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Reasons symptomatic breast cancer patients delay seeking medical care

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Abstract

Aim: To assess for factors contributing to the total delay in care, and specifically the behavioral delay-interval portion of that delay, experienced by a group of symptomatic breast cancer patients.

Methods: This retrospective cohort pilot study included 24 females greater than 40 years-old with symptomatic breast cancer at time of diagnosis (including palpable mass, breast pain, other pain, discharge, nipple inversion). Participants were asked demographic information, as well as to identify, from a predefined list of options, the three most relevant causes for their delayed breast cancer diagnosis. Data sources included electronic medical record query and phone surveys.

Results: Overall, 21/24 of our study's participants identified at least one of our predetermined barriers to care as relevant to their cause for delay. The most commonly identified reasons for delay were health system utilization factors contributing to behavioral delay, including dependents/pressing matters, employment responsibilities, transportation costs and difficulty, fear of being judged by healthcare workers, and fear of not being able to afford treatment.

Conclusion: Women with breast cancer can experience delays to eventual diagnosis and treatment during various time-intervals between first noticing a symptom and finally presenting to medical attention. This study provides evidence that one such possible interval is the behavioral delay interval. Health system utilization factors, psychological factors, demographic factors and help-seeking habits can contribute to an increased behavioral delay interval. Further research is warranted to address these factors and minimize their impact on patient care delivery.



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Keywords: Cancer, breast, delay, symptomatic

INTRODUCTION

There has been extensive interest in researching causes of delay in breast cancer patients' diagnosis and treatment^[1-8]. This interest has no doubt stemmed from the knowledge that the earlier female breast cancer is identified, the better chance a person has of surviving five years after being diagnosed^[9,10]. Since up to 86% of patients will self-discover their initial sign or symptom of breast cancer, patient-related intervals of delay have received particular attention^[11-13].

The portion of patients' overall delay to treatment between when a patient first detects a symptom of breast cancer and when they first obtain medical attention has been described by Olesen *et al.*^[14] (2009) as the patient interval. This has been widely adopted by medical help-seeking behavior researchers, including those who formed the widely-referenced Aarhus checklist for early cancer-diagnosis research^[15]. Many researchers have recognized that this period of delay can be broken down into shorter sub-intervals including, an appraisal interval, known as the time a patient takes to interpret new symptoms as concerning for illness, and a help-seeking interval, known as the time from when a patient develops illness concern and when they obtain medical evaluation^[16].

However, whether the help-seeking interval can be further divided into smaller sub-intervals, including behavioral delay is controversial. Despite being initially described by Andersen *et al.*^[17] in 1995, there is currently limited evidence to support the existence of this delay-interval, defined as the time between when a patient decides they should seek medical evaluation for their symptom and when they eventually take action to obtain that evaluation^[17,18]. As a result, the behavioral delay interval has been largely excluded from more recent models of health-seeking behavior. In this study, we specifically aim to assess for causes of behavioral delay and thereby add to the fairly limited body of evidence in support of its existence.

METHODS

Study population

We conducted a retrospective cohort pilot study including all women greater than 40 years old with symptomatic breast cancer at the time of their diagnosis (including palpable mass, breast pain, other pain, discharge, nipple inversion) who were patients at the Penn State Hershey Breast Cancer Clinic between 2011 and 2016. Our study's population was subsequently finalized by means of phone recruitment and informed consent.

Participants were excluded if there was a minimal delay in their presentation of less than 3 months, which is a time criterion arbitrarily used by many investigators^[19-21], or if their tumor size at time of diagnosis was less than 2 cm, since tumors greater than or equal to this size have been associated with significant mortality benefits and more consistent detection by screening mammogram^[22,23]. We also excluded participants who had received a mammogram within 1 year of their diagnosis, as they utilized preventative services in accordance with the strictest available guidelines^[24,25] and could most clearly be classified as interval cancers, which have been associated with longer mean waiting times to breast cancer diagnosis compared with screen-detected cancers^[26]. Women with invasive lobular carcinoma were also excluded, because standard screening mammography has been reported to have a relatively lower ability to detect this cancer subtype compared to other invasive breast cancers^[27,28].

Questionnaire development

Prior to initiating the study, the investigators developed a questionnaire, with scripted, consistent language and question order. Although this novel questionnaire was not formally validated, it was utilized in the

absence of any other previously validated questionnaire designed to specifically assess factors relevant to behavioral delay. The few validated questionnaires applicable to early-diagnosis research in breast cancer patients, including the Breast Cancer Screening Beliefs Questionnaire, the Breast Cancer Delay Questionnaire, and the ALGA-Breast Cancer Questionnaire, focus primarily or exclusively on factors relevant to the appraisal interval^[29-32]. Therefore, these tools were determined to be inappropriate for use in our study.

Our questionnaire is well-aligned with help-seeking theory, and each question relates directly or indirectly to the empirical and theoretical frameworks proposed by multiple researchers^[33-36]. Our questionnaire was designed to collect data on influencing factors including, knowledge and beliefs (perceived severity of illness, alternate therapy utilization), psychosocial factors (fear, uncertainty), social factors (role obligations), health system accessibility (economic and transportation constraints), as well as demographic and health-seeking habit data of participants (mammogram and clinical breast exam pre-diagnostic recency). Questions were developed to assess mostly behavioral delay factors, but some questions were included that captured earlier-stage intervals, including appraisal and illness delay intervals.

In response to each factor assessed by our questionnaire, participants were asked to assign a Likert-type scale value corresponding to that factor's relevance to their delayed medical presentation, specified as: (1) completely irrelevant; (2) somewhat irrelevant; (3) uncertain relevance; (4) somewhat relevant; and (5) completely relevant. After completing value assignments for each of the pre-defined categories, the phone-interviewer verbally read-out all categories assigned a value of two or greater, then asked participants to identify the three reasons they felt were most important causes for their delay, ranked in order from greatest to least importance.

Data collection

Eligible women were contacted between 3 months and 5 years of their diagnosis. First contact was made by phone, by a trained member of our research team who was not a clinician and not part of any patient's healthcare team. This information was clearly stated to contacted patients at the start of the scripted interview. Patients were then read a scripted informed consent, which was approved by our facility's Institutional Review Board. Lastly, they were read a scripted questionnaire form, also approved by our facility's Institutional Review Board [[Supplementary Table 1](#)].

Since the accuracy of time-relevant information was vital to both the study inclusion/exclusion criteria and to the integrity of collected data, the case-note audit method was used to validate data provided by participants, as suggested in the Aarhus statement. At the conclusion of each completed phone interview, participants' medical records were accessed and relevant case-notes were reviewed, including primary care provider notes, gynecologist notes, mammogram reports, pathology reports, and breast center clinician notes.

Hand-written "field" notes were taken during each phone interview, to collect participants' qualitative explanations of the factors influencing their delay. Data from all participants was compiled in a password-protected Excel spreadsheet. De-identified supplementary data from case-notes in patients' electronic medical records were also compiled in the spreadsheet.

Data analysis

Descriptive statistics were used to summarize the survey questionnaire data. Data accessed from participants' electronic medical records were used to verify, and in some cases correct, responses in the "Demographic Data" portion of our questionnaire. Participant qualitative comments were captured in an Excel spreadsheet and then used to provide context to associated questionnaire responses.

Table 1. Demographic data and clinical characteristics

	% (n)
Mean Age (years)	60
Self-identified race	
White/non-Hispanic Caucasian	95.8% (23/24)
Black/African-American	4.2% (1/24)
Pathologic diagnosis	
Invasive ductal carcinoma	95.8% (23/24)
Invasive adenocarcinoma	4.2% (1/24)
Mean months of delay from symptom discovery to presentation	14.7
Cancer stage at time of diagnosis	
Stage 2A	4.2% (1/24)
Stage 3A	29.2% (7/24)
Stage 3B	16.7% (4/24)
Stage 3C	8.3% (2/24)
Stage 4	41.6% (10/24)
Years between last mammogram and diagnosis	
1-2 years	25% (6/24)
3-5 years	25% (6/24)
6-10 years	17% (4/24)
> 10 years	8% (2/24)
Never had mammogram	25% (6/24)
Years between last clinical breast exam and diagnosis	
< 1 year	12% (3/24)
1-2 years	25% (6/24)
3-5 years	29% (7/24)
6-10 years	17% (4/24)
> 10 years	17% (4/24)
Initial symptom patient reported	
Lump	62.5% (15/24)
Nipple inversion	12.5% (3/24)
Open ulcer	8.3% (2/24)
Breast pain	4.2% (1/24)
Other (non-breast) pain	8.3% (2/24)

RESULTS

There were 24 subjects included in this analysis, with an average age at the time of diagnosis of 60 years. All subjects were female, 95.8% (23/24) self-identified as white and 4.2% (1/24) of subjects self-identified as black. Ninety-five point eight percent (23/24) of subjects had invasive ductal carcinoma, and 4.2% (1/24) had invasive adenocarcinoma consistent with breast. The average number of months from the time patients reported noticing their initial symptom until seeking medical attention was 14.7 months [Table 1].

Breast cancer stage at time of diagnosis

Clinical staging data was recorded for all 24 subjects. One participant (4.2%) was diagnosed as clinical stage 2A, 7/24 (29.2%) participants as clinical stage 3A, 4/24 (16.7%) as clinical stage 3B, 2/24 (8.3%) as clinical stage 3C, and 10/24 (41.6%) as clinical stage 4 [Table 1].

Years between last mammogram and diagnosis

The dates of participants' most recent mammograms were obtained through querying the electronic medical record and were verified verbally by phone. The length of time between each participant's most recently documented pre-diagnosis mammogram and the time of diagnosis was used to group each into one of five categories. None of our subjects had a mammogram less than one year before their diagnosis, as this was one of our study's exclusion criteria. Twenty-five percent (6/24) of subjects had mammograms within 1-2 years of their diagnosis, in accordance with one or more accepted guidelines on screenings. Twenty-five percent (6/24) had

not had a mammogram for 3-5 years prior to their diagnosis, 17% (4/24) had not had a mammogram for 6-10 years prior to their diagnosis, 8% (2/24) had not had a mammogram for more than 10 years prior to their diagnosis, and 25% (6/24) reported never having had a mammogram prior [Table 1].

Years between last clinical breast exam and diagnosis

The dates of the participants' most recent clinical breast exam were gathered by a combination of electronic medical record query and direct questioning of participants. The length of time between each participant's most recently identified pre-diagnosis breast exam and the time of cancer diagnosis was used to group them into five categories. There were no women in our study who reported never having had a clinical breast exam. Twelve percent (3/24) had a clinical breast exam < 1 year prior to their diagnosis, 25% (6/24) had an exam 1-2 years prior, 29% (7/24) had an exam 3-5 years prior, 17% (4/24) had an exam 6-10 years prior, and 17% (4/24) of participants did not have a clinical breast exam for greater than 10 years prior to their diagnosis of breast cancer [Table 1].

Initial symptom patient reported

The initial symptoms that participants brought to the attention of a health care worker were collected by a combination of electronic medical record query and direct questioning of participants. When asked what their initial symptom was, 62.5% (15/24) self-identified a lump, 12.5% (3/24) noted nipple inversion, 8.3% (2/24) reported an open ulcer, 4.2% (1/24) breast pain, 8.3% (2/24) other (non-breast) pain, and 4.2% (1/24) vision changes [Table 1].

Self-reported reasons participants delayed seeking medical evaluation

All of the study's 24 subjects, identified at least one of our pre-defined categories as contributory to their delay. However, only 87.5% (21/24) were willing to rank their selected categories in order of 1st-, 2nd-, and 3rd- highest importance. As some participants identified fewer than three causes for their delay, there was a corresponding decrease in number of 2nd-most important (83.3%, 20/24) and 3rd-most important (50%, 12/24) ranked responses. The complete list of pre-defined categories and responses for 1st-, 2nd-, and 3rd-most important reasons for delay are displayed in Table 2.

Appraisal interval influencing factors

Only one factor assessed by our questionnaire pertained to the appraisal interval. Specifically, we assessed if patients initially perceived their symptom to be benign, which pertains to patients' knowledge and beliefs about cancer. Women reported multiple reasons for initially perceiving their symptoms to be benign. One assumed her breast lump was a hematoma, since she had a recent minor breast trauma prior to noticing it. One reported having a history of benign cysts in both breasts and assumed this lump was similarly benign because of that personal health history. Another woman with a history of breast benign cysts said she thought menopause might explain why her lump continued to increase in size.

Illness delay-interval influencing factors

Illness delay, described as the period of delay between when a patient first infers their symptom might be indicative of illness and when they decide to seek medical attention, was also assessed for by this questionnaire. Specifically, the influence of religious or spiritual beliefs and initially seeking alternative treatments were surveyed. No participants reported these factors having a significant impact on the timing of their presentation to medical attention.

Behavioral delay-interval influencing factors

Multiple factors related to health system utilization were assessed by our questionnaire. Several women reported primary responsibility for their dependents' caretaking needs, including both child and adult dependents, as an important reason for their diagnostic delay. One woman was a primary caretaker for her

Table 2. Self-reported reasons for delayed help-seeking

Influencing factors, by delay-interval	Most important (<i>n</i> = 21)	2nd most important (<i>n</i> = 20)	3rd most important (<i>n</i> = 12)
Appraisal interval			
Knowledge and belief factors			
Initial perception that benign	<i>n</i> = 4	<i>n</i> = 2	<i>n</i> = 1
Illness delay interval			
Knowledge and belief factors			
Religious or spiritual beliefs			
Initially seeking alternative treatment			
Behavioral delay interval			
Health system utilization factors			
Dependents/pressing matters	<i>n</i> = 9	<i>n</i> = 3	
Employment responsibilities	<i>n</i> = 2	<i>n</i> = 3	
Transportation costs and difficulty	<i>n</i> = 2	<i>n</i> = 2	
Fear of being judged by healthcare workers	<i>n</i> = 2	<i>n</i> = 2	<i>n</i> = 1
Fear of not affording treatment	<i>n</i> = 2		<i>n</i> = 3
Psychological factors			
Fear of losing breast		<i>n</i> = 2	<i>n</i> = 1
Fear of losing hair			<i>n</i> = 1
Fear of changes to appearance			<i>n</i> = 1
Fear of other chemotherapy side effects		<i>n</i> = 1	<i>n</i> = 3
Fear of surgery/anesthesia complications		<i>n</i> = 1	
Fear of affecting relationship with partner			<i>n</i> = 1
Health seeking habits			
Preference to avoid cancer screening		<i>n</i> = 2	
Demographic factors			
Mental health		<i>n</i> = 2	

husband until his death from ALS which, in combination with a delay in scheduling his memorial service, contributed to her delay in seeking healthcare for her symptom. Another woman was in the process of helping her father with advanced dementia move into a skilled nursing facility. One woman's son was about to start college, and she wanted to wait until after she finished helping him move in.

Other important factors were also reported. For example, one woman noticed her breast symptom shortly after she had a "massive heart attack" and thought it was best to wait until she recovered from her cardiac event before seeking evaluation of her breast symptom. Participants also reported employment responsibilities as reasons for delaying their medical care, including "running out of sick days", being initially "unable to afford missing a day's wages", and noticing their symptom "in the middle of an especially busy time at work". Others reported a lack of self-owned transportation and difficulty affording or arranging transportation to a medical facility as contributing to their delay. Notably, several women identified a relatively novel reason for their delay, which was a fear that they would be judged by healthcare workers for "not coming in sooner," "not getting a mammogram in so long," or "not going to any doctor for a while". One woman said she felt embarrassed for not doing frequent self-breast exams when her sister had just died of breast cancer earlier that year and thought "doctors would judge [her] for how large the lump was".

Psychological factors were assessed although less commonly reported. All psychological factors, including fear of losing their breast, losing hair, appearance changes, other chemotherapy side effects, surgery/anesthesia complications, and effects to relationship with partner, were reported by at least one participant.

Health-seeking and demographic factors, including preference to avoid cancer screening and mental health diagnosis, were surveyed and each category was reported by two participants. One participant reported suffering from depression at the time when she noticed her breast cancer symptom, and another reported being in treatment for her cocaine addiction at the time of her first symptom.

DISCUSSION

Study participants reported multiple, varied circumstances, providing support for the existence of the behavioral delay-interval. This component of the total patient delay, as proposed by Andersen *et al.*^[17] in their 1995 foundational model for early cancer-diagnosis, has been largely abandoned in more modern models, such as that put forth by Walter *et al.*^[16] in 2012, and endorsed within the influential Aarhus statement later that year. The basis for dismissal of this interval was lack of widespread evidence, with very few studies reporting on its existence within only a few patients, and even then reports were confined to the limited context of competing events (e.g., holidays) and emotions (e.g., coming to terms with the meaning of symptoms)^[37,38]. Bairati *et al.*^[39] report the existence of behavioral delay within breast cancer patients, but did not include specific questions for identification of this stage of delay.

In our study, while psychologic factors (i.e., fears) were reported as influencing behavioral delay factors, in line with some of the limited prior research on this delay interval, health system utilization factors were much more widely commented on by this study's population. Dependents and other pressing matters, employment responsibilities, transportation costs and difficulty, fear of healthcare worker judgment and fear of not being able to afford treatment were all specifically referenced as factors that caused women, at a time when they were already concerned about their breast cancer symptom, to delay making an appointment for its evaluation. Therefore, each of these circumstances meets criteria for behavioral delay and offers evidence that behavioral delay on its own can contribute to significant periods of delay preceding initial medical attention for a breast cancer symptom.

Out of the above-mentioned health system utilization factors, one in particular is novel to this study. We noted that patients reported shame and fear of healthcare worker judgment specifically regarding their chief presenting medical complaint. Although, fortunately, these participants reported their eventual experience with the healthcare system far exceeded their expectations, the variety of circumstances provided by our study's participants as to why they feared they would be judged by healthcare workers certainly raises alarm that something inherent in the medical community's culture or within the typical provider-patient interaction must be addressed. There has been limited reporting on prejudice as a contributing factor to total patient delay, but when it has been reported it has only been within the context of racial prejudice^[40]. It is deeply troubling if providers themselves may show prejudice and possibly contribute to patients delaying vital medical evaluation and treatment for their breast cancer symptoms. Further research is warranted to explore the frequency of healthcare workers actually holding such prejudices, the bases for patients' beliefs that they would be judged by healthcare workers for presenting with a breast cancer symptom, and whether education of healthcare trainees and training for current healthcare workers is warranted to address this issue.

An additional concerning finding with public health implications was that participants in our study reported delaying medical presentation for their breast symptom due to a "fear of not being able to afford treatment". This is consistent with recent results reported by Taber *et al.*^[41], which found "high cost" and "lack of health insurance" to be reasons why patients reported avoiding medical care. This phenomenon may create an even greater burden in cancer patients, as a delay in presentation may translate to more costly treatment plans that may be even more expensive for the patient. Zafar *et al.*^[42], describes this "financial toxicity" of cancer treatment in a survey of mostly breast cancer patients where he reports that approximately 60% of cancer patients either fail to fill, partially fill their cancer medication prescriptions or take less medication than what was prescribed due to financial concerns. While Zafar looked at the financial implications of patients already diagnosed with cancer, we believe that our study is the first to identify cost as a factor for delay in presentation for the cancer patient.

The risk of recall bias was noted and minimized by use of the case-note audit method for all important dates, including the date of first noticing a symptom and the date of first presentation to a medical professional.

All reviewed case-notes included specific descriptions of the help-seeking interval (time taken between interpretation of bodily changes/symptoms and acting upon those interpretations to seek help) in their subjective sections, and so all participants' reported help-seeking time-intervals were able to be verified by reports written at the time of their diagnosis, which were therefore unlikely to be impacted by recall bias.

Our study had several limitations, including a small sample size, albeit similar to other qualitative early breast cancer diagnosis studies^[43-45]. Additionally, our participants were fairly racially homogenous and were all female. These characteristics may limit the generalizability of our results to broader populations. Our use of a non-validated questionnaire was a limitation, but perhaps this study's questionnaire might in the future become validated for the purpose of assessing factors contributing to the behavioral delay-interval. Use of close-ended questioning may also be a limitation, since our method only allowed for a finite number of response-categories to be captured. However, we feel this method also offered certain strengths such as reducing the influence of investigator interpretation on participants' responses and normalizing answer categories that might otherwise be difficult for participants to freely divulge.

In conclusion, we found that many different factors may prolong the behavioral delay-interval, including factors pertaining to health system utilization, psychological fears, health seeking habits, demographics, mental health, and knowledge/beliefs. This study elaborated on a variety of reasons why patients did not immediately take action to seek help after deciding they wanted to do so, which is the very definition of the proposed behavioral delay concept. Participants in our study reported shame and fear of healthcare worker judgment, which is a novel report within the context of the patient interval pertinent to early breast cancer diagnosis. The fact that participants cited concern for treatment costs as a factor that delayed their initial medical presentation has serious public health implications. Further studies are needed to elaborate on the existence of the behavioral health interval, including the need to replicate and expand on the influencing factors identified in our study within this particular interval's context. Investigating and developing strategies to minimize the impact of these factors on patient care delivery is also critical to reducing avoidable morbidity and mortality in patients and also to helping understand the various factors contributing to the differences in patient outcomes.

DECLARATIONS

Authors' contributions

Conception and design of the work: Heath J, Paulishak M, Kasales C, Kass R

Acquisition of data: Heath J

Analysis of data: Heath J, Paulishak M, Kasales C, Kass R

Interpretation of the results: Heath J, Paulishak M, Kasales C, Schubart J, Kass R

Drafting the manuscript: Heath J, Kasales C, Kass R

Revising the manuscript critically for important intellectual content: Heath J, Kasales C, Schubart J, Kass R

Final approval of the version to be published: Heath J, Paulishak M, Kasales C, Schubart J, Kass R

Availability of data and materials

Data collected in this study cannot be shared beyond members of the study team, as doing so was not part of either this study's Institutional Review Board approval or the informed consent process of each study participant.

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None.

Conflicts of interest

All authors declared that there are no conflicts of interest.

Ethical approval and consent to participate

The study protocol was reviewed and approved by the Institutional Review Board of the Milton S. Hershey Medical Center in Hershey, PA, under reference numbers PSHCI 16-034 and STUDY00004334. A written informed consent was reviewed with each participant and consent was obtained from each participant prior to their participation in the study.

Consent for publication

Not applicable.

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