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Social Support and the Waiting Game (for Breast Cancer Diagnosis)

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Abstract

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Introduction

Waiting is hard. It is even more difficult when one is waiting for uncertain news regarding their medical status – cancer, in particular. Among females throughout the United States of America, breast cancer is the one of the most prevalent causes of death (Nausheen, et al., 2009). Still, despite the understanding that anxiety and uncertainty are significantly higher before cancer diagnoses, there has been very little research done on this initial waiting period (Liao, et al, 2008). In general, waiting periods are often considered times of high distress (Lebel, et al., 2003). Luckily, this distress level tends not to increase over the course of this uncertain period (Poole, et al., 1999). Regardless, this is precisely why active coping mechanisms are vital in decreasing patients' anxiety levels throughout this time (Nausheen, et al., 2009). The current study examined one particular aspect associated with healthy coping mechanisms, social support availability, during the wait for breast biopsy results.

Coping

Two of the most effective coping strategies are instrumental and emotional coping. Instrumental coping centers around finding solutions to present problems (through seeking advice and/or assistance; UCLA Dual Diagnosis Program, 2019). This strategy is the most successful in diminishing patient anxiety, and social support is a positive consequence of partaking in this coping mechanism (Drageset & Lindstrom, 2005). Social support, which will be discussed in depth below, initiates a positive feedback loop that ultimately lowers emotional distress and perpetuates adaptive coping methods (Drageset & Lindstrom, 2003). Patients also have the opportunity to use emotion-focused coping strategies, during which they gather additional resources to tend to their emotional health over the course of their waiting period (UCLA Dual Diagnosis Program, 2019).

Social Support

Individuals' social networks consist of their immediate family, close friends, and, in appropriate circumstances, their medical providers. Each of these sources can act as barriers or facilitators of early cancer detection and, as such, are integral parts of maintaining patients' well-being (Ogedegbe, et al., 2005). Social support is commonly known to have a positive effect on the health of women who have been diagnosed with breast cancer, so it is understandable that this logic is also consistent when addressing the time before patients receive an official cancer diagnosis (Lindop & Cannon, 2001). In fact, social support is an essential aspect of positive coping – the quality of women's social support system can explain the differences in their overall coping ability (Montgomery, 2010).

The larger concept of social support can further be broken down into six social necessities: attachment, social integration, opportunity for nurturance, reliable alliance, guidance, and reassurance of worth. Among these, attachment (i.e., intimate, secure relationships) is a strikingly important type of social support, as this provision allows individuals to satisfy their needs for socialization, assistance, information, and belonging (Drageset & Lindstrom, 2005).

On a broader scale, social support can also be classified as either emotional, informational, or tangible. In our study, we focused primarily of these three classifications of social support. Emotional social support is based on comforting and empathetic relationships, whereas informational social support focuses on acquiring information and advice from peers – and tangible social support aids with solving practical problems (such as medical care, transportation, etc.; Pineault, 2007).

It is helpful for patients to have social support from their early pre-diagnostic stages so that they will have less anxiety in later stages of cancer coping and treatment (Pineault, 2007). It

is also important to point out that, while a strong social support system is often considered a coping resource in and of itself, it is more accurately described as result of good coping methods (Drageset & Lindstrom, 2005). As such, individuals with defensive or hostile coping styles may receive poor social support (Drageset & Lindstrom, 2005), making them prime candidates for more professional support from healthcare specialists or therapeutic interventions (Nausheen, et al., 2009). These psychosocial interventions work to improve social support by focusing on psychosocial needs, information access, family interactions, and stress management (Liang, et al., 1990). Establishing a strong foundation of social support can help moderate patients' anxiety and depression in future, if they are indeed diagnosed with breast cancer (Burgess, et al., 2005).

Given the vast importance of social support in patients' health, this study was concerned with identifying the levels to which participants felt that they had access to social support and linking those perceptions to well-being throughout the pre-diagnostic period. By understanding these relationships, researchers can investigate the clinical implications in hopes of improving patients' experiences in future.

Method

Participants

Before undergoing a clinical breast biopsy within the radiology department of a Southern California county hospital between April 2017 and May 2019, female patients ($N = 137$; demographic information noted in Table 1) had the opportunity to participate in a structured interview. Breast biopsies were recommended to patients whom had received a prior abnormal mammography. Eligible participants included those who were not currently under criminal prosecution, spoke English and/or Spanish fluently, and were at least 18 years of age. For the purposes of this study investigators conducted 53% of interviews in English and 47% of

interviews in Spanish. Upon completion of their breast biopsy, patients typically waited seven to ten days before receiving their results, either at the same site or a different location, depending on their insurance.

Procedures

      Biopsy interview. Hospital staff initially introduced the study to patients during their routine biopsy appointment-reminder call. If interested in learning more and/or participating in the study, patients were asked to arrive 30 minutes before the time of their regularly-schedule biopsy appointment. Upon arrival, patients were brought into a private room within the radiology department to meet a trained research team member (undergraduate students). These researchers then explained the study in further depth, completed consent procedures and, if the patient was willing to participate, conducted the interview. Researchers discussed the consent form with patients and provided them with a 'Participant Bill of Rights'. Patients who chose to proceed with the interview, were also given an additional copy of the study overview (to take home). Within the consent form, patients signed up to participate in all three aspects of the study; Patients could revoke their participation if, at any time, they decided they no longer wished to participate.

      After receiving consent, researchers conducted a 20-minute structured interview, which covered topics of social support, life satisfaction, rumination, intolerance of uncertainty, and current/anticipated emotions (details below). After the conclusion of this interview, participants received a binder of daily measures, which were to be completed at home, during the waiting period between their biopsy and follow-up (i.e., diagnostic) appointment, and monetary compensation for their time and effort.

Daily measures. To date, 46 participants have completed daily surveys. The binder that participants received at the end of their initial biopsy interview contained ten days' worth of daily measures. These surveys asked participants to reflect on various aspects of their well-being and physical health. In the mornings, participants reported their sleep duration and quality; in the evenings, participants reported their emotions, coping strategies/effectiveness, physical symptoms, rumination, and social support. Participants were asked to complete the binder up until the day of their follow-up appointment, and to bring this completed binder with them to the appointment – where a research team member would once again meet them to conduct a final follow-up interview (if scheduled at the same county hospital). Participants who did not have a follow-up interview scheduled at the same site were met by a research team member at a time/location of both parties' convenience, to present the binder and receive compensation for their participation.

This study, in its entirety, was approved by the Institutional Review Board (IRB) at the University of California, Riverside, where the study was originally developed, and the county hospital, where the data collection procedures were conducted.

Measures

The measures of interest for this study were social support, rumination, life satisfaction, and intolerance of uncertainty – primarily from the initial biopsy interviews, with additional input from the daily measures.

Biopsy interview measures.

Social support. Participants reported in the initial interview the degree to which they believed they had social support available to them. The measure consisted of four items from the Medical Outcomes Study (MOS; Sherbourne & Stewart, 1991) and assesses four types of

support with one item each (tangible support, "How often do you have someone to help you with your daily chores if you were sick?"; informational support, "How often do you have someone to turn to for suggestions about how to deal with a personal problem?"; positive social interaction, "How often do you have someone to do something enjoyable with?"; affectionate support, "How often do you have someone to love and make you feel wanted?"; for all, 1 = none of the time, 4 = all of the time"). The responses of these items were then averaged into a social support composite (M = 3.12, SD = .74, Cronbach's α = .77).

Rumination. This measure consisted of three items in the initial interview (e.g., "Breast cancer was never far from my mind"; 1 = strongly disagree, 7 = strongly agree) that evaluated persistent thoughts about breast cancer throughout the participant's day. These items were also averaged to form a composite score (M = 4.63, SD = 1.94, α = .77).

Life satisfaction. Consisting of five items (e.g., "So far I have gotten the important things I want in life"; 1 = strongly disagree, 7 = strongly agree), this measure evaluated participants' general life satisfaction (Diener et al., 1985). The items were averaged to form a composite score (M = 5.81, SD = 1.14, α = .77).

Intolerance of uncertainty. The Intolerance of Uncertainty Scale—Short Form (Carleton et al., 2007) measure evaluated the ways in which participants mentally adapt to uncertain situations. The measure consisted of 12 items (e.g., "A small, unforeseen event can spoil everything, even with the best of planning"; 1 = strongly disagree, 7 = strongly agree). The items were averaged to form a composite score (M = 5.04, SD = 1.23, α = .84).

Mental health symptoms. We assessed participants' mental health symptoms with the 4-item Patient Health Questionnaire-4 (PHQ-4; Löwe et al., 2010). All items begin with the prompt, "Thinking of the past week, how often have you been bothered by the following

problems?";1 = none of the time, 4 = all of the time). Two items assess depression ("feeling

down, depressed, or hopeless"; "little interest or pleasure in doing things"; $M = 1.67$, $SD = 0.72$,

$r = .58$), and two items assess anxiety ("feeling nervous, anxious, or on edge"; "not being able to

stop or control worrying"; $M = 2.20$, $SD = 0.76$, $r = .60$)

 Emotions. Emotion and anxiety are also evaluated over different time frames. One set of

emotion items assessed participants' emotional state in the present ("How much of the time

today have you felt [anxious / sad / happy]?"; 1 = none of the time, 4 = all of the time; $M_s = 2.27$,

1.66, 2.21, $SD_s = 0.95$, 0.88, 1.00, respectively). A second set of emotion items asked

participants to recall how they had felt emotionally since their abnormal mammogram result

("During that time, between the mammogram results and today, how much of the time did you

feel [anxious / sad / happy]?"; 1 = none of the time, 4 = all of the time; $M_s = 2.40$, 2.00, 2.41,

$SD_s = 0.87$, 0.86, 0.86, respectively). A final set measures asked participants to predict how they

would feeling during the upcoming week (i.e., during the waiting period; "On average, how

much of the time each day do you think you will feel [anxious / sad / happy] while you're

waiting for your biopsy results?"; 1 = none of the time, 4 = all of the time; $M_s = 2.54$, 1.86, 2.66,

$SD_s = 0.90$, 0.82, 0.85, respectively).

 Daily diary measures.

 Social support. During the daily surveys, the social support measure consists of one item

("How supported did you feel in your interactions with friends and family today?"; 1 = not at all,

5 = completely; $M = 3.76$, $SD = 1.02$). This question was asked in the evening questionnaires.

 Emotions. Emotions were evaluated with a 24-item measure (adapted from the GRID

measure, Fontaine, Scherer, Roesch, & Ellsworth, 2007; "How much of the time today did you

feel each of the emotions below?"; 1= none of the time, 4 = all of the time). Nine items assessed

positive emotions (e.g., love, joy, pleasure, pride; $M = 2.07$, $SD = 0.58$, $\alpha = .96$), and 15 items assessed negative emotions (e.g., stress, anger, fear, irritation; $M = 1.40$, $SD = 0.42$, $\alpha = .97$). These items were included in the evening questionnaires.

Rumination. The rumination measure consisted of a three item evaluation of the degree to which participants could control thoughts about breast cancer and the impact of these thoughts (e.g. "Breast cancer was never far from my mind"; 1 = strongly disagree, 5 = strongly agree; $M = 2.60$, $SD = 1.20$, $\alpha = .95$). These items were included in the evening questionnaires.

Sleep quality. The daily surveys note how participants sleep quality was for the preceding night through a single item measure ("How would you rate the quality of your sleep last night?"; 1 = very bad, 4 = very good; $M = 2.97$, $SD = 0.68$). This item was included in participants' morning surveys.

Results

Associations among Biopsy Interview Measures

We first examined associations between social support availability as reported at the biopsy appointment and measures of emotional and psychological well-being. As anticipated, social support availability was generally associated with positive indicators of well-being and inversely associated with negative indicators. Specifically, participants who felt that they had more social support available to them were lower in intolerance of uncertainty, $r(137) = -.24$, $p = .005$, higher in satisfaction with life, $r(137) = .25$, $p = .003$, lower in rumination, $r(137) = -.21$, $p = .01$, lower in anxiety symptoms, $r(137) = -.31$, $p = .0003$, and lower in depression symptoms, $r(137) = -.42$, $p < .0001$.

Regarding specific emotions, participants who felt that they had more social support available to them reported less sadness in the moment, $r(137) = -.36$, $p < .0001$, recalled less

sadness in the previous week, $r(137) = -.24$, $p = .004$, and anticipated less sadness during the upcoming wait for biopsy results, $r(137) = -.38$, $p < .0001$. Participants who felt that they had more social support available to them also reported more happiness in the moment, $r(137) = .29$, $p = .0005$, recalled more happiness in the previous week, $r(137) = .26$, $p = .002$, and anticipated more happiness during the upcoming wait for biopsy results, $r(137) = .22$, $p = .01$.

The only exception to this pattern of findings arose for feelings of anxiety. Social support was not significantly associated with anxiety in the moment, $r(137) = -.06$, $p = .52$, recalled anxiety during the previous week, $r(137) = -.11$, $p = .18$, or anticipated anxiety during the upcoming wait for biopsy results, $r(137) = -.12$, $p = .18$.

Associations among Daily Diary Measures

Additionally, we investigated relationships between feelings of social support (reported throughout participants' waiting period) and the measures of emotional and psychological well-being assessed during that period. We discovered that, as expected, there were strong relationships between perceived support and positive emotion, $r(45) = .64$, $p < .0001$, negative emotions, $r(44) = -.42$, $p = .005$, sleep quality, $r(45) = .50$, $p = .0004$, and rumination, $r(45) = -.52$, $p = .0003$. Specifically, participants who felt more supported reported, on average, feeling more positive emotions, feeling fewer negative emotions, having better sleep quality, and ruminating less throughout this uncertain time.

To examine the possibility that perceived support was associated with other experiences due to the influence of third variables, we examined those associations controlling for measures assessed at the biopsy appointment. Specifically, we first examined the link between perceived support and positive emotions controlling for happiness at the biopsy appointment (thus addressing the possibility of a general positivity bias) and found that the relationship remained

strong, $\beta = .62$, $t(36) = 4.77$, $p < .0001$. Second, we examined the link between perceived support and negative emotions controlling for sadness at the biopsy appointment (thus addressing the possibility of a general negativity bias) and found that the relationship weakened considerable, $\beta = -.22$, $t(36) = -1.38$, $p = .18$. Finally, we examined the link between perceived support and rumination controlling for rumination at the biopsy appointment and found that the relationship remained strong, $\beta = -.46$, $t(36) = -3.19$, $p = .003$. Thus, we are relatively confident in concluding a meaningful link between perceived support during the wait for biopsy results and both positive emotion and rumination, but less so for negative emotion.

Associations between Biopsy Measures and Daily Measures

We also examined associations between perceived support availability as assessed at the biopsy appointment and perceived support, emotions, sleep quality, and rumination during the waiting period, as well associations between key measures at the biopsy appointment and perceived support during the waiting period.

We found that participants who noted having more support available during their biopsy appointment reported more feelings of support throughout the subsequent week, $r(39) = .63$, $p < .0001$. Participants who perceived that they had more support available also reported more positive emotion, $r(40) = .52$, $p = .0007$, and less rumination, $r(39) = -.35$, $p = .03$, during the waiting period. However, support availability was not significantly associated with negative emotions, $r(40) = -.19$, $p = .23$, or sleep quality, $r(40) = .13$, $p = .44$, during that period.

Finally, we turned to links between measures at the biopsy appointment and perceived support during the waiting period. Consistent with the findings for support availability, participants who were more satisfied with their life, $r(39) = .54$, $p = .0004$, and had fewer anxiety symptoms, $r(39) = -.52$, $p = .0008$, and depression symptoms, $r(39) = -.41$, $p = .009$, perceived

more social support during the wait for biopsy results. Intolerance of uncertainty was not significantly associated with perceived support during the wait, $r(39) = -.13$, $p = .43$. We also examined links between participants' anticipated emotions during the waiting period (reported at the biopsy appointment) and perceived support during that period. Participants who anticipated less sadness, $r(39) = -.46$, $p = .003$, and more happiness, $r(39) = .41$, $p = .009$, during the wait also reported more social support during the wait. The association with anxiety was weaker but approached statistical significance, $r(39) = -.30$, $p = .07$.

Discussion

Over the course of this study, we discovered that social support availability was positively correlated to positive emotions and negatively associated with negative emotions – indicating that perception of social support availability can be positively associated with individuals' overall well-being. This general trend was sustained even when evaluating measures of perceived daily support with regards to emotional, psychological, and physical well-being (as evaluated by feelings positive/negative emotions, rumination levels, and sleep quality, respectively). The fact that controlling for baseline emotion and rumination did not eliminate the relationships between social support and positive emotion and rumination throughout the waiting period was also noteworthy, suggesting that social support during the wait for biopsy results might be uniquely important for well-being during that time.

Still, whenever we found associations within and between our subjective measures, we also found at least one relationship that was not significant. These findings are equally, if not more, important – for they indicate the possibility of alternative explanations or moderating factors.

Most remarkably, the fact that support availability is correlated to positive and negative emotions but not to anxiety at the biopsy appointment may indicate that the acute nature of the crisis, as appraised by individuals preparing to go in for their breast biopsy, may supersede any potential affects social support can have. Indeed, because these feelings were evaluated at a time of high stress, the presence of support may not have been effective in alleviating in the anxiety induced by the anticipation of the event itself. Previous studies have found that, despite the strong negative relationship between distress and support availability, support has no significant relationship with coping mechanisms – which may be a key component in moderating anxious feelings (Sweeny, Christianson, & McNeill, 2018).

This reasoning may also explain the absence of an association between uncertainty intolerance and daily support. Unlike a benign or malignant diagnosis, after which individuals can plan their next steps accordingly, an uncertain diagnosis leaves individuals making decisions for hypothetical situations – which can be particularly distressing. As such, individuals may feel that their social network is not offering the type of support that they need or may even be adding an additional layer to these patients already-elevated biochemical stress levels.

The lack of a significant relationship between social support availability and negative emotion or sleep quality during the wait for biopsy results may be more difficult to explain. Having social support available does not necessarily mean that patients will choose to seek it out - which may, in turn, have the same effect as the absence of social support at all (at least in terms of distress and sleep). However, this reasoning would still not explain why positive emotions still have a positive relationship and, as such, should be studied further in future studies. Given that negative emotions also do not correlate to daily support perceptions, when general negative affect is controlled for, understanding this complexity may also aid in future explanations as to

why negative emotion is the variable with results that deviate from otherwise consistent trends in our data.

Overall, this study demonstrated the importance of support for bolstering positive well-being and mitigating distress, even after controlling for the type of person participants naturally are. These findings provide a solid foundation for future studies, using interventions to increase perceptions of support in an effort to improve the psychological experience of awaiting breast diagnosis.

Limitations

Although this study uses a relatively large sample, at least at the biopsy appointment, there were some limitations to the study as a whole. The scope of our study is confined to one hospital in the Southern California area, which significantly limits our population and may have skewed our current findings toward the demographics in this location. This study was run over the course of the past two years and, while the undergraduate researchers conducting the studies are well-trained, there still may be slight deviations between how information is conveyed between researchers or towards participants – which also may have caused confounds.

Due to the nature of this study, eligibility is restricted to females who have already chosen to come in to the hospital to receive a biopsy. Therefore, the results of this study may have left out the impact that abnormal mammograms have on individuals who chose not to complete a biopsy. We also operationalize the waiting period as the time between conducting the initial breast biopsy until receiving the biopsy results – but others may argue that this waiting period could technically begin from the moment when patients are told that they have an abnormal mammography.

The sample size for daily surveys is also currently considerably smaller than those of the initial biopsy interview, often because of difficulties retrieving the binders (although data collection is still underway). Speaking of the daily surveys, we decided to use only the first five days of every participants' binder in order to maintain consistency across participants. In reality, there was a lot of variation in the length of waiting periods between participants. These limitations are aspects that future studies can improve upon, but this study efficiently created a starting point from which these studies can build upon to understand the relationship between well-being and social support.

Future Directions

In the future, it is important the researchers investigate the potential confounds that may have influenced our results, in order to rule out alternative explanations and investigate whether social support truly does have a causal effect on pre-diagnostic patients' well-being. In order to establish external validity, this study should also expand to a variety of hospitals in order to obtain a more diverse set of demographics. This expansion may ultimately introduce the concept of cultural influence, as cultural background plays an important role in the social support available to patients and could also work as a moderating variable in promoting well-being during these stressful period. All in all, future research should build upon the research presented here in order to establish stronger relationships between these variables and identify other potential influencing variables.

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Conclusion

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Social support plays a significant role during uncertain waiting periods, and prior studies have demonstrated the need for social support in a variety of stressful situations. This study builds upon that previous literature to reiterate the importance of the perceived support

availability and daily feelings of support in association with indicators of well-being. By understanding the relationships between social support and these indicators of well-being (sleep quality, intolerance of uncertainty, rumination, and positive/negative emotion), research can continue to seek out positive coping strategies that improve patients' experiences during this stressful time. In future, this research may revolutionize the way that medical professionals approach patients' treatment plans and may enable individuals to more efficiently maintain their health during moments – or waiting periods – like these.

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Table 1

Sample Characteristics

Patient Characteristic	(*n* = 137)
% female	100%
Mean age	44.7
Education	--
Did not complete high school	39%
Completed high school only	49%
Completed college (2- or 4-year degree)	12%
Insured (any)	86%
Employed	38%
Ethnicity: Hispanic/Latina	77%
Race	--
White/Caucasian	72%
Black/African-American	7%
Asian	0%
Native Hawaiian/Pacific Islander	1%
American Indian/Alaska Native	2%
Other/multiple	17%
Completed interview in Spanish	48%
Religious affiliation (any)	93%
Health history	
Personal history of breast cancer	8%
Family history of breast cancer	34%
Marital status: Married	49%