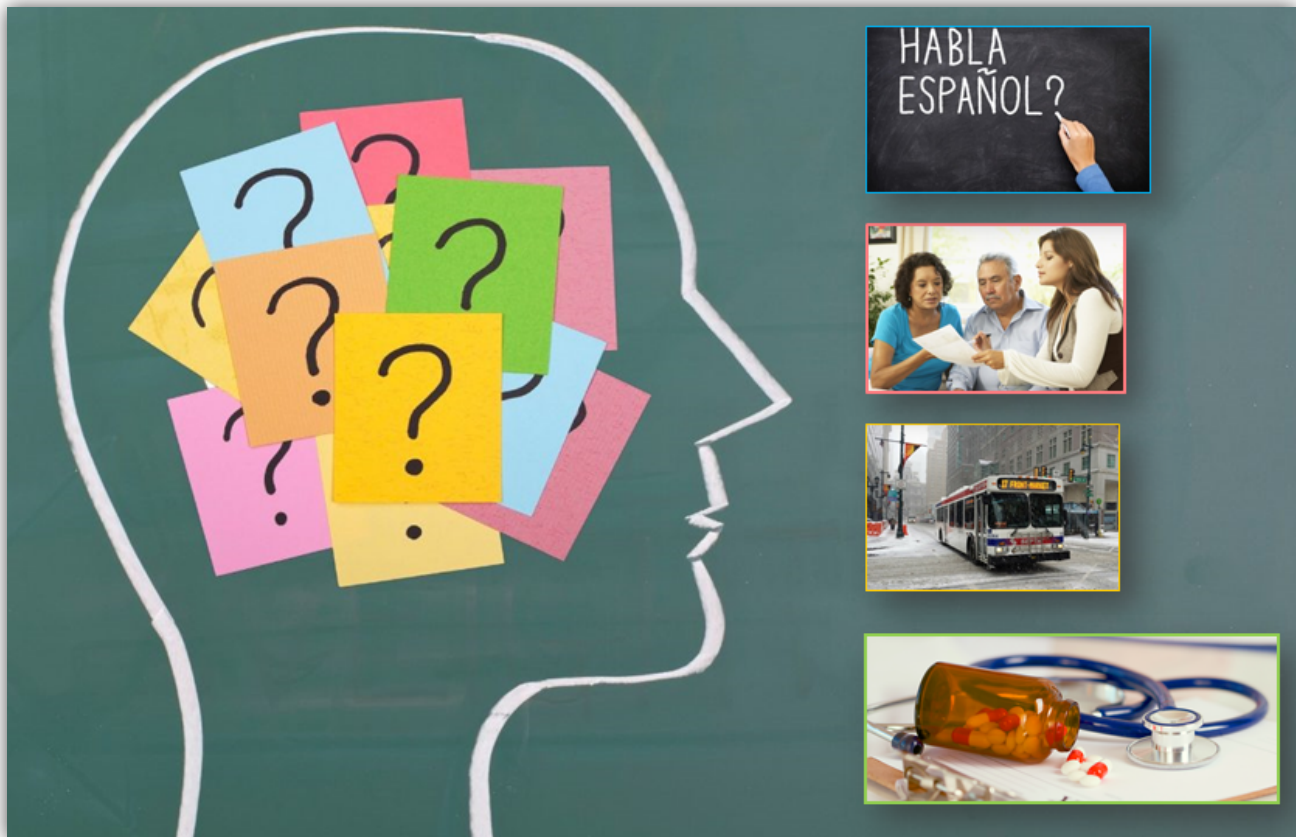


## Barriers to Cancer Treatment Adherence Among Older Latinos and their Caregivers in Philadelphia



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## Overview

The goal of this study was to identify barriers to completing treatment for cancer among older Latinos living in Philadelphia. The study has two origins. The first author (Schwartz) previously studied African American caregivers of cancer patients in rural North Carolina, with a focus on the barriers experienced by both patients and caregivers in adhering to treatments. The second and third authors (Ring and Glicksman) have spent several years conducting background research on barriers to cancer treatment for low income older Philadelphians, and have developed several projects designed to better connect Latino elderly to available health and social services in the city.

Across major cities, in 2016, the Hispanic poverty rate in Philadelphia was highest at 37.9% (Eichel & Howell, 2017). In addition, low income Hispanics in Philadelphia are more geographically concentrated than any other racial or ethnic group, with the majority of the population living in eastern North Philadelphia and the lower Northeast (Eichel & Howell, 2017). Of Latino/Hispanic households in the city, 6.7% include a person age 60 or older (Philadelphia Corporation for Aging, 2017), and the senior poverty rate among Hispanics is particularly high at 34.1% (Glicksman, 2016, as cited in Eichel & Howell, 2017). Poverty among older adults is an important risk factor for poor health outcomes, as it is associated with other social risks, such as lack of health insurance, lack of access to healthcare, and lower educational attainment levels.

Informal caregivers are instrumental in caring for older adults in the community, and are heavily relied upon for home care and cancer treatment symptom management (Hendrix, Bailey, Steinhauser, Olsen, et al., 2015). In Philadelphia, older Latinos typically have less access to supportive services, and are less informed than other groups regarding the availability of pharmacy, meal, transportation and housing programs for low income elders (PHMC, 2015). The literature has also identified Spanish speakers as reporting greater difficulty in searching for and understanding cancer and health information than English-speakers of any race (Vanderpool, Kornfeld, Rutten, & Squiers, 2009; Clayman, Manganello, Viswanath, Hesse, & Arora, 2010).

## Study Overview

Despite practice experience indicating that key barriers for older Latino cancer patients exist, a comprehensive understanding of the social and physical environmental barriers, as well as how they can be ameliorated by patients, caregivers, social work case managers, and health professionals remains understudied. This study attempts to fill the gap in evidence by collecting data on the challenges older Latino cancer patients face in adhering to treatment protocols, and the role of professionals and caregivers in ameliorating these barriers. Although the study's primary focus was cancer treatment adherence in the Latino community, focus group conversations also resulted in an understanding of challenges faced in adhering to other health care treatment, as well as barriers experienced by non-Latino patients from other low-income, non-English speaking communities.

In an effort to explore these issues, focus groups were conducted with a total of 20 individuals. The groups included: older adult Hispanic cancer patients (7 attendees), social workers (BSW/MSW prepared individuals) or those completing care management tasks (7 attendees), nurses (4 attendees), and stakeholders/employees who work at Asociación Puertorriqueños en Marcha (APM) (2 attendees). The older adult, social worker, nurse, and stakeholder groups took place at The Mann Older Adult Center, Philadelphia Corporation for Aging, Pennsylvania Hospital, and APM

respectively. These locations were chosen based on convenience for the attendees, and the focus group discussions took place between May and October of 2017.

Although the initial study design included a focus group comprised of caregivers of older Latino cancer patients, two attempts to convene this group were unsuccessful. Conducting the group with APM stakeholders was the most appropriate proxy for the caregiver focus group, as these individuals interact with members of the study population on a regular basis, and APM itself is a trusted bilingual/bicultural organization that has been providing social service and economic development in Eastern North Philadelphia since 1970 (Asociación Puertorriqueños en Marcha, 2016).

An interview guide consisting of open-ended questions was composed for each of the focus groups and included as a series of questions to facilitate conversation among attendees while addressing the study aims. Appendix A includes sample questions utilized as a guide during each focus group meeting.

## Overarching Themes from the Focus Groups

### **Difficulties with Transportation**

Transportation to and from doctor's appointments, to the pharmacy, etc. were mentioned in each of the focus groups as a major issue faced by older Latinos. SEPTA, Philadelphia's public transportation system, offers accessible bus service as well as a Shared-Ride program called CCT, which provides door to door service for Philadelphia residents age 65 and older. However, SEPTA's Shared-Ride program was cited as one of the most problematic public transportation options by several participants, and many older Latinos experienced transportation difficulties related to long wait times, language barriers, and misunderstandings regarding how and when rides are scheduled.

*Social workers.* The social work group described transportation issues related to timeliness, and explained how these issues often caused patients to miss appointments. For example, older adults do not want to wait several hours to be picked up by the CCT service, and in some instances missed appointments because the bus was late. In addition, the possibility of having a driver who did not speak Spanish was a deterrent to many patients.

*Sometimes they [older adults] don't even want to use the medical transportation... they think they can't even schedule the ride [in Spanish] 'they're not gonna have anybody who can attend to me in Spanish, so I don't want to go through it.'*

*Nurses.* In addition to identifying the need for a hospital based transportation service for patients ("*It would be great if I just had a van with a driver!*"), the nurse group also indicated that many patients and their family members faced financial concerns related to traveling to medical appointments, and many were unaware of financial supports offered by the hospital for low-income patients. For example, although social workers and nurse navigators employed at the hospital will often help to locate affordable transportation for those in need (e.g., via American Cancer Society or SEPTA CCT), patients and families were often unaware of this option.

*"A family member, if they come here... we want to make sure they understand that... there's a voucher service ... or parking paid for [them]."*

**Stakeholders.** The APM stakeholder group described an environmentally based barrier to accessing public transportation which is common among older adults in the community they serve. Although some of their clients are willing to take public transportation, many of the bus stops in the APM service area do not offer a bench or a shelter, which means that older adults must be able to stand for long periods of time, and have no protection from rain or snow. This caused at least one client to change or cancel her medical appointments on a regular basis. Issues of trust and discomfort regarding both drivers and other passengers were also discussed.

*It takes energy to work with strangers and to build up that trust and even if you're sharing a van like CCT ... the energy of getting in a vehicle with a bunch of strangers and then if you're going through treatment you might want privacy. Because maybe you don't feel great*

### **Language Barriers: Interpreter Issues & Use of Family Members**

Spanish-speaking patients (who may or may not also speak some English), were reported to experience additional barriers throughout the treatment process. Family members are often an essential part of the health care process for these patients, providing both emotional support and translation services.

**Social workers.** Participants indicated that although interpreters were generally provided for non-English speaking patients at medical appointments, the patients often preferred to use trusted friends or family members to fill this role. Of particular concern was the accuracy with which interpreters were translating patient statements

*I've had people who speak Spanish, and their informal [caregiver/family member] speaks Spanish too, and that informal can't even help them... I've been told that it's just they feel as if what they're saying isn't being represented in the form that they are saying it [by the interpreter]*

**Patients.** The lack of trust in translation services described by the social work group was reiterated among patients. One participant described a negative experience she had with the interpreter while attending medical appointments with her husband. As a more proficient English speaker than her spouse, she felt that the interpreter was not properly communicating her husband's questions and concerns to the doctor.

*Sometimes they [the interpreters] don't say the right words.*

**Nurses.** Participants in this focus group provided further insight into the controversy surrounding translation services provided at medical facilities. They explained that using family members as interpreters or translators is against hospital protocol, as they may give incomplete or incorrect information regarding medical procedures that they don't understand, or in some cases, that they don't agree with. This was often problematic for the nurses, as it can make building trust with the patient and their family more difficult.

*I have found that a lot of patients are resistant to translators, they just want their family to do it. So, we have to be careful and you never want a family member to think that we do not trust them... it's really tricky with the whole translator situation because the family member's like, 'I care for this person... and we don't need a translator.'*

The nurse group also noted that a lack of health literacy among patients, especially when combined with a patient's unwillingness or inability to admit that they don't understand something often further complicates treatment provision. Despite a translator being present, or the patient speaking English, a patient *"might just not understand what certain words mean, like using the medical jargon and they leave like just not understanding ...how important going to follow up [is]. So that gets delayed in their care."*

## **Interdisciplinary Collaboration and Cultural Competency**

The social worker and nurse groups in particular felt that interdisciplinary collaboration and cultural competency education for health professionals was of utmost importance in ensuring that the best care was being provided to patients.

*Social workers.* Referring to an agency in Philadelphia that provides case management services to older Latinos, one social worker explained the importance of connecting with individuals in other agencies to the benefit of clients' care. She felt that this kind of collaboration helped both parties/agencies to do a better and more efficient job, while also improving the patient's care directly. Social workers also felt it was important to make healthcare providers aware of additional supportive services that are available to patients so that they can better support patient needs. As stated by one social worker, physicians can also provide such resources to patients especially with the knowledge of the type of insurance they have.

*At the time they are diagnosed with the cancer... the healthcare provider they probably know what type of insurance they [have] ... [and could provide] the most appropriate resource for that...I think the physicians need to be educated.*

*Nurses.* Cultural competency was discussed as an important step in building trust between the patient, their family, and the care team. Participants felt it was important to be educated about homeopathic treatments traditionally used in certain cultures in order to identify those that might be harmful. A nurse participant indicated that it is part of their responsibility to have cultural sensitivity and be aware of culturally appropriate means of healing that the Latino population has traditionally used.

*I know the Latino population sometimes uses diet for healing and certain prayer... I think we have to respect that... but to also encourage them to come in to see us if we think that what they're doing won't work.*

## **Access to Emotional Support**

Receiving a diagnosis, undergoing treatment, and the various experiences across the cancer care trajectory can be wrought with emotional stress for the patient and those in their social network. Although the importance of mental health services for individuals has been documented, social worker and stakeholder attendees reported how patients and/or their caregivers experienced barriers in accessing these services.

*Social workers.* Providing patients with immediate access to resources after delivering a cancer diagnosis was also mentioned within the context of the patient's need for emotional support. By providing support while the patient is still present, especially for those who are alone and do not have a caregiver, the social workers felt patients would be more likely to take advantage of mental health services. They also felt it was beneficial for patients to be given an opportunity to discuss what they are feeling at the time of diagnosis.

*[It's important to be] able to get out how you're feeling and someone could let you know it's normal to feel this way. 'These are all the other services you have access to... we're here, we'll be here with you.'*

In this part of the discussion, social workers hearkened back to the idea of interdisciplinary work benefitting both professionals and patients. In particular, a social worker expressed how the emotional effects of a diagnosis can interfere with a patient's adherence to treatment.

*[If the team] could work [together]- like let's say [the] oncologist and mental health therapist, or counselor. Because I notice in my participants who are diagnosed with cancer... they have anxiety [and] depression that extremely gets in the way of... cancer treatment.*

**Stakeholders.** While mental health services are available within the city, they are not necessarily located in the same areas where patients and caregivers live. Stakeholders at APM felt that many patients and caregivers in their service area would be unlikely to attend a support group outside of their community. Stakeholders felt that most mental health services (e.g., support groups) were located in parts of the city that are not convenient for people in their service area to attend, and they are often reticent to join discussions with those outside of their community or peer group. In addition, with caregivers being bogged down with various responsibilities, the time it takes to travel to another location is time that can be better spent completing a caregiving, work, or family-related task.

*There's not a lot of spaces nearby where they can meet folks who are going through that, where they can say oh these are folks who do want to listen to me... Because again, not everybody wants to talk about it with people that they don't know.*

## Challenges Specific to Cancer Caregivers

As previously discussed, the initial study design included conducting a focus group with caregivers of older Latino cancer patients. However, attempts to convene this group were unsuccessful. The APM stakeholder/employee focus group was convened in an effort to understand additional challenges faced by Latino caregivers, and to provide insight as to why those who agreed to participate were ultimately unable to attend any of the three scheduled meetings.

**Multiple Roles and Time Management.** As previously mentioned, caregivers have multiple roles within the family and community, with little time to complete all of the related duties. This was described in detail by the APM employees based on their interactions with caregivers.

*One of our residents where her daughter is her caregiver. But she's in school, she has another job, and she has children of her own. So, she's really pressed for time...I talk to her mom a lot and ...she was like, "well you know she needs to go to school so she can get a better job, and she can better provide and she can have more time."*

This quote alludes to the sandwich generation caregivers who are constantly caregiving for either an adult family member and/or their children, in addition to working. Thus, the time caregivers do have is extremely valuable and isn't used necessarily for relaxing or tending to their own emotional needs, but rather for dealing with other tasks such as paying bills or grocery shopping.

**Role of multigenerational families.** Many families in the Hispanic community are multigenerational (either living together or in close proximity) and rely on each other for support. However, it can be challenging to accomplish one's own tasks while providing support for multiple family members. As an example, an APM employee described how one family in the community tries to address the transportation needs of all its members.

*There's one gentleman who takes care of his brother and his sister who don't have a car... So, he has to plan his work schedule around their doctor visits and their needs... So, he does carpooling with them.*

**Multi-family support.** In addition to the support provided among family members, separate families within the larger community also help each other. Another client example involved the way community members assist each other in accessing APM's food buying club.

*Our food buying club for example, where we do...fresh produce from here. We'll have certain individuals who will pick up orders for multiple families...And we've seen those connections building that way.*

**Need for child care and elder care.** One major reason APM employees believe caregivers did not attend the focus group was the need for supplemental child and/or elder care while attending. In previous projects with the community, APM experienced individuals asking, *"do you have childcare; do you have care for the people that we won't be able to care for while we're there?"* If such care is unavailable, individuals cannot show up to such group meetings because the support is not in place.

## Conclusions

Each of the focus groups provided insight into the challenges that older Latino patients and caregivers face in adhering to cancer and other health treatments. This data can be used to develop specific interventions that support cancer caregivers and patients in adhering to treatment protocols and health needs in general. Based on what was learned from the focus groups, such modifications or interventions should account for:

- 1) There were various transportation issues that Latino residents face as they relate to attending appointments and treatments that were identified. Alternative options for transportation that take into account cultural factors such as the Spanish language and preference for privacy, and the multiple demands that caregivers (a primary source of transportation) face that may impede their ability to transport patients should be considered.
- 2) There often appears to be a disconnect between providers of different sets of services used by Latino cancer patients. This included not only a lack of coordination across care venues, but a lack of communication regarding what services are available and when they should be used. Focus groups also identified the need for cultural competency training among health professionals and other service providers (e.g. bus and CCT drivers) so that they can better understand the ways health and other needs are traditionally addressed (e.g., diet, prayer) within the Latino community.
- 3) It is important to recognize that many of the caregivers in this community are part of the sandwich generation. In order to provide supportive programming directly to these individuals, there is often a great need for child and/or elder care to relieve them of these

duties while they participate. In addition, such supports should be culturally and linguistically accessible, and conveniently located within the individual's neighborhood.

- 4) Although interpreters are available for use during medical appointments, a number of difficulties arose concerning the perceived accuracy of the translation services. Latino patients and their caregivers did not always feel that their concerns were properly communicated to medical staff, and medical staff worried that a lack of medical background might cause informal caregivers to misrepresent important information regarding the patient's care plan.
  - 5) Worth noting is how families within the community help one another. This should be capitalized upon if possible.
  - 6) It was apparent that social networks are of great importance to patients and their caregivers (e.g., #5). Use of social networks for medical information, support, and transportation
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## Appendix A

### Sample Focus Group Questions

Focus Group Type	Exemplary Questions
Social Workers	<ol style="list-style-type: none"> <li>1. Are there certain environmental barriers that you have experienced in helping your clients that you have been able to overcome? Please explain the challenge and how you overcame it.</li> <li>2. Are there certain programs or services that you wish existed in that would help your clients? If you could design a service or support, what might it look like?</li> <li>3. What role do you think social workers play in helping older Hispanic cancer patients adhere to treatment regimens?</li> </ol>
Nurses	<ol style="list-style-type: none"> <li>1. What barriers do you think your older Hispanic cancer patients experience in adhering to treatment protocols?</li> <li>2. What role do you think health professionals play in helping older Hispanic cancer patients adhere to treatment regimens?</li> <li>3. What role do you think health professionals COULD play in helping older Hispanic cancer patients adhere to treatment?</li> </ol>
APM Stakeholders	<ol style="list-style-type: none"> <li>1. In your correspondence with clients, particularly caregivers of older adults, what have individuals reported as challenges in helping a loved one adhere to cancer treatment/health treatments? Health-related tasks in general?</li> <li>2. In the focus group we had with cancer patients, we were told that some of the challenges that they experienced in adhering to treatment protocols and health-related appointments in general included _____. In addition to the challenges you have already discussed, have caregivers reported the same challenges patients did? Any additional challenges?</li> <li>3. In your experience in working with a caregiver for an older cancer patient(s), what has been reported as most helpful in helping you ensuring their loved one completed their treatments and doctor's appointments?</li> </ol>
Patients	<ol style="list-style-type: none"> <li>1. How do you get to your radiation, chemotherapy, and other visits related to your illness?</li> <li>2. What if anything makes it difficult to get to your appointments?</li> <li>3. What could be explained or provided to you that could help you follow treatments?</li> </ol>