



Avoidable tragedies: Disparities in healthcare access among medically underserved women diagnosed with cervical cancer[☆]



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HIGHLIGHTS

- Barriers to care between early and locally advanced cervix cancer
- Health Beliefs Inventory, Literacy test, and Health Locus of Control Scales
- Late-stage Cervix Cancer associated with more ER visits and lack of primary care provider

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ABSTRACT

Background. The purpose was to identify barriers including logistical and health belief correlates of late stage presentation of cervical cancer (CxCa) among medically underserved women presenting to a safety net health care system.

Methods. Women presenting with newly diagnosed CxCa were asked to complete a detailed health belief survey that included questions about barriers to care and their knowledge of CxCa. All information was collected prior to initiating cancer treatment. Comparisons were made among women diagnosed at early stages of disease amenable to surgical treatment (\leq IB1) and those diagnosed at a stage requiring local-regional or systemic/palliative treatment (\geq IB2).

Results. Among the 138 women, 21.7% were diagnosed with \leq IB1 disease, while 78.3% were diagnosed with \geq IB2 disease. Late-stage diagnosis was associated with a greater number of emergency room (ER) visits ($p < .001$) and blood transfusions ($p < .001$) prior to diagnosis. Compared to 88% with \leq IB1 disease, only 53% of patients with \geq IB2 disease had a car ($p = .003$). Women with \geq IB2 disease were more likely to be without a primary care provider (75.0% vs. 42.3%, $p = .001$).

Conclusion. Access to transportation and lack of a regular primary care provider or a medical home are associated with late-stage of CxCa at diagnosis. Many medically underserved women continue to use the ER as their primary source of health care, and as a result their CxCa is diagnosed in advanced stages, with higher medical costs and lower chances of cure. The lack of Medicaid expansion in Texas may result in a worsening of this situation.

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1. Introduction

When cervical cancer (CxCa) is diagnosed in an early stage (\leq IB1), surgical intervention is curative in 92% of cases [1,2]. In contrast, locally advanced and advanced stage cancers (\geq IB2) require 8 weeks of combined chemotherapy and radiotherapy. Although stage \geq IB2 can sometimes be cured, treatment is often associated with significant acute and long-term adverse effects, greater emotional stress and financial burden, and decreased overall survival [1, 3]. Five year survival rates for

patients with stage II disease are approximately 60–70% and for stage III can be as low as 30–50% [4]. Unfortunately, women who have received inadequate screening for CxCa often present with advanced stage disease, and as a result, are faced with limited treatment options and significantly reduced survival rates [1,2,5].

The single most important contributing factor to the development of invasive CxCa is a paucity of screening [6–9]. No cancer illustrates the socioeconomic and gender disparity of health care more than CxCa [8, 9, 10]. CxCa contributes to approximately 25% of cancer deaths in some minority populations [11]. Multiple factors contribute to this difference, including comorbid factors, lack of care access, underutilization of Pap/HPV screening tests, lack of health knowledge, and fear, shame, and cultural issues [12–16].

Locus of control (LOC) is a theory that categorizes the way in which individuals perceive the forces influencing their life [17]. The LOC is composed of two factors: internal control and external control. Internal control represents the perception that outcomes are determined by one's own actions [17]. External control is the perception that outcomes are controlled by outside factors (i.e. chance or powerful others) [17]. The chance subcategory represents “luck,” “fate,” or a random occurrence that controls events: powerful others represents “other” individuals in a position of power such as a superior, a physician/provider, or a deity [17]. Prior research has suggested that a high internal LOC is associated with positive health habits [18–22].

Houston, Texas (Harris County), as the fourth largest city and one of the most ethnically diverse cities in the United States, provides an excellent setting to evaluate access to cancer care among indigent patients [23]. Prior to roll out of The Affordable Care Act (ACA) in 2013, Harris County was home to more uninsured residents than almost any other county in the US [24,25]. Fortunately, in Harris County, county residency status alone permits some to obtain preventative, diagnostic, and treatment care at multiple settings throughout the city of Houston. Despite this, many with CxCa in the Harris Health System (HHS), a public hospital system, are diagnosed with advanced stage disease. The HHS supports 23 community health centers, five school-based clinics and two full-service hospitals that provide care for under/uninsured residents and uses a payment system tailored to patient's income. Of those that visit the hospital, approximately 25% are African-American and 60% are Hispanic [26]. The goal of this prospective study was to determine if there was a difference in perceived logistical barriers to care, health beliefs and health LOC in those who were diagnosed with early stage CxCa (\leq IB1) compared with those with locally advanced disease (\geq IB2).

2. Methods

2.1. Patients

The University of Texas MD Anderson Cancer Center and the Lyndon Baines Johnson (LBJ) Hospital granted IRB approval. From 2006 to 2013, screening the new patient lists permitted identification of women with newly diagnosed invasive CxCa. Women were eligible if they were \geq 18 years of age and spoke English or Spanish. A research coordinator explained the purpose of the study and all women provided written informed consent.

2.2. Survey instruments

Demographic information was collected including age, race, nationality, preferred language, ability to speak and/or read English, education level, employment status, marital status, date of diagnosis, stage, household income, number of children, and basic CxCa knowledge.

Patients completed a Modified Health Beliefs Inventory modeled after a questionnaire by Byrd et al. [27], a Test of Health Literacy in Adults (TOFHLA) [28,29, 21]], and the Multidimensional Health Locus

of Control (MHLC) Scales [21,30]. The health belief survey (HBS) questions were designed to understand the patient's level of knowledge about causes of CxCa and also about initial symptoms leading to treatment. Patients were asked about factors that could interfere with decision to seek care and receipt of timely cancer treatment [27]. Questions were asked using a Likert scale indicating “not a problem”, “a little bit of a problem”, “a medium problem”, and “a big problem”; “a medium problem” and “a big problem” were combined into one category. The TOFHLA consists of 36 questions and is available in both English and Spanish. Scores range from 0 to 36, where higher scores reflect better health literacy [21]. The MHLC Scale, Form C is a validated, 18 questions LOC instrument designed to understand whether a person with a specific health condition believes primarily in individual control or that of a powerful other, or chance has the largest influence on their fate. This instrument measures 4 subscales of LOC: internal (self-determination of a healthy lifestyle) and external: chance (luck), doctors, and other people (others who may influence health outcome) [31]. The LOC scale measures an individual's attitudes toward death related topics. Higher scores reflect stronger perception of control within the dimension.

Patients could ask that survey questions be read to them instead of completing written surveys. The surveys took approximately 30 min to complete. Patients were given a \$10 gift certificate at the time of completion. To be considered “evaluable” patients, each must have completed at least 50% of the questions on each survey.

2.3. Statistical analysis

Descriptive statistics were calculated to present demographic and clinical characteristics of the study population, as well as survey responses. Chi-square and Fisher's exact tests were used to evaluate differences in characteristics and survey responses between women with advanced (\geq IB2) and early stage (\leq IB1) disease.

3. Results

3.1. Demographics and healthcare access and utilization

The final study population consisted of 138 patients. Eighteen patients were lost to follow up and were excluded. Demographic characteristics are summarized in Table 1. We did not collect information on the people who declined participation. We can however report that this number was less than 5 total individuals and reasons were related to lack of symptom control at the time of visit. The median age was 46.2 years (range 24.9, 72.3) and 55.1% were Hispanic and 25.4% Black; 21.7% were diagnosed at \leq IB1, while 78.3% were diagnosed with \geq IB2 disease. The median time between diagnosis and enrollment was 4.3 weeks (mean 6.3 weeks). There were no statistically meaningful differences between stages regarding age, race, ethnicity, body mass index (BMI), primary language, education level, smoking status, or partner (relationship) status. Sixty percent did not have a computer and 68% did not know how to use the internet. Thirty seven percent did not have a driver's license and 39.4% did not have a car. This significantly differed by stage: 52.4% with \geq IB2 had a car vs. 88% of \leq IB1. ($p = .001$) Twenty six percent reported having to care for other family members, 14% \leq IB1 and 30% \geq IB2 ($p = .078$). The distribution of annual household income is shown in Table 2. Thirty-nine percent reported an annual household income of \$10,000 or less. Overall, 30.5% were employed at the time of diagnosis (47% \leq IB1, 25.5% \geq IB2 $p = .028$).

3.2. Screening and symptom history

Table 3 details screening and symptom history in both groups of disease stages.

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