

# 'Queremos tener las cosas ocultas pero pienso que también somos guerreras': Non-disclosure and Secrecy among Latina Breast Cancer Survivors

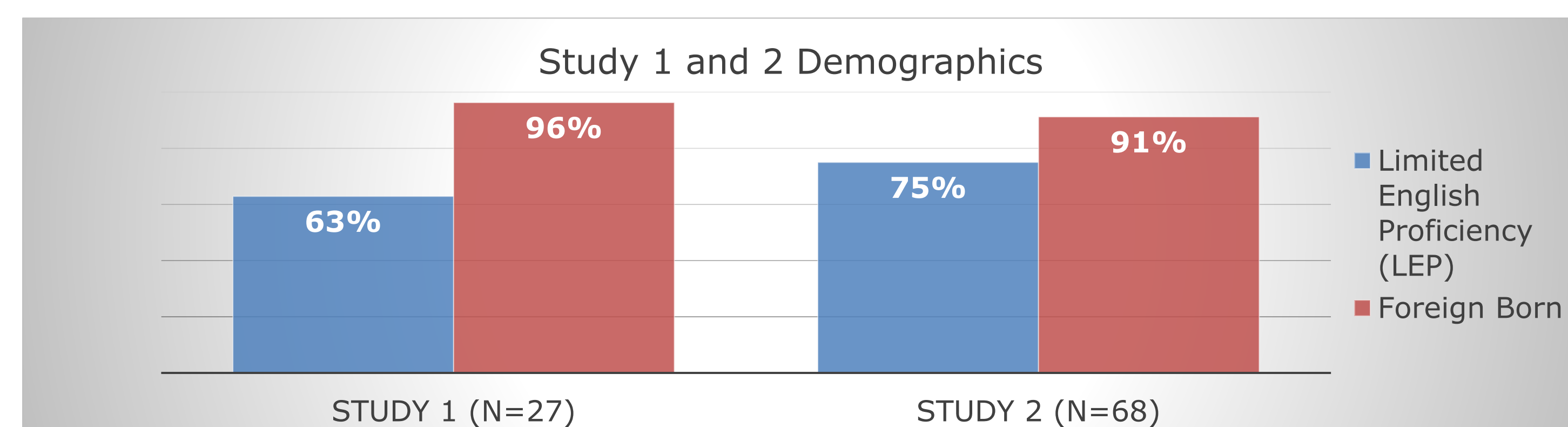
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## Background

An estimated 19 million cancer survivors is projected by 2024, an increase of 31%.<sup>1</sup> Breast cancer is the most common cancer among Latina/Hispanic women (incidence rate 93.0 per 100,000) with a 5-year cause-specific survival rate of 87.0%.<sup>2,3</sup> Over two-thirds of Latina women diagnosed with breast cancer experience distress such as depression and anxiety<sup>4,5</sup>, which can negatively impact quality of life, treatment adherence, and overall survivorship. Yet, mental health services are underutilized, especially among Latinos. An examination of two exploratory studies with Latina breast cancer survivors (LBSC) revealed an emerging, culturally informed theme of non-disclosure and secrecy surrounding cancer diagnosis that exacerbated distress. This presentation examined non-disclosure and secrecy among LBSC and its role in cancer survivorship and mental health. For this study, non-disclosure refers to not sharing personal information to others (e.g., formal and informal supports).

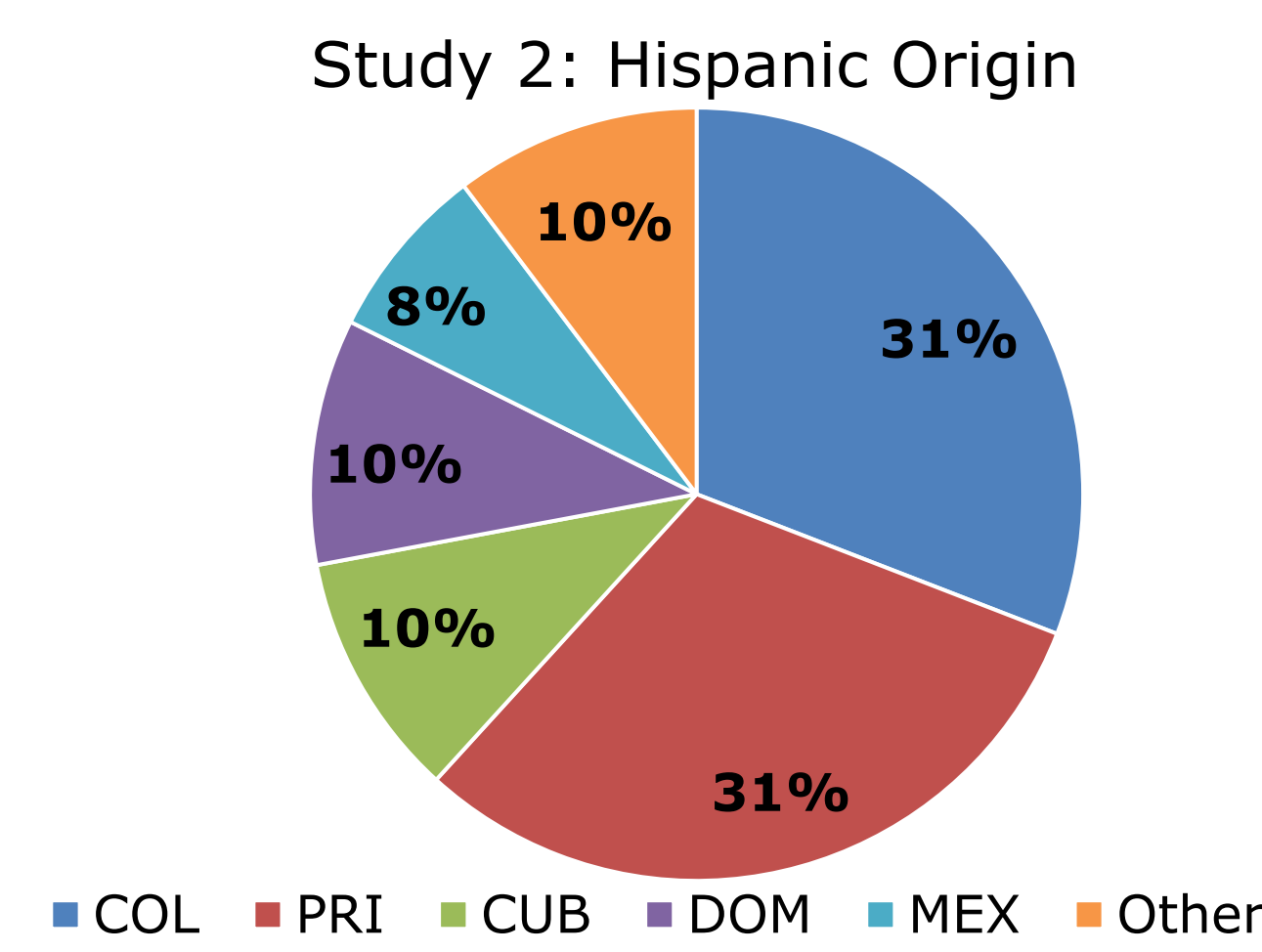
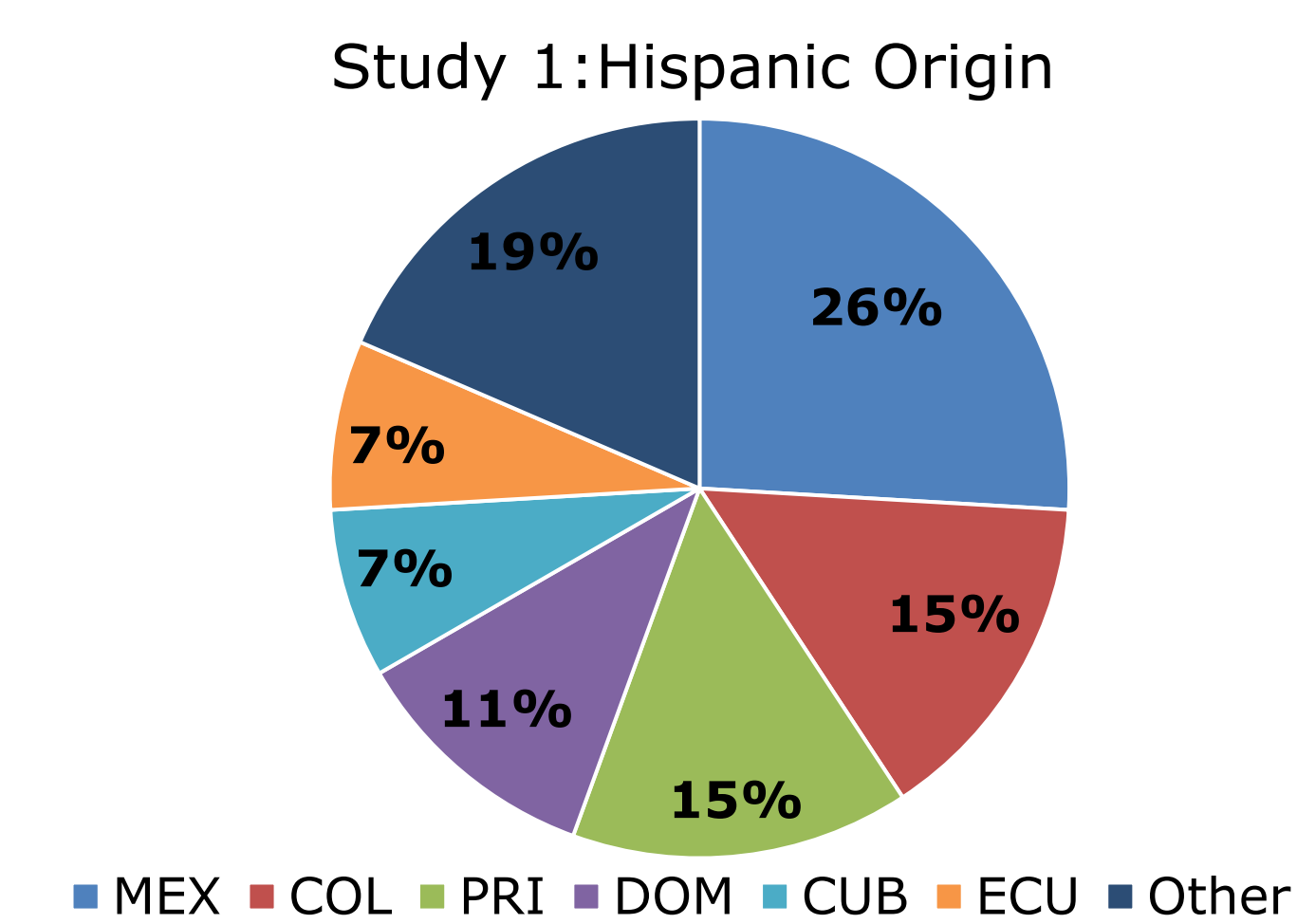
## Study Sample

Study sample was drawn from two studies with LBSC. Participants included in this analysis were LBSC residing in West Central Florida. Women were within 5-years of initial breast cancer diagnosis and at least 18 years of age. All participants were self-identified as Latina/Hispanic.



- Study 1**
- mean age=49 (SD, 10.76)
  - women undergoing primary treatment were excluded

- Study 2**
- mean age=55.4 (SD, 10.4)
  - women with an ECOG performance status ≥4 and women with recurrent cancer were excluded



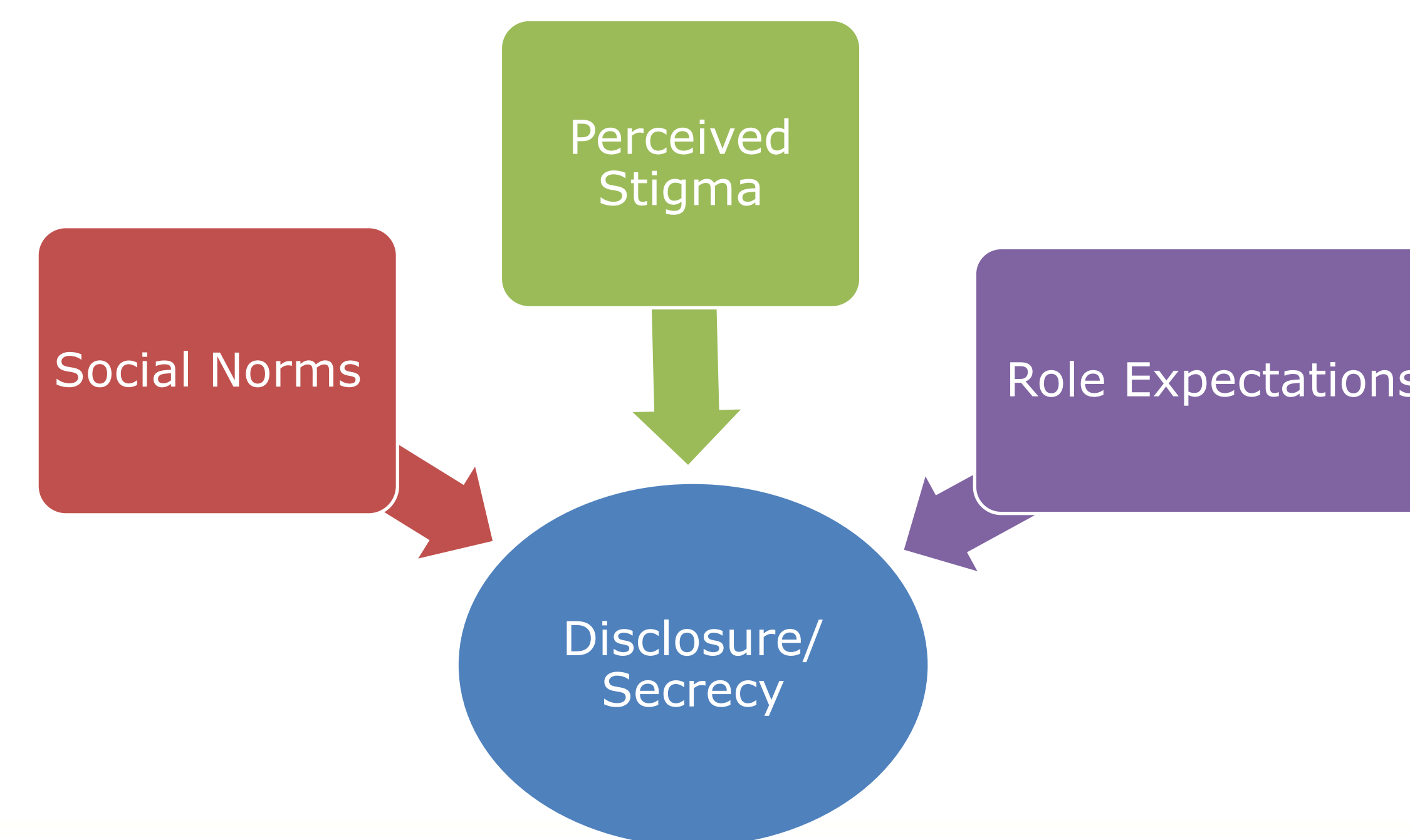
## Methods

Drawing from in-depth, semi-structured interviews (n=95) gathered during two studies with LBSC in west central Florida, this presentation analyzed the emerging theme of non-disclosure and secrecy through axial coding, focusing on how it impacted coping strategies, sources of support, and help-seeking behavior. Both studies utilized purposive and snowball sampling. Women were grouped according to region of origin: Latin America, Spanish Speaking Caribbean, and Mexico/ Central America.

## Results

Resistance to disclosure was linked with a variety of motivators (i.e. desires to avoid burdening family and fears of stigma).

Non-disclosure and Secrecy Motivators	
Social Norms	"...We are women, who in reality are sensitive, we often handle issues of modesty and shame/embarrassment, we handle moral values and often want to keep things hidden but I think that we are also warriors..." [Latin America] "Latinas are very reserved and do not want to open such a super vulnerable thing." [Caribbean]
Perceived Stigma	"...I went out after my treatments, I saw people move from the [store] line I was at to another or did not want to be close to me. I know it is because of my physical appearance...They would see my color compared to everyone else and I did not have hair." [Caribbean]
Role Expectations (i.e. staying strong, worry for family)	"...We are Latinas we are strong women; we are supposed to be strong for our kids or grandkids or for everybody; we are not supposed to be weak [Caribbean] "...especially when to going through the treatment...felt a little lonely and I didn't want to ask for help...I thought I was supposed to be strong and just keep going like everybody else..." [Caribbean] "...On one hand I had fear, but on the other hand I wanted to act strong because I never like for my family to suffer for me..." [Mexico/ Central America]



## Results Continued

Non-disclosure/ secrecy functioned as impediments to seeking formal mental health services and informal support from family and friends which further compounded distress. Among some women, disclosure led to positive outcomes such as catharsis.

"...we, as Latinos withhold all of our things for ourselves and do not share them, we don't get them out and that causes damage inside, that hurts more inside..." [Latin America]

"Many times the person is diagnosed with cancer and they remain silent, they do not want to tell anyone, they do not want anyone to speak to you of that, they don't want to know. However, we must talk about it, you must say what's wrong, what's happening to you, because if you don't talk, if you don't tell me what you feel then I'm not going to know." [Caribbean]

"I have seen many people, including people I know who have different types of cancer and they don't say anything to the family. They are afraid, feel guilty, but if you haven't done anything wrong why feel [this]. They hide it completely and not tell anyone they are struggling alone...They tell me exactly that they do not want the family to suffer and I know it's true because when I was diagnosed I was a little sad and I didn't say anything until I told myself 'No, I have to tell everyone.' I felt better when I told my family." [Caribbean]

## Discussion

Determinants of distress are multifaceted, and LBSC's hesitations towards disclosure appear to be rooted in cultural beliefs of privacy and social risks of disclosing (social norms, stigma, fear, and role expectations). Not disclosing feelings have led to less formal and informal social support<sup>6</sup> which can negatively impact emotional and psychological well-being. Findings suggest that interventions seeking to reduce the perceived cost of disclosure while leveraging its benefits may improve help-seeking behaviors, contributing to improved survivorship and quality of life.

In conclusion, public health efforts must identify ways to reduce perceived and actual risks of self-disclosing. Practice should also create a safe environment, reduce stigma, educate family and friends about cancer, and implement best-practice safeguards that identify women in need of social and mental health support.

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## References

Please see the provided handout.