

“I Felt Defeated. I Felt Helpless”: Social Determinants of Health Influencing the Cancer Survivorship of a Young Latina Mother

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Abstract

Social determinants of health (SDOH) contribute to cancer disparities among young Latina women (<50 years) residing in the counties along the US-Mexico border. These SDOH are particularly burdensome to young Latina mothers diagnosed with cancer while they are raising school-age children. *Conexiones*, a culturally adapted program designed to improve mother and child adjustment to maternal cancer, was piloted with diagnosed Latina mothers residing in border counties in New Mexico and Texas. The purpose of this case analysis was to highlight the SDOH affecting a young Latina mother’s cancer survivorship in the U.S.-Mexico border region. The participant’s *Conexiones* education sessions were recorded, transcribed, translated to English, back translated to Spanish to establish accuracy, and inductively coded. The participant’s baseline survey indicated she was a young (<50 years), married, Spanish-speaking Latina mother diagnosed with breast cancer while raising a teenage daughter. Seventeen SDOH themes affecting the participant’s cancer experience were identified in the cancer-related emotional triggers she reported across five *Conexiones* sessions. These themes were organized using Yanez’s conceptual model of determinants of cancer outcomes in Hispanics (*i.e.*, socioeconomic, healthcare, cultural context, and psychosocial). Findings provide direction for cultural adaptations of evidence-based programs.

Keywords

Cancer Survivors, Latinas, Social Determinants of Health, U.S.-Mexico Border

1. Introduction

Public health officials recognize the contribution of geographic location, race/ethnicity, and socioeconomic status to health disparities [1]. Cancer disparities driven by social determinants of health (SDOH) are evident among young Latina women (<50 years) living in counties along the US-Mexico border region. Significant proportions of Latinas on the border experience poverty and lack insurance, limiting their cancer treatment options and elevating their stress levels [2] [3]. Differences in culture, language, and health literacy also result in poor patient-provider communication for young Latinas on the border [2] [4]. The scarcity of cancer health services in medically underserved border regions requires greater travel distance to healthcare facilities for cancer treatment. Combined, these SDOH can exacerbate disparities in cancer incidence, mortality, and survivorship among young Latina women on the border [2] [5] [6].

Many young adult survivors (<50 years) are raising school-age children at the time of their diagnosis [7]. Diagnosed child-rearing women experience greater cancer burden, psychological distress, and fear of recurrence than those without children [8]. Latina survivors also report distress associated with the impact of cancer on their children [9]. Culturally relevant psychosocial support is lacking for these young Latina mothers diagnosed with cancer [9].

Interviews with young Latina cancer survivors (YLCS) informed the cultural adaptation of *Enhancing Connections* [10], an evidence-based intervention (EBI), designed to improve mother and child adjustment to maternal cancer [9] [11]. Latina mothers then evaluated the culturally-adapted program (renamed *Conexiones*) for cognitive, cultural, and environmental fit for YLCS living in the border region, contributing to further refinement [12]. The subsequent *Conexiones* pilot test revealed additional SDOH that could potentially confound the program's primary outcomes to reduce cancer-related depression and anxiety in the diagnosed Latina mother and her child. The purpose of this case analysis was to describe the SDOH disclosed by a YLCS participating in the *Conexiones* pilot study.

2. Methods

2.1. Procedure

After receiving New Mexico State University IRB Approval (#16122), Latina mothers were invited to participate if they were diagnosed with early-stage cancer in the past two years, raising a school-age child, living in New Mexico or Texas border counties, and able to read and write in their preferred language (*i.e.*, English or Spanish). The study design included a baseline survey, five bi-weekly education sessions, and a post survey, all completed by telephone in the participant's preferred language. Survey measures included demographics (*e.g.*, ethnicity, income, and marital status), a short acculturation scale [13], the State Trait Anxiety Inventory [14] [15], and the Center for Epidemiological Studies Depression Scale [16] [17]. All education and assessment sessions by phone

were audio recorded.

Eighteen participants completed each of the five *Conexiones* education sessions where they reported cancer-related emotional triggers they had experienced [18]. A single case meeting the eligibility criteria for the pilot study was selected for this qualitative analysis to gain a better understanding of the SDOH impacting a YLCS in the U.S.-Mexico border region. The selected YLCS reflected the population with whom we were working in the pilot study and provided rich in-depth information regarding the SDOH impacting her cancer survivorship experience [19].

For this analysis, her audio recorded sessions were transcribed, Spanish sessions were translated to English and translated back to Spanish to ensure accuracy, and uploaded into ATLAS.ti, a qualitative analysis software.

2.2. Analysis

Using an inductive analysis process, four researchers established the units of analysis and identified prominent themes (*i.e.*, categories of SDOH) across the units [20]. Categories were carefully reviewed, defined, and used to code the units. A conceptual model of SDOH for cancer in Hispanics was then applied to organize categories into sociocultural, cultural, psychosocial, and healthcare dimensions [2] [21]. Coding to consensus, peer debriefing, and maintaining audit trails protected the trustworthiness of the analysis [22].

3. Results

Carmen (pseudonym for the YLCS) was under 50 years of age and reported being a married, low income, Spanish-speaking Latina mother of a young teenage daughter, Lola (pseudonym). Carmen was diagnosed with breast cancer before age 50 and her anxiety and depression scores exceeded clinical levels. From the cancer-related emotional triggers she reported during her participation in the five *Conexiones* sessions, the researchers identified SDOH themes affecting Carmen's cancer experience. These were organized using Yanez's conceptual model of determinants of cancer outcomes in Hispanics (*i.e.*, socioeconomic, healthcare, cultural context, and psychosocial) [2].

3.1. Socioeconomic

Three categories were organized within the socioeconomic determinant.

3.1.1. Living in a Shelter

Carmen disclosed difficulties her daughter experienced while living in a shelter. She stated, "I had noticed that she seemed disoriented from having to move [from shelter to shelter]."

3.1.2. Not Having Insurance

As she reported losing her insurance, Carmen emphasized her immigrant experience. She described canceling medical appointments even after discovering a

new lump and enduring untreated pain. “It’s how I see myself as an immigrant, that I can’t find resources, I don’t have insurance.”

3.1.3. Going through Domestic Violence

Struggling through treatment and recovery, Carmen maintained being unable to return to the abusive relationship despite her partner’s insistence. “He said...that he would always be there for me...even though I’m not with him...He wants me to forgive him for hurting me.”

3.2. Healthcare

Two categories were organized into the healthcare determinant.

3.2.1. Being My Doctor for Everything [PCP]

Carmen shared feeling comfortable with and trusting her primary care provider. “I feel like...my primary care doctor...knows me better than I know myself.”

3.2.2. Having Three Months to Live

Despite an early-stage cancer diagnosis, Carmen described a poor prognosis after communicating with her oncologist via interpretation by her social worker. “The oncologist talked to her [social worker] about the condition I was in...and that I would have three months to live, at the most.”

3.3. Cultural Context

Seven categories were organized in the cultural context determinants.

3.3.1. Needing to Tell My Children [About the Cancer]

After months of encouragement from her oncologist and social worker, Carmen told her children about her cancer diagnosis. “I told her [social worker] that I don’t know how to talk to my daughter. I can’t find a way. I just don’t know.”

3.3.2. Seeing My Daughter Suffer

Carmen described her daughter’s anguish over their predicament (e.g., diagnosis, uninsurance, homelessness). “When I said the word ‘cancer,’...She just sat there, and tears started going down her face. I was heartbroken...she locked herself up for two days...and didn’t talk to me...I could tell that she was suffering.”

3.3.3. Wondering What Will Happen to Her [Lola] If I Die

After learning Lola’s father would not take responsibility for their daughter, Carmen reported deliberating Lola’s living options should she die. “Sometimes she asks where she will go, who she will stay with...What is going to happen with her?” Carmen stated Lola preferred foster care placement in the U.S. rather than living in Mexico with her sister.

3.3.4. Supporting My Daughter

Carmen described protecting Lola following her diagnosis, such as concealing

cancer-related information and emotions while providing comfort. “I wanted to cry, but toughed it out because, well I had told her that she is my support and that I was her support.”

3.3.5. Being Overprotective of Me

After sharing her diagnosis with Lola, Carmen reported her daughter worked to lessen their worries. “She’s looking for ways to get a proof of address and things like that. And so that has been stressful for her and she tells me, “That’s okay, what matters is that you are okay mom.”

3.3.6. Talking to My Daughter [About Cancer]

Carmen described talking to Lola about cancer (*i.e.*, risk factors, causes, and survival). “I told her that it’s going to be okay, that there are a lot of people that survive cancer.”

3.3.7. Having Faith in God

After her cancer diagnosis, Carmen referenced praying and having faith in God. “I told her [Lola] that she needed to have more faith because faith can move mountains, and next week I’ll have my results and I have faith in God that everything will be okay.”

3.4. Psychosocial

Five categories were organized into the psychosocial determinants.

3.4.1. Feeling Helpless

Carmen shared feeling helpless due to her cancer and other stressful life events. Carmen explained, “[While at an appointment] There was a moment where I sat down, and I cried an ocean of tears...I couldn’t stop feeling like that.”

3.4.2. Having Severe Depression

After her cancer diagnosis, Carmen expressed concerns about taking antidepressants for clinical depression. “She [Doctor] said...not to skip them...and that you will not become dependent on the medication, no, it doesn’t mean you’re an addict. You have to take them.”

3.4.3. Needing Support

Carmen mentioned not having anyone to talk to about cancer-related problems and wanting moral support from a partner. “I’m in this situation only with her [Lola], without any...moral support.”

3.4.4. Trying Not to Show It

Carmen tried to hide her emotions and sense of helplessness from others. “I sat down and said, ‘I don’t want anybody seeing me like this.’”

3.4.5. Having to Fight This

Carmen shared needing to overcome the cancer and survive. “I said to myself, I’m not going to be another statistic...I have to fight this.”

4. Discussion

When asked to report her cancer-related emotional triggers during her participation in the *Conexiones* program, Carmen revealed she and her daughter were struggling to meet basic (*i.e.*, safety and physiological needs) and psychological needs (*i.e.*, social support) known to influence cancer survivorship among Latinos [2] [23]. After leaving her abusive husband, Carmen and Lola ended up in a shelter without financial resources or social support. In this state of economic and environmental instability, Carmen's cancer diagnosis left her feeling helpless. Exacerbating her situation, Carmen lost her insurance and continuity of care in the middle of her cancer treatment. These events are consistent with findings that women leaving abusive relationships are more vulnerable to poverty, uninsurance, limited social support, and poor cancer outcomes [24].

Compounding her distress, miscommunication with providers led Carmen to believe that she only had three months left to live, despite an early cancer diagnosis. Prior research shows that communication about cancer diagnosis and treatment among Latinas is hindered by cultural misunderstanding and language barriers [2] [4]. With no family nearby, Carmen reported needing support (*e.g.*, moral, financial) and desiring support from a partner. In a previous study, Latina immigrant cancer survivors shared feeling lonely and isolated from friends and family back home [25]. While a cancer diagnosis is agonizing for anyone, the interaction of socioeconomic, healthcare, and psychosocial determinants appeared to intensify Carmen's distress, putting her at risk for poor quality of life and negative cancer outcomes [2] [26].

Upon disclosing her diagnosis to Lola, Carmen expressed concern over the emotional pain her teenage daughter exhibited, including the fear of being left alone should Carmen die. Without paternal placement as an option, Carmen considered placing her daughter with relatives in Mexico. This was unacceptable to Lola since she did not want to leave the U.S., a common sentiment among children of immigrants [27]. Unable to protect Lola from this emotional pain, Carmen feared her daughter was missing out on her childhood. With guidance from her *Conexiones* health educator, Carmen was able to create a space where Lola could share her feelings about her mother's cancer and fears of losing her mom to cancer. Carmen also encouraged Lola to be optimistic, have faith in God, and focus on school while providing her support and reassurance.

Carmen's diagnosis of severe depression is consistent with past findings that Latina cancer survivors often experience depression and poor quality of life [28] [29]. Not wanting to be another statistic, she became determined to fight the cancer, a resiliency common among Latina cancer survivors [9] [30].

Limitations

Given this is a case study, findings cannot be generalized. While Carmen may not represent all YLCS in the U.S.-Mexico border region, she described multi-faceted, complex issues that may impact other YLCS' participation in cancer

education and their overall cancer survivorship. This information is helpful to future studies and interventions that attempt to address cancer health disparities among the U.S.-Mexico border.

5. Conclusions

Negative SDOH, like those highlighted in this case study, may account for the higher levels of depression and lower quality of life in Latina cancer survivors reported in previous studies [28] [29]. While a rigorous cultural adaptation and community evaluation made the *Conexiones* cancer education program more relevant and engaging for YLCS in the U.S.-Mexico border region [12], this case analysis revealed SDOH affecting cancer survivorship and pilot program outcomes (*i.e.*, psychosocial well-being). In response, researchers incorporated bilingual, low-cost social services into the existing cancer resource directory for *Conexiones*. Researchers also created protocols directing participants to these resources at the end of education and survey sessions to complement *Conexiones* while protecting program fidelity. When implementing cultural adaptations of EBIs, researchers need to screen for SDOH given their potential to moderate program impact and health outcomes.

Given the rapid growth of the U.S.-Mexico border region observed in recent decades [31] [32], we can expect increasing numbers of Latino cancer survivors and a greater need for survivorship education and services tailored to their needs. This case analysis highlighted the need for researchers to address SDOH as they culturally adapt EBIs for this underserved population on the border. This may require developing strong relationships with social service providers to refer cancer survivors experiencing adverse SDOH [33]. This will ensure they are meeting regional needs and addressing health disparities among this priority population.

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Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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