira Zuchowski, Vanessa Boshell and Lyndsay Hughes. The first draft of the manuscript was written by Lyndsay Hughes, Zoe Moon, Mira Zuchowski and Vanessa Boshell and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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