



Published in final edited form as:

Support Care Cancer. 2020 July ; 28(7): 3179–3188. doi:10.1007/s00520-019-05119-y.

Multi-level determinants of financial toxicity in breast cancer care: perspectives of healthcare professionals and Latina survivors

Perla Chebli¹, Jocelyne Lemus¹, Corazón Avila¹, Kryztal Peña¹, Bertha Mariscal², Sue Merlos², Judy Guitelman², Yamilé Molina¹

¹School of Public Health, University of Illinois at Chicago, Chicago, IL

²ALAS-Wings, Chicago, IL

Abstract

Purpose—Financial toxicity is a multidimensional side effect of cancer treatment. Yet, most relevant research has focused on individual-level determinants of financial toxicity and characterized only patient perspectives. This study examined the multi-level determinants of financial toxicity from the perspectives of Latina breast cancer survivors and healthcare professionals.

Methods—We analyzed qualitative data from focus groups with 19 Latina breast cancer survivors and interviews with 10 healthcare professionals recruited through community partners and venues in Chicago.

Results—At the individual-level, the lack of knowledge and prioritization regarding financial aspects of care (e.g., costs of treatment, insurance coverage) were identified as important determinants of financial toxicity. However, healthcare professionals emphasized the need for early financial planning, while survivors prioritized survival over financial concerns immediately after diagnosis. At the interpersonal-level, social networks were identified as important platforms for disseminating information on financial resources. At the community-level, community norms and dynamics were identified as important barriers to seeking financial assistance. Access to culturally astute community-based organizations was considered one potential solution to eliminate these barriers. At the organizational/healthcare policy-level, financial assistance programs' restrictive eligibility criteria, lack of coverage post-treatment, limited availability, and instability were identified as major determinants of financial toxicity.

Terms of use and reuse: academic research for non-commercial purposes, see here for full terms. <http://www.springer.com/gb/open-access/authors-rights/aam-terms-v1>

Corresponding author: Yamilé Molina, Mail address: 649 SPHPI MC923, University of Illinois at Chicago, Ph: 312-355-2679, Fax: N/A, ymolin2@uic.edu.

Conflict of Interest

The authors have no conflicts of interest to disclose.

Publisher's Disclaimer: This Author Accepted Manuscript is a PDF file of an unedited peer-reviewed manuscript that has been accepted for publication but has not been copyedited or corrected. The official version of record that is published in the journal is kept up to date and so may therefore differ from this version.

Conclusion—Our findings suggest that multi-level interventions at the individual-, interpersonal-, community-, and organizational/healthcare policy-levels are needed to adequately address financial toxicity among Latina and other survivors from disadvantaged communities.

Keywords

breast cancer disparities; financial burden; Latinas; multilevel

Introduction

Latina breast cancer survivors suffer from worse quality of life, more symptom burden, and more comorbidities when compared to non-Latina White (NLW) cancer survivors [1–5], in part due to lower adherence to treatment and survivorship guidelines [6–10]. These disparities are complex. For example, extant research has compared non-Latino Whites and Latinos “in general.” Both populations, however, exhibit rich variation in factors that contribute to disparities, including: ethnic/cultural identities; immigrant status; English language proficiency; and, socioeconomic status in the United States. Another potential factor contributing to breast cancer disparities is financial toxicity [11–13]. Lentz and colleagues [13] define financial toxicity as “the adverse impact of a cancer diagnosis on a patient’s financial well-being resulting from direct or indirect costs.” The financial impact of cancer on survivors’ well-being includes: disrupted workforce participation; loss of or limited insurance; out-of-pocket expenses associated with breast cancer; and competing living expenses [13–16]. NLW-Latina disparities in financial toxicity likely contribute to the aforementioned NLW-Latina disparities in breast cancer survivorship. Specifically, relative to general populations of NLWs, Latina breast cancer survivors are: less likely to have income/savings to cover out-of-pocket costs; more likely to be worse off financially post-diagnosis; more likely to cut other costs to address medical needs; less likely to return to work within 6 months of their diagnosis; and, more likely to report cost-related medication non-adherence [17–20]. The current study adds to existing literature through characterizing determinants of financial toxicity at multiple levels that negatively affect Latina breast cancer survivors.

Recent efforts to characterize causes of financial toxicity among cancer survivors have highlighted individual-level risk factors that are common among Latina breast cancer survivors. A few examples include demographic factors before or at the point of diagnosis (e.g., lower socioeconomic status, precarious employment), cancer-related factors (e.g., late stage diagnosis), and type of recommended treatment (e.g., medications, need for surgery/radiation) [13, 21]. *Some* Latina breast cancer survivors also experience employment challenges related to non-citizen status; ineligibility to obtain insurance; and, language barriers in accessing treatment-related financial assistance [22–24]. Less work has focused on contextual determinants. Qualitative approaches are needed to understand *how* determinants of financial toxicity manifest and interact at different levels. To do so, capturing multiple perspectives is necessary. For example, patients may have a particularly rich understanding of factors in and outside of the healthcare system at individual, interpersonal, and community-levels. Simultaneously, healthcare professionals may have a particularly rich understanding of factors in the healthcare system at the organizational/

healthcare policy-levels [25–27]. Yet, to date, most research has focused on patients [17, 18, 20–23]. Relatively few studies have examined the perspectives of healthcare professionals (but see [19]) and other stakeholders.

Our specific aim for this current project was to identify individual-, interpersonal-, community-, and organizational/healthcare policy-level factors that could contribute to financial toxicity among Latina breast cancer survivors. Toward that goal, we conducted semi-structured interviews with a Chicago-based sample of Latina breast cancer survivors and healthcare professionals. Our goal was to provide a platform to enumerate the types of multilevel interventions that can effectively reduce financial toxicity among Latina breast cancer survivors. This study also sought to assess if some factors may be applicable to survivors from other immigrant populations and disadvantaged, marginalized groups overall (e.g., other racial/ethnic minorities, sexual/gender minorities, rural populations). Given this, we highlighted specific determinants that may be important to consider for disadvantaged populations and immigrant communities overall.

Methods

Procedures

The current study was based on a larger qualitative study regarding post-treatment effects of breast cancer among Latina survivors, with a focus on lymphedema and mental health consequences. The project included community (Guitelman) and academic principal investigators (Molina). All methods and materials were approved by the University of Illinois at Chicago's Institutional Review Board.

Between February and September 2018, we collected data. We used a multi-frame convenience sampling to recruit participants. We engaged Latina breast cancer survivors through: 1) posted flyers throughout community venues; and, 2) word-of-mouth recruitment via community advocates. We engaged healthcare professionals through: 1) recruitment e-mails via professional organizations; and, 2) word-of-mouth recruitment via community advocates and leaders. Interested participants contacted study staff to be screened. Eligibility criteria for survivors were: 1) self-identification as being Latina, Hispanic, or Chicana; 2) age of 18 years or older; 3) a definitive diagnosis of invasive breast cancer; and 4) receipt of a lumpectomy or mastectomy within the past five years. Eligibility criteria for healthcare professionals were: 1) self-identification as being aware of and having experience with financial aspects of cancer care; and 2) age of 18 years or older.

Eligible, interested Latina breast cancer survivors were scheduled to participate in a focus group in their preferred language (English or Spanish) within a community venue near their residence. Focus groups included 8–9 individuals and lasted approximately 2 hours. Focus group discussions centered on participants' experiences navigating the cancer care continuum, including their perspectives on financial burden. Sample questions included, "What are the economic effects of having cancer?" and "What financial resources were you aware of during/after treatment?" Participants received \$40 incentives.

Eligible, interested healthcare professionals participated in one-on-one interviews that lasted approximately 30–60 minutes. Interviews were administered by phone or in person, based on participants' preferences. Interviews centered on participants' knowledge of financial assistance programs; and, their experiences with Latina breast cancer patients seeking financial assistance. Sample questions included, "How did you become familiar with patients' finances and the costs of breast cancer?" and "What are the challenges or barriers to enrolling women in financial assistance programs?" Participants received \$50 incentives.

Qualitative data analysis

Interviews and focus groups were audio-recorded, transcribed verbatim by bilingual members of the study team, and uploaded into Dedoose. A team of four coders (PC, KP, JL, CA) led a content analysis with deductive (theory-derived themes) and inductive approaches (themes emerging from iterative analysis) [28, 29]. An initial coding scheme with deductive codes was informed by existing literature on financial toxicity [11–13] and socio-ecological research with Latina breast cancer survivors [30]. New inductive codes emerged from raw interview and focus group data. The team of coders independently read each transcript and met weekly to ensure a consistent interpretation of codes and to foster inter-coder reliability. Disagreement was resolved by reviewing transcripts and discussing perspectives until consensus was reached. Coders then grouped similar concepts into categories illustrative of the identified emergent themes. Based on socio-ecological models, we grouped themes as individual-, interpersonal-, community-, and organizational/healthcare policy-level factors. Based on frameworks specifically focused on cancer disparities [31, 32], we classified themes based on their potential relevance for all breast cancer survivors, for women from disadvantaged/marginalized communities, and for breast cancer survivors from immigrant communities. Peer debriefings were held after coding was completed, wherein principal investigators (YM, JG) reviewed analyses, interpretations, and framing [33, 34]. We did not quantify information regarding our qualitative data, given that our study was not designed to enumerate associations [35]. Providing percentages would have led to misleading counting for determinants identified in this study [36, 37].

Results

Descriptive information for the 19 Latina breast cancer survivors and 10 healthcare professionals is provided in Table 1. Themes with illustrative quotes and theoretical implications for other populations are presented in Table 2.

Individual-level Determinants: Lack of knowledge and financial planning

Both survivors and healthcare professionals identified the *lack of knowledge* and *delayed financial planning* as individual-level determinants of financial toxicity for all breast cancer survivors. These individual-level factors were considered universally important, but more common among disadvantaged communities. Healthcare professionals perceived that Latina breast cancer patients' lack of knowledge compromised their ability to obtain financial assistance efficiently. Latina breast cancer survivors explained these delays differently. They emphasized that survival at any cost was initially prioritized over financial concerns, in line with theoretical models regarding disadvantaged communities' competing priorities.

Interpersonal-level Determinants: Access to Social Networks with Cancer Experiences

Healthcare professionals and survivors both emphasized the importance of *access to individuals with relevant cancer experiences within their networks* (e.g., other survivors, caregivers of cancer patients) as a protective interpersonal-level determinant of financial toxicity. Healthcare professionals perceived that survivors with such access had greater knowledge about financial assistance programs and applied for financial assistance early in the process of cancer treatment. Survivors confirmed the importance of social networks for sharing information. They specifically described situations wherein they themselves disseminated information on financial assistance to family members.

Community-level Determinants: Cultural Norms and Community Dynamics

Healthcare professionals highlighted *cultural norms* (e.g., vergüenza/embarrassment, stigma) and *community dynamics* regarding documentation status as community-level determinants of financial toxicity. Healthcare professionals and Latina breast cancer survivors identified the importance of culturally- and linguistically-congruent personnel and organizations to address cultural norms, language barriers, and barriers associated with non-citizenship status. Survivors specifically expressed gratitude for a local community-based organization led by Latina breast cancer survivors.

Organizational/Healthcare Policy-level Determinants: Limitations of Existing Financial Assistance Programs

Healthcare professionals and survivors referenced several financial assistance programs commonly utilized by Latina breast cancer patients and survivors from disadvantaged communities. These included public (e.g. local affiliate of the National Breast and Cervical Cancer Early Detection Program), foundational (e.g. Patient Access Network, Patient Advocate Foundation) and hospital-based programs. These programs however had some limitations. First, some programs had *restrictive eligibility criteria* in terms of insurance status and income. Ineligible patients who were underinsured and/or who had minimal assets reported high levels of financial stress. Relatedly, these program criteria impacted eligible participants' behaviors in potentially maladaptive ways. Having to re-apply for programs without guarantee of support was a major stressor. As well, some participants declined employer-based health insurance plans, because these plans provided less comprehensive coverage than financial assistance programs. In addition, healthcare professionals discussed most financial assistance programs' *nearly exclusive focus on medical costs during treatment*. Both groups agreed that survivors lacked access to financial resources for competing costs (e.g., costs of living, family care) and indirect costs associated with treatment (e.g., travel, housing). Finally, healthcare professionals stressed *the limited amounts of money offered and the instability of funds*. These problems were particularly common for financial assistance programs that covered all costs and were discretionary.

Discussion

Financial toxicity is a multidimensional side effect of cancer treatment, with negative impacts on patient well-being and mortality risk [11–13, 38]. our work cataloged some multi-level determinants of financial toxicity. Below, we first describe results that are

pertinent to Latinas, the priority population for this study. Second, we provide an overview of how our study may be helpful in understanding the manifestation of financial toxicity for other disadvantaged groups.

At the individual-level, lack of knowledge regarding treatment-related costs and insurance coverage was a shared concern between survivors and healthcare professionals. This finding aligns with previous research on general survivor populations [39]. However, survivors provided important context as to why informational services may not always be effective, even if available. Specifically, Latina survivors were primarily focused on survival during the early phases of treatment. One potential solution may be to integrate financial toxicity in the patient-provider encounter as part of a patient-centered care approach. This approach would involve training healthcare providers to lead a discussion on value in cancer care and to adopt cost-saving strategies in line with clinical recommendations [13, 39]. Of course, if this type of patient-centered care were provider-dependent, disparities would result.

At the interpersonal-level, social networks were considered integral platforms for disseminating information about cancer-related financial resources. Healthcare professionals focused on how networks could provide information to survivors, whereas survivors discussed how *they* themselves had disseminated information to their family members. This knowledge-sharing system may be beneficial for patients embedded within informed social networks. Interpersonal-level interventions would also offer opportunities for Latina survivors to become opinion leaders to their peer survivors. However, such interventions would not be as beneficial for less connected patients and patients who are connected to more misinformed networks.

At the community-level, cultural norms and dynamics were perceived as barriers to seeking financial assistance. Our findings paralleled other research on Latinas and other survivors from marginalized groups [23,24]. However, culturally astute community-based organizations were perceived to reduce these barriers and enhance survivors' readiness to access financial resources. This perspective aligns with growing efforts to eliminate Latinas' disproportionate breast cancer burden through community-based practices and partnerships [40, 41]. Yet, these community resources are not consistently or sustainably funded, leading to disruptions in efforts to address Latinas' financial toxicity.

At the organizational/healthcare policy-level, healthcare professionals and survivors cited the restrictive eligibility criteria of financial assistance programs as barriers to access. Women who were ineligible for assistance reported worse financial stress. As healthcare reform continues to shift, a persistent criticism is the limited dedication to improve the implementation of survivorship care plans with adequate reimbursement schemes [42]. Relatedly, both groups indicated that financial assistance was limited post-treatment. Healthcare professionals further observed that financial assistance programs were typically limited and funding-dependent. These findings align with emerging research on long-term financial toxicity and the lack of resources for long-term survivors [43, 44]. In addition, availability of resources may not entail utilization by Latina patients, due to the potential individual, interpersonal, and community-level determinants described above.

Overall, our work highlights barriers and opportunities to address Latinas' financial toxicity across multiple levels. As noted above, it may be more efficient and effective to implement solutions across multiple levels to comprehensively mitigate financial toxicity. These interventions should aim to: 1) improve knowledge of cancer treatment-related costs through interpersonal networks and community-based resources (e.g. culturally astute community-based organizations); 2) to integrate financial resources in a broader patient-centered cancer care model at the organizational-level; and, 3) codify financial assistance resources throughout survivorship and ensure they are sustainable for all populations at the healthcare policy-level.

While the current study focused on financial toxicity among Latina breast cancer survivors, our work may have helpful implications for survivors from other populations [13, 18, 43]. First, informational determinants may be crucial for all breast cancer survivors, including women's personal knowledge of financial factors (individual-level) and exposure to knowledgeable family/friends (interpersonal-level; e.g., peer survivors, caregivers of patients). Yet, breast cancer survivors from disadvantaged backgrounds may be more limited in their knowledge and have less access to informational supports due to community norms and dynamics. Second, societal marginalization and community-level determinants (norms, dynamics) may be particularly relevant for breast cancer survivors from disadvantaged backgrounds. In the context of societal marginalization, breast cancer survivors from disadvantaged communities may have limited abilities for future or long-term financial planning (individual-level) due to multiple competing needs. For these communities, cancer-related financial toxicity may be one of many financial stressors, restricting women's ability to plan for that specific stressor. Because of their "baseline" impoverished status at individual- and contextual levels, breast cancer survivors from disadvantaged communities may also be more vulnerable to shifts in healthcare policy and organizational capacity that may restrict financial supports [13, 24, 31, 32]. Simultaneously, community dynamics and norms may heighten women's risk of financial toxicity, if there are shared health-averse beliefs that limit disclosure and access of social networks (e.g., fear of burdening networks, cancer-related stigma [45]). Under these circumstances, formal community organizations may be crucial in providing the unmet needs of survivors from disadvantaged communities overall. Third, certain manifestations may be particularly relevant for breast cancer survivors from immigrant communities. For example, community resources that offer linguistic supports may be necessary for immigrant communities whose primary language is not English. Concurrently, immigrant communities may be particularly vulnerable to organizational/health care policies that contain citizenship/immigration-based eligibility criteria.

Limitations

This study had several limitations. First, our scope was limited to Latina breast cancer survivors. There is a need for future parallel research that can offer more nuance regarding which determinants of financial toxicity are shared and are unique to different marginalized groups. Above, we offered a few insights regarding specific factors that may be relevant for health disparity populations overall and other immigrant groups. Future research is warranted to confirm these hypotheses. This study used convenience sampling through

community partners to recruit Latina survivors, therefore our findings may not be generalizable. For example, financial burden may be more severe among patients without access to supportive community-based organizations. Their perspectives should be captured in future studies to adequately characterize financial toxicity in the most vulnerable patient populations to inform timely and targeted interventions. Relatedly, the majority of survivors had undergone a mastectomy (68%) coupled with combination cancer therapy (39%) due to the parent study's overarching aims. Since type of recommended treatment is a predictor of financial toxicity [13], our findings may have been more illustrative of the experiences of patients undergoing invasive cancer treatment. In addition, healthcare professionals self-selected into the study, which may have resulted in a sample with higher awareness or investment in addressing financial toxicity.

Implications

Despite its limitations, this study has several implications for research and practice. Findings from this study demonstrated the value of engaging multiple stakeholders when exploring financial toxicity and associated disparities. Their complementary perspectives specifically provided insights into *how* and *where* to intervene. Indeed, healthcare professionals' characterization of delays in financial planning supported the incorporation of screening for financial burden in clinical practice, which is in line with existing recommendations [13]. Healthcare professionals also denounced the limited availability and instability of financial assistance programs, warranting advocacy efforts at the hospital/organizational and public policy-levels. This study also identified community-level factors as determinants of financial toxicity, more specifically support from culturally astute community organizations. Such findings suggest that leveraging existing community resources in cancer care may be helpful for all communities that are disadvantaged *and* resilient.

Acknowledgments

The authors would like to thank study participants for their time, effort, and perspectives. They would also like to thank Mr. Hunter T. Norris for editorial support. This work was supported by the University of Illinois at Chicago's Institute for Race Research and Public Policy under a 2018–2019 Policy & Social Engagement Fellowship as well as by the National Cancer Institute under grant number K01CA154938. YM was also supported by the University of Illinois Cancer Center and Center for Research on Women and Gender. The opinions or assertions contained herein are the private ones of the authors and are not considered as official or reflecting the views of the National Institutes of Health.

References

1. Ashing K, Rosales M, Lai L, Hurria A (2014) Occurrence of comorbidities among African-American and Latina breast cancer survivors. *J Cancer Surviv* 8:312–318. 10.1007/s11764-014-0342-x [PubMed: 24473830]
2. Fu OS, Crew KD, Jacobson JS, et al. (2009) Ethnicity and persistent symptom burden in breast cancer survivors. *J Cancer Surviv* 3:241–250. 10.1007/s11764-009-0100-7 [PubMed: 19859813]
3. Lockett T, Goldstein D, Butow PN, et al. (2011) Psychological morbidity and quality of life of ethnic minority patients with cancer: a systematic review and meta-analysis. *The Lancet Oncology* 12:1240–1248. 10.1016/S1470-2045(11)70212-1 [PubMed: 21996168]
4. Yanez B, Thompson EH, Stanton AL (2011) Quality of life among Latina breast cancer patients: a systematic review of the literature. *J Cancer Surviv* 5:191–207. 10.1007/s11764-011-0171-0 [PubMed: 21274649]

5. Yanez B, McGinty HL, Buitrago D, et al. (2016) Cancer outcomes in Hispanics/Latinos in the United States: An integrative review and conceptual model of determinants of health. *Journal of Latina/o Psychology* 4:114–129. 10.1037/lat0000055 [PubMed: 27429867]
6. Advani PS, Ying J, Theriault R, et al. (2014) Ethnic disparities in adherence to breast cancer survivorship surveillance care. *Cancer* 120:894–900. 10.1002/cncr.28490 [PubMed: 24258799]
7. Breslau ES, Jeffery DD, Davis WW, et al. (2010) Cancer screening practices among racially and ethnically diverse breast cancer survivors: results from the 2001 and 2003 California Health Interview Survey. *J Cancer Surviv* 4:1–14. 10.1007/s11764-009-0102-5 [PubMed: 19882379]
8. Fedewa SA, Ward EM, Stewart AK, Edge SB (2010) Delays in Adjuvant Chemotherapy Treatment Among Patients With Breast Cancer Are More Likely in African American and Hispanic Populations: A National Cohort Study 2004–2006. *JCO* 28:4135–4141. 10.1200/JCO.2009.27.2427
9. Palmer NRA, Kent EE, Forsythe LP, et al. (2014) Racial and Ethnic Disparities in Patient-Provider Communication, Quality-of-Care Ratings, and Patient Activation Among Long-Term Cancer Survivors. *JCO* 32:4087–4094. 10.1200/JCO.2014.55.5060
10. White A, Pollack LA, Smith JL, et al. (2013) Racial and ethnic differences in health status and health behavior among breast cancer survivors—Behavioral Risk Factor Surveillance System, 2009. *J Cancer Surviv* 7:93–103. 10.1007/s11764-012-0248-4 [PubMed: 23212604]
11. Kale HP, Carroll NV (2016) Self-reported financial burden of cancer care and its effect on physical and mental health-related quality of life among US cancer survivors. *Cancer* 122:283–289. 10.1002/cncr.29808 [PubMed: 26991528]
12. Koskinen J-P, Färkkilä N, Sintonen H, et al. (2019) The association of financial difficulties and out-of-pocket payments with health-related quality of life among breast, prostate and colorectal cancer patients. *Acta Oncologica* 0:1–7. 10.1080/0284186X.2019.1592218
13. Lentz R, Benson AB, Kircher S Financial toxicity in cancer care: Prevalence, causes, consequences, and reduction strategies. *Journal of Surgical Oncology* 0: 10.1002/jso.25374
14. Pearce A, Tomalin B, Kaambwa B, et al. (2019) Financial toxicity is more than costs of care: the relationship between employment and financial toxicity in long-term cancer survivors. *J Cancer Surviv* 13:10–20. 10.1007/s11764-018-0723-7 [PubMed: 30357537]
15. Timmons A, Gooberman-Hill R, Sharp L (2013) The multidimensional nature of the financial and economic burden of a cancer diagnosis on patients and their families: qualitative findings from a country with a mixed public-private healthcare system. *Support Care Cancer* 21:107–117. 10.1007/s00520-012-1498-4 [PubMed: 22987093]
16. Zafar SY, Peppercorn JM, Schrag D, et al. (2013) The Financial Toxicity of Cancer Treatment: A Pilot Study Assessing Out-of-Pocket Expenses and the Insured Cancer Patient’s Experience. *The Oncologist* 18:381–390. 10.1634/theoncologist.2012-0279 [PubMed: 23442307]
17. Blinder VS, Patil S, Thind A, et al. (2012) Return to work in low-income Latina and non-Latina white breast cancer survivors: A 3-year longitudinal study. *Cancer* 118:1664–1674. 10.1002/cncr.26478 [PubMed: 22009703]
18. Jagsi R, Pottow JAE, Griffith KA, et al. (2014) Long-Term Financial Burden of Breast Cancer: Experiences of a Diverse Cohort of Survivors Identified Through Population-Based Registries. *J Clin Oncol* 32:1269–1276. 10.1200/JCO.2013.53.0956 [PubMed: 24663041]
19. Jagsi R, Ward KC, Abrahamse PH, et al. (2018) Unmet need for clinician engagement regarding financial toxicity after diagnosis of breast cancer. *Cancer* 124:3668–3676. 10.1002/cncr.31532 [PubMed: 30033631]
20. Lee M, Salloum RG (2016) Racial and ethnic disparities in cost-related medication non-adherence among cancer survivors. *J Cancer Surviv* 10:534–544. 10.1007/s11764-015-0499-y [PubMed: 26620816]
21. Ashing-Giwa KT, Padilla GV, Bohorquez DE, et al. (2006) Understanding the Breast Cancer Experience of Latina Women. *Journal of Psychosocial Oncology* 24:19–52. 10.1300/J077v24n03_02 [PubMed: 17088240]
22. Buki LP, Garcés DM, Hinestrosa MC, et al. (2008) Latina breast cancer survivors’ lived experiences: Diagnosis, treatment, and beyond. *Cultural Diversity and Ethnic Minority Psychology* 14:163–167. 10.1037/1099-9809.14.2.163 [PubMed: 18426289]

23. Azzani M, Roslani AC, Su TT (2015) The perceived cancer-related financial hardship among patients and their families: a systematic review. *Support Care Cancer* 23:889–898. 10.1007/s00520-014-2474y [PubMed: 25337681]
24. Ashing-Giwa KT, Padilla G, Tejero J, et al. (2004) Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology* 13:408–428. 10.1002/pon.750 [PubMed: 15188447]
25. Zapka JG, Taplin SH, Solberg LI, Manos MM (2003) A Framework for Improving the Quality of Cancer Care: The Case of Breast and Cervical Cancer Screening. *Cancer Epidemiol Biomarkers Prev* 12:4–13 [PubMed: 12540497]
26. Molina Y, Watson KS, San Miguel LG, et al. (2019) Integrating multiple community-based approaches in intervention development. *Health Education Research*. *Health Educ Res*
27. Nevin PE, Blas M, Bayer A, et al. (2019) Positive cancer care in Peru: Patient and provider perspectives. *Health Care for Women International* 0:1–14. 10.1080/07399332.2019.1608206
28. Bernard HR, Wutich A, Ryan GW (2016) *Analyzing Qualitative Data: Systematic Approaches*. SAGE Publications
29. Hsieh H-F, Shannon SE (2005) Three Approaches to Qualitative Content Analysis. *Qualitative Health Research* 15:1277–1288. 10.1177/1049732305276687 [PubMed: 16204405]
30. Lopez-Class M, Gomez-Duarte J, Graves K, Ashing-Giwa K (2012) A contextual approach to understanding breast cancer survivorship among Latinas. *Psycho-Oncology* 21:115–124. 10.1002/pon.1998 [PubMed: 21674680]
31. Wamecke RB, Oh A, Breen N, et al. (2008) Approaching Health Disparities From a Population Perspective: The National Institutes of Health Centers for Population Health and Health Disparities. *Am J Public Health* 98:1608–1615. 10.2105/AJPH.2006.102525 [PubMed: 18633099]
32. Blackman DJ, Masi CM (2006) Racial and Ethnic Disparities in Breast Cancer Mortality: Are We Doing Enough to Address the Root Causes? *JCO* 24:2170–2178. 10.1200/JCO.2005.05.4734
33. Creswell JW, Miller DL (2000) Determining Validity in Qualitative Inquiry. *Theory Into Practice* 39:124–130. 10.1207/s15430421tip3903_2
34. Morse JM, Barrett M, Mayan M, et al. (2002) Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods* 1:13–22. 10.1177/160940690200100202
35. Suri H (2011) Purposeful Sampling in Qualitative Research Synthesis. *Qualitative Research Journal* 11:63–75. 10.3316/QRJ1102063
36. Sandelowski M (2001) Real qualitative researchers do not count: The use of numbers in qualitative research. *Research in Nursing & Health* 24:230–240. 10.1002/nur.1025 [PubMed: 11526621]
37. Sandelowski M, Barroso J (2003) Classifying the Findings in Qualitative Studies. *Qual Health Res* 13:905–923. 10.1177/1049732303253488 [PubMed: 14502957]
38. Carrera PM, Kantarjian HM, Blinder VS (2018) The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. *CA: A Cancer Journal for Clinicians* 68:153–165. 10.3322/caac.21443 [PubMed: 29338071]
39. Yousuf Zafar S (2016) Financial Toxicity of Cancer Care: It's Time to Intervene. *J Natl Cancer Inst* 108:. 10.1093/jnci/djv370
40. Molina Y, Thompson B, Espinoza N, Ceballos R (2013) Breast Cancer Interventions Serving US-Based Latinas: Current Approaches and Directions. *Women's Health* 9:335–350. 10.2217/WHE.13.30
41. Galván N, Buki LP, Garcés DM (2009) Suddenly, a Carriage Appears: Social Support Needs of Latina Breast Cancer Survivors. *Journal of Psychosocial Oncology* 27:361–382. 10.1080/07347330902979283 [PubMed: 19544182]
42. Moy B, Polite BN, Halpern MT, et al. (2011) American Society of Clinical Oncology Policy Statement: Opportunities in the Patient Protection and Affordable Care Act to Reduce Cancer Care Disparities. *Journal of Clinical Oncology* 29:3816–3824. 10.1200/JCO.2011.35.8903 [PubMed: 21810680]
43. Kent EE, Forsythe LP, Yabroff KR, et al. (2013) Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? *Cancer* 119:3710–3717. 10.1002/cncr.28262 [PubMed: 23907958]

44. Pisu M, Kenzik KM, Oster RA, et al. (2015) Economic hardship of minority and non-minority cancer survivors 1 year after diagnosis: Another long-term effect of cancer? *Cancer* 121:1257–1264. 10.1002/cncr.29206 [PubMed: 25564986]
45. Licqurish S, Phillipson L, Chiang P, et al. (2017) Cancer beliefs in ethnic minority populations: a review and meta-synthesis of qualitative studies. *European Journal of Cancer Care* 26:e12556 10.1111/ecc.12556

Table 1.

Study sample demographic and role-specific factors.

	Healthcare professionals (n=10)	Latina breast cancer survivors (n=19)
Demographic factors		
Age (years)		
<40–50	7 (70%)	4 (22%)
51+	3 (30%)	15 (78%)
Gender		
Female	8 (80%)	19 (100%)
Male	2 (20%)	0 (0%)
Race/Ethnicity		
Latina	6 (60%)	19 (100%)
Non-Latina	5 (40%)	0 (0%)
Household language		
Spanish	1 (10%)	16 (84%)
English	6 (60%)	1 (5%)
Spanish & English	2 (20%)	2 (11%)
Other	1 (10%)	0 (0%)
Educational attainment		
< High School	0 (0%)	9 (50%)
High School or more	10 (100%)	9 (50%)
Income		
<\$30,000	0 (0%)	10 (63%)
\$30,000 or more	9 (100%)	6 (37%)
Marital status		
Married	5 (50%)	12 (63%)
Not married	5 (50%)	7 (37%)
Insurance status		
Insured	10 (100%)	12 (67%)
Uninsured	0 (0%)	6 (33%)
Role-specific factors: Patients		
Years since diagnosis		
0–2		6 (34%)
3–5		10 (56%)
6–11		2 (10%)
Surgery type		

	Healthcare professionals (n=10)	Latina breast cancer survivors (n=19)
Lumpectomy		6 (32%)
Mastectomy		13 (68%)
Treatment type		
Chemotherapy only		1 (5%)
Radiation only		3 (17%)
Hormone therapy only		5 (28%)
Surgery only		2 (11%)
Combination		7 (39%)
Role-specific factors: Healthcare professionals		
Occupation		
Social Worker	3 (30%)	
Patient/Nurse navigator	3 (30%)	
Cancer Support Specialist	1 (10%)	
Counselor	1 (10%)	
Other	2 (20%)	
Years working in breast cancer		
0–5	4 (40%)	
6–10	3 (30%)	
11+	3 (30%)	
Years working in financial aspects of breast cancer care		
0–5	5 (50%)	
6–10	3 (30%)	
11–15	2 (20%)	
Proportion of Latina breast cancer patients		
59%	5 (50%)	
60%	5 (50%)	
Proportion of uninsured Latina breast cancer patients		
59%	5 (50%)	
60%	5 (50%)	
Proportion of under-insured Latina breast cancer patients		
59%	7 (70%)	
60%	3 (30%)	

Table 2. Emergent themes and illustrative quotes by socio-ecological model dimension and participant perspective

Socio-ecological model dimension	Healthcare professionals	Latina breast cancer survivors	Populations that may be vulnerable to this determinant of financial toxicity & brief theoretical rationale
Individual	<p>Latinas' limited knowledge about the financial aspects of breast cancer "I had a patient that had insurance and needed to pay \$200 upfront... she couldn't come up with that chunk of money, so she cancelled her appointment... And she told me, I don't have that money. I have insurance, why can't my insurance pay it? I have to go to the counselor and get a little more information and, um, background on how insurance works, and sure enough, the insurance that she has asks not only a copayment, but also a deductible. [...] And she's like, well I didn't know that." (Healthcare Professional Respondent #7)</p> <p>Latinas' limited ability for future or long-term financial planning "You can't force them to apply for certain programs, but you're there to give them that information, provide those guidance and tools, and material for them. [Then,] all of a sudden, you get a call back from them three to four months later and they're like, 'I need your help now.'" (Healthcare Professional Respondent #8) "It's just that um, there are people that just couldn't go beyond thinking long-term and so, financially what would be the impact of this diagnosis on me and should I start asking for help now or should I wait until I get to that point?'" (Healthcare Professional Respondent #3)</p>	<p>Latinas' limited knowledge about the financial aspects of breast cancer "I have a private insurance from my husband... we don't worry about anything, right? But there was a time in which my husband was receiving notices, that he became aware of the actual costs [related to my breast cancer] because they were very expensive." (Survivor Focus Group #1 Respondent #6)</p> <p>Latinas' prioritization of survival over financial aspects "Regarding the money, I didn't even think about it. One would just say 'operate me, so that I can survive from this.'" (Survivor Focus Group #1 Respondent #3) "At that moment when they told me you have cancer, I did not think about how much they would charge me... at that moment it's not when you think about money. You do not think about how much they will charge me, [it's whether] I'll be fine." (Survivor Focus Group #1 Respondent #5)</p>	<p>All breast cancer survivors may suffer without knowledge about financial aspects of cancer. Lack of knowledge may be more common in disadvantaged populations.</p> <p>Breast cancer survivors from disadvantaged communities may be more likely to have to prioritize competing economic needs due to individual/collective poverty.</p>
Interpersonal	<p>Social networks that have lived experiences with cancer can provide Latinas with information about financial resources "I would say maybe 30% of people identify immediately at the point of diagnosis [that they should seek financial assistance], because either they've seen friends, family, neighbors go through this and so they sort of know what's going to happen, or they're just really savvy, they can anticipate their needs." (Healthcare Professional Respondent #1) "I don't think there's enough awareness on their end that these resources exist, and um, what they have to go through to receive these – the financial part... they are immigrants coming into the United States... the only way these resources get around them is when somebody – from what they know, or listen from a radio station or advertisement, that they actually exist... instead of actually going into the web and seeing what's out there, just because they don't have access to those things." (Healthcare Professional Respondent #9)</p>	<p>Social networks that have lived experiences with cancer can provide Latinas with information about financial resources "Now I'm learning so much more with the [support] group because at least I know where to ask [for financial assistance] at least, right?'" (Focus Group #1 Respondent 4) "I'm going to tell my cousin, because in March they removed both her breasts and she paid a lot for her medicine. So, I am going to tell her [about financial assistance]." (Focus Group #2 Respondent #6) "I have sent people who also do not have insurance to [social worker name]." (Focus Group #2, Respondent 7)</p>	<p>All breast cancer survivors may benefit from social networks with relevant lived experiences. Disadvantaged populations may not have as much access to such informed peers.</p>
Community	<p>Community norms and dynamics regarding documentation negatively affect Latinas' willingness to access resources "I had one patient before whose concept of applying for disability is so embarrassing that she would not want to do it until her savings were depleted." (Healthcare Professional Respondent #3) "There's a little bit of pride in asking for help. I've had so many situations... patients have said, well I don't want to ask for help, like I don't want to go to public aid and ask for help. I've worked hard all my life, I don't want to ask for help, I don't want to be one of those people... I think not having forms or organizations with enough bilingual Spanish speaking staff [is a problem], when they [Latina breast cancer</p>	<p>Culturally astute Latino community-based organizations facilitate Latinas' willingness to access resources "I am going to call and ask what is covered because it is important to know and there's people that speak Spanish. If you don't get something let them know and tell them to explain it again." (Focus Group #2 Respondent #6) "Thanks to the girls from [a Latino community-based organization] who are our angels. They have helped us</p>	<p>Breast cancer survivors from disadvantaged communities may be more likely to experience health-averse community norms and dynamics. Breast cancer survivors from immigrant communities may in particular experience health-averse community</p>

<p>Socio-ecological model dimension</p>	<p>Healthcare professionals</p>	<p>Latina breast cancer survivors</p>	<p>Populations that may be vulnerable to this determinant of financial toxicity & brief theoretical rationale</p>
<p>survivors] do actually get the resource and call in, or make the connections to call in. If someone on the other line spoke Spanish I think it'd be helpful for them." (Healthcare Professional Respondent #6)</p> <p>"I think documentation status, especially for Latina women [is a barrier to seeking financial assistance]. Even if they themselves are documented, if their husband or partner or whoever is not, I think that they are just afraid to be on anyone's radar in any point of time... Sometimes their documentation status or family members' documentation status comes into play. We hear a lot of that. Certainly could be a cultural thing, I think it could be a mix of things for different people." (Healthcare Professional Respondent 1)</p>	<p>Programs' eligibility criteria make them inaccessible for Latinas</p> <p>"There were people in the middle that maybe did have insurance but didn't have a lot of other resources [due to ineligibility], that they could afford kind of a financial hit that cancer provides most of our folks." (Healthcare Professional Respondent #4)</p> <p>"We use 4 times the federal poverty limit for whether or not somebody would be eligible... we also know that somebody may, on paper, have a good disability benefit, or they have money coming into the house, but most homes these days – or households these days – are dependent on usually 2 or 3 salaries, so regardless of the size of them, if one of them is missing or significantly reduced, that just stresses everything else." (Healthcare Professional Respondent #2)</p>	<p>a lot, they are always helping us with appointments—they simply help us fill out papers to see if we qualify or do not qualify. But thanks to them. They are the ones who are helping us a lot, we thank them." (Focus Group #1 Respondent #3)</p>	<p>Populations that may be vulnerable to this determinant of financial toxicity & brief theoretical rationale</p> <p>dynamics and factors related to non-citizenship status and limited English proficiency.</p>
<p>Organizational/Health-related policy</p>	<p>Limited availability of financial assistance programs post-treatment negatively impacts Latinas</p> <p>"When the patient have cancer and they need all those services like chemo, wigs, prosthesis, and that one, [federal program name] don't cover that." (Healthcare Professional Respondent #5)</p> <p>"There's not a lot of financial resources that assist people that are post treatment. I think unfortunately, in some ways, the medical community, but definitely in the world, I think survivors feel this expectation [from others] to just rejoin society and go back to normal and so we see that a lot in the resources as well. They sort of cut off after you're done with treatment." (Healthcare Professional Respondent #4)</p>	<p>Latinas who are not eligible for programs suffer worse financial burden than eligible counterparts</p> <p>"Because we are a low income family the coverage is up to the sky. When you are low income the coverage is 100% but when you aren't, low income then you have to pay." (Focus Group #2 Respondent #2)</p> <p>"I was diagnosed this past October... and there's a lot of things we have to worry about including economically plus or well-being... when you have health insurance, costs are higher because you don't qualify as low income or having insurance or etc. and well sometimes you have too many bills." (Focus Group #2 Respondent #9)</p>	<p>Breast cancer survivors from disadvantaged communities may be more likely to be ineligible for assistance, while needing support due to their status as "underinsured."</p> <p>Breast cancer survivors from immigrant communities may not be eligible for insurance due to their non-citizenship status.</p>
<p>Limited availability and instability of financial assistance programs</p> <p>"They [foundations] have so much [funding] and they have so many applications that month and then, that's it. So, they have to close it until they save enough again. [...] You'll find out if they are funding or not because sometimes, they're not and they'll say, "we will open again next year." Which, it doesn't help the patient because this is when they need it." (Healthcare Professional Respondent #3)</p> <p>"We also have here... a patient assistance fund... that fund has helped with everything from buying winter boots and a winter coat... to helping somebody pay for rent, or utilities, or pharmacy copay as the case might be. It's a very flexible fund, it can be used to plug a hole that we can't find anything else for. But we're limited, it's not a huge fund. We have a finite amount that we can help with any one patient with during a given calendar year." (Healthcare Professional Respondent #2)</p> <p>"You have to apply for that [program's] application annually. And stuff changes annually. And it's very stressful. A patient can have 100% coverage this year, and next year even though she's in the middle of her treatment, she can get 20%... [Latinas]</p>	<p>Limited availability of financial assistance programs post-treatment negatively impacts Latinas</p> <p>"We were left with nothing... then you are in recovery. Every time I went to the doctor after the operation, the nurse told me, 'You have this [bill]!' I would say, 'Look, please right now I am not working.'" (Focus Group #1 Respondent #4)</p>	<p>Breast cancer survivors from disadvantaged communities may be particularly vulnerable to limited assistance programs due to individual/collective poverty.</p>	<p>Breast cancer survivors from disadvantaged communities may be particularly vulnerable to limited assistance programs due to individual/collective poverty.</p>

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Socio-ecological model dimension	Healthcare professionals	Latina breast cancer survivors	Populations that may be vulnerable to this determinant of financial toxicity & brief theoretical rationale
	They understand like, if I don't get approved, there's no way I can afford it. It's not even a question.' (Healthcare Professional Respondent #10)		