Challenges and Rewards of Creating a Caregiving Website for New London, Connecticut

Mónika López-Anuarbe  
Connecticut College, manuarbe@conncoll.edu

María Amparo Cruz-Saco  
Connecticut College, macru@conncoll.edu

Joyce Bennett  
Connecticut College, jbennet4@conncoll.edu

Follow this and additional works at: http://scholarlyrepository.miami.edu/collaborations

Part of the Anthropology Commons, and the Economics Commons

Recommended Citation

This article is brought to you for free and open access by Scholarly Repository. It has been accepted for inclusion in Collaborations: A Journal of Community-Based Research and Practice by an authorized administrator of Scholarly Repository. For more information, please contact repository.library@miami.edu.
Challenges and Rewards of Creating a Caregiving Website for New London, Connecticut

Abstract
This paper addresses the successes and challenges of our community-engaged learning experience on long-term caregiving for Hispanics in New London, Connecticut. Our earlier research revealed lack of accessible information for caregivers in this community. Accordingly, we developed a website in a culturally and linguistically competent format to help alleviate such information shortage. Before launching the website, we used focus groups for constructive feedback to enhance its helpfulness. This four-year long research project will culminate with the website activation and another partnership between Connecticut College and community organizations. We recognize the importance of collaborating with community partners to manage and ensure the effectiveness and sustainability of this project. The absence of sufficient resources supporting Hispanic families caring for their aging loved ones makes it increasingly necessary that public policy changes, such as the creation of a case management office, improve the well-being of aging minorities and underserved families.

Keywords
caring for aging relatives, Hispanic caregivers, websites for caregivers, underserved populations

This article is available in Collaborations: A Journal of Community-Based Research and Practice: http://scholarlyrepository.miami.edu/collaborations/vol1/iss1/10
In this paper, we document our community learning project of developing a website on long-term caregiving for Hispanic families in New London, Connecticut. The analysis is concentrated on the last phase of its design - before going live - to validate its usefulness for the community it aims to serve. Focus groups were used to identify possible needs not originally considered in the website. We confirmed the absence of sufficient resources supporting the care of aging Hispanics and resolved to incorporate small additions to the present website design to enhance its usefulness. Our findings illustrate relatable universal challenges and commonalities when conducting community-based research anywhere, when studying Hispanic communities outside of New London, and when understanding families attempting to provide caregiving to their aging relatives and friends. This makes it increasingly necessary for public policy to improve the well-being of aging minorities and their families.

Our project contributes to the overall community-based research in higher education aimed at suggesting targeted public policies for underserved populations. This paper addresses the systematic challenges of effectively doing community learning work and highlights the importance of public policy advocacy as a critical component of community learning work. Colleges and their hometowns have realized the mutual benefits of partnering through community-based learning and research. Learning communities and towns share a living environment and a space where residents can engage with one another to work collaboratively and communicate, thus achieving their aspirations (Bringle & Hatcher, 2002). Much work has been done in the area of community-engaged learning, specifically regarding how to manage community-college relationships so as to be equitable and best meet the needs of all partners, not just the college or university (Heffernan, 2015; Mitchell, 2008). Many academics have noted the challenges of community learning, including bringing to fruition, sharing equal ownership with local communities, and others (Dostilio et al., 2012; Meens, 2014; Tryon et al., 2008). “Community learning” or “community-engaged scholarship” has a long history often connected to the term “service learning.” Mitchell (2008) distinguishes between “traditional” versus “critical” service learning, indicating that traditional service learning
could often be compared to forced volunteerism and a form of patronizing local communities. Our approach is critical community-engaged learning that acknowledges diversity across ethnicities and values in the city of New London, aiming to incorporate the perspectives and experiences of Hispanics in the challenges of caregiving. In our use of the term "community learning," we mean to reflect the notion that our students are working with us in community, and through that work are learning to be responsible global citizens who put their liberal arts education into action. Additionally, the community learns from and with students. In this sense, the term is meant to represent a more critical approach to service learning. Our College is beginning to systematically use this more respectful and mutually beneficial approach which puts the needs of our New London community first, although we here document some of the challenges of implementing such systems.

New London is one of the smallest cities in Connecticut (under six square miles). Its total population is approximately 30 thousand, of which one third are Hispanic residents, particularly Puerto Ricans and immigrants from Central and South America. In 2014, its median per capita income was $41,230 which represented 59% of the per capita income in Connecticut (U.S. Census, 2014). With almost four hundred years of history, New London has a rich tradition as a natural port, a whaling city in the eighteenth and nineteenth century, and a transportation hub. Over the course of these years, it did not succeed in building an industrial base and its economic activity and population dropped during the twentieth century (Decker, 1976). The city is attempting to find ways to provide better services to its residents with a relatively small tax base due to real estate tax exemptions offered to not-for-profit-organizations. In 2014, its poverty rate was 25.3% in contrast to 10.8% for Connecticut (U.S. Census, 2014). With a median age of 30.7 years and 42% of the population between the ages of 18 and 44, New London’s total population is relatively young, largely due to the inflow of immigrants. In contrast, the state of Connecticut has an older median age of 40.5 years reflecting the country’s overall aging (In City Data, n.d.). Combined, these factors indicate that the aging Hispanic population in New London will soon need elder care.

Hispanics and individuals aged 65 and older are the two fastest growing populations in the United States (U.S. Census, 2010). Most people will need long-term care, but formal (paid) long-term care averages over $100,000 a
year for nursing home residence nationwide, and can reach $200,000 in Connecticut (U.S. Department of Health and Human Services, 2016). Hence, long-term care is primarily provided by families and friends who are not remunerated. This type of care is known as informal care, and the latter is very popular in the US: approximately two-thirds of individuals who are 65 and older only rely on their families and friends to assist them (Family Caregiver Alliance, 2015). This proportion is even higher for Hispanic families than for non-Hispanic Whites or African Americans (Angel & Angel, 2015; Torres-Gil, 2005). In fact, one out of three Hispanic households has at least one relative assisting an older person (Angel & Angel, 2015).

Despite these historically above average informal caregiving rates for Hispanics, family-based support systems are becoming increasingly strained as well (Ruiz & Ransford, 2012; Silverstein & Giarrusso, 2010). Informal caregiving by itself may prove to be unsustainable, particularly if it is mostly provided by Hispanic women (Angel & Angel, 2015). Thus, there is an immediate need to supplement informal care with formal care and governmental assistance programs.

Most individuals know nothing about long-term care until they have to provide it, nor do they know where to find assistance or incomplete sources (Angel & Angel, 2015; Lucke, Hernando-Martinez, Mendez, & Arevalo-Flechas, 2013). Hispanics often do not take full advantage of formal caregiving support options for which they may be eligible (Herrera, Benson, Angel, Markides, & Torres-Gil, 2013). Possible reasons include lack of awareness, rejection of outside assistance, and lack of culturally sensitive training programs that are geared towards their specific needs (Almendarez, 2007; Angel & Angel, 2015; Espino, Neufeld, Mulvihill, & Libow, 1988). If not addressed pro-actively, Hispanic families and Hispanic elders in particular risk increasing isolation, disenfranchisement, and hardship.

This is where and why our specific and helpful project comes to play. The issues facing Hispanic families regarding long-term care for aging elders are particularly relevant in New London, CT. Early in our project, we decided to develop a centralized and highly customized website specifically catered to a unique community of Hispanic families, their friends, neighborhoods and caregivers as an important first step. The remainder of our paper describes the methods we employed, including a discussion of the context and origins.
of our community learning project. We detail the needs and justification for developing the website, present its structure, and describe the focus groups that we used. We summarize the results and follow with a discussion of the emerging themes identified by our participants. Our conclusions are presented at the end.

**Methods**

*Focus Groups*

We used focus groups because they can help researchers identify underlying cultural meanings (Ragin & Amoroso, 2011) and facilitate the gathering of multiple salient and shared opinions in a brief time period (Borrayo, Goldwaser, Vacha-Haase, & Hepburn, 2007; Kelley, Wenger, & Sarkisian, 2010; Koenig, 2004; Ragin & Amoroso, 2011; Warren & Karner, 2009). This methodology is particularly useful with non-sensitive questions which do not raise concerns about participants’ comfort levels. Increasingly, focus groups are used to gather information about attitudes or motivations related to aging in specific communities (Borrayo et al., 2007; Kelley, et al., 2010; Koenig, 2004). Our goals for the focus groups were twofold: first, to assess to what degree the website was comprehensive and sufficient; and second, to obtain information about how the website could be improved. Thus, we formulated our research questions to promote an open and frank conversation about how a website on aging could be enhanced. In particular, our questions were: (i) What other information would be helpful to include in this website? (ii) What is the best aspect of the website? (iii) Which area(s) could use more work? (iv) How should we disseminate this information? Our focus group research was approved by the Connecticut College Institutional Research Board in early June of 2015.

*Study Background*

Our study results from previous community-engagement research in New London. Collaborations with community partners on mutually agreed upon research about aging attitudes and planning for long-term care among Hispanic families made it clear that there is a dearth of easily accessible and culturally friendly information on long-term care and aging resources in this community. In response, we discussed with the Community Health Center and the Hispanic Alliance the possibility of designing an information
instrument that could begin to fill this void. Such an information instrument, for example, a website on aging and long-term care, would be created for Hispanic families and administered in conjunction with representative service organizations. We combined our disciplinary expertise in economics, healthcare policy, aging, cultural anthropology, and migration in the development of the website. We also benefited from team-work with our undergraduate students at Connecticut College who were either funded through small institutional grants or were our independent study or seminar students. Bennett conducts extensive ethnographically-based community research in New London serves on the College’s Holleran Center steering committee (our academic center for community learning and research). Cruz-Saco has resided in New London County for nearly three decades and is involved with the Hispanic Alliance of Southeastern Connecticut through the La Latina Network program. López-Anuarbe is also on the Holleran Center steering committee and, together with Cruz-Saco, has published a number of papers on Hispanics and planning for aging within the Hispanic community in New London. All three researchers are bi-cultural and advocates for the need to enhance social services benefiting our Hispanic population. Figure 1 shows the four distinctive phases of our community-based research.

Phase I
Lack of information on long-term care among Hispanic families

Website idea

Interviews/Consultations with Social Service agencies and Hispanic stakeholders

Phase II
Field work with students and community partners

Website development

Design of Focus Groups with community members
Phase III

Focus Group implementation → Website improvement → Consultation with Social Service agencies and Hispanic stakeholders on website administration

Phase IV

Agreements about launching the website → Website goes live → Ongoing update and assessment

Figure 1. Four phases of Website Project Development.

Community-Based Research Phases

Phase I refers to the website origin. We shared our ideas with six healthcare providers and community leaders whom we interviewed in the fall of 2012. The interviewed participants included one employee of the Senior Resources Agency on Aging (an entity that aims to provide information and resources to the aging population, their families and care providers), the director of the New London senior citizen’s center, a healthcare advocate for Hispanics, a pastor from the oldest local Hispanic Christian church, the director of the Community Health Center, and the Chief Operations Officer of the Thames Valley Council for Community Action (TVCCA) center. These conversations helped us better understand what type of information would be most useful for Hispanic families in New London. Some interviewees thought that a website would be worthwhile because Hispanic residents would trust “us” (bilingual academics with Hispanic ties) much more than a state agency representative. It would also help promote visits to the New London Senior Center and, in general, raise awareness of existing resources, where to go, and when to request a particular service or counseling. This consultation process concluded Phase I.

During Phase II, we researched our potential website content by becoming familiar with the existing regional online resources and, most importantly,
by studying the most pressing long-term care topics and content components that we wanted to include in our webpage. We developed a co-taught community-based learning course as an independent study for students interested in exploring what types of information would fill the information gap. Five college students enrolled in a research independent study, meeting weekly during the entire academic year. We studied how non-governmental organizations, colleges, and think tanks prepare and distribute information on aging and care-giving. When this exploration was completed, we spent time thinking about ways to organize information on caregiving and social security benefits. To diminish language barriers, we designed a bilingual website (in English and Spanish) that would have four main topics: formal (paid) caregiving, informal (unpaid) care-giving opportunities, government benefits (Social Security, Medicare, and Medicaid), and other resources. We also carefully and explicitly brainstormed ideas for our website name; created a section on the city of New London; drafted our mission and vision; included a section that had each team member’s contact information, profile, and picture; and consulted with a professional website creator in New London for feedback.

Website

In Figure 2 we show a picture of the website with the preliminary name of “New London Hispanic Care (NLHCare).”

![Website Image](image)

Figure 2. Our webpage.

Formal caregiving refers to paid, long-term care. These services are offered by trained, supervised professional care providers primarily employed by care agencies and institutions. In contrast, the informal caregiving section highlights which care is usually provided by untrained and unpaid caretakers. Typical informal caregivers include family members, friends, and
neighbors. Informal caregivers assume responsibility for the care recipient’s physical, emotional, and developmental well-being. Two additional sections on Social Security and government support provide a summary of eligibility conditions for a Social Security pension and describes Medicare. The website also includes contact information for the New London Social Security Office. Social Security is the largest source of income for the majority of older persons in the U.S., and Medicare is the nation’s health care insurance system for persons over the age 65. The Other Resources section includes information on long-term financial planning and savings in addition to examples of housing, meals, recreation, and transportation resources. It also contains information on resources offered by the city’s hospital, the Senior Resources Agency on Aging, and the New London Senior Center. The latter two entities are underutilized by the Hispanic community.

*Sample and Community*

Our target audience included New London adult Hispanic residents who were at least 18 years old. We grouped participants into four categories by gender and college education.¹ This classification was based on the highly gendered nature of care-giving in addition to the access and management of information that is influenced by education level. Given previous research findings (Cruz-Saco & López-Anuarbe, 2016) on gender roles in caregiving, we hypothesized that Hispanic women would mostly be interested in informal long-term care, while Hispanic men would be interested in Social Security programs and pensions, hence the division of focus groups along gendered and educational lines.

*Focus Groups Details*

Each focus group had five to eight adult Hispanics for a total of 27 participants, which is consistent with best practice (Debus, 1988; Warren & Karner, 2009). Participants were drawn from the New London community and had resided in the United States for at least three years. They were initially recruited through the Hispanic Alliance network, the Community Health Center, the Provenance Center, and through the use of snowball sampling. In addition, we recruited participants at other locations including cultural centers, educational institutions, supermarkets, Latino restaurants,

¹ One or more years of college education.
beauty shops, and travel agencies that serve the Hispanic community. Our participants had the following descriptive statistics: fifteen women ages 18 to 63, mostly in their thirties; twelve men ages 21 to 62, mostly in their fifties. Men identified as being from Puerto Rico (most frequently cited), the Dominican Republic, Peru, Venezuela, and from two or more countries or ethnicities. Women identified as being from Peru, Puerto Rico, Dominican Republic, Honduras, El Salvador, Venezuela, and Argentina. Ten women identified as native Spanish speakers, four as native English speakers, and one as growing up in a bilingual home. Eleven men identified Spanish as their first language, with only one man identifying English as his first language. Three men were actively providing informal care to an elder in their family, while seven women were caring for elders in their families.

We explained the purpose of our project to potential recruits and solicited their participation in one of our focus groups. As a token of our appreciation, participants received a $25 supermarket gift card (a grant from the Hispanic Alliance, one of our community partners) and a beach chair (funded by a research grant from Connecticut College in 2013).

We conducted our focus groups in June (women) and November (men) of 2015. Each focus group took place at different times of the day to accommodate our participants’ work schedules. All three researchers are versed in qualitative analysis and bilingual in Spanish and English. Participants seemed at ease with the researchers and their preference was for the sessions to be conducted in Spanish. The first two focus groups took place at the Community Health Center of New London and the last two at the Provenance Center-Hispanic Alliance, both located in downtown New London. Participants gave written consent to participate in the focus groups and to be audiotaped. We also digitally recorded each session to best capture their ideas. At the end of each session, each participant received written debriefing statements. Before beginning the focus groups, we administered a short survey that included demographic questions.

We began each focus group with a five-minute explanation of the project and its goals. Then, we gave a brief preview of the website. Afterwards, we opened the floor to comments and questions from participants. We taped 27”X 34” flip chart sheets (or easel pad sheets) on the walls and one of us wrote their responses on them so that participants could see the conclusions we were reaching as a group. This worked well because it encouraged
participants to clarify and specify their points as we wrote them down. Another facilitator, a trained ethnographer, took notes and observations during the session about the conversation and the interactions of participants. In addition to our digital recording, we took supplementary notes while the conversations unfolded. Our data came from three sources: (i) written transcripts from the audiotaped focus group conversations, (ii) written notes on the pads, and (iii) notes on non-verbal responses and discussions that we took while we led the discussions. Each researcher used content analysis and came together to identify patterns across themes and summarize our findings. We met several times to extract the main themes from each of the focus groups by comparing our notes and by cross-checking for accuracy. Using a reiterative process, we agreed on the themes that are summarized below. Given the uniqueness of the focus groups, we separately summarize the main results from each session in chronological order below. In addition to these focus groups results, we also include a discussion section that identifies commonalities among the four groups and noted observations without recursive elements but important enough to be highlighted. The summary of this second analysis is presented in the discussion section.

Results

*Focus Group 1: Women with College Education*

The first focus group took place in June 2015 at a multipurpose meeting room in the New London Community Health Center. We gathered with five college-educated women. In discussing the website, this group interacted calmly and with reserve. Participants left physical space between each person at the table and waited for each other to finish speaking before the next one began. The group was communicative, analytical, and constantly provided feedback on ways to best design a website about care-giving for the Hispanic community in New London. The discussion focused on two main ideas: the website’s audience and the need for in-person resources in New London for the aging Hispanic community.

The first salient idea was that the website should most likely be for caretakers, not for elders. Most participants doubted that elders would access the site themselves; one participant shared that she often finds information on long-term care for her grandparents on the internet and
then relays it to them. Participants noted that if there were a central place in New London associated with the website, such as a Hispanic Senior Center, some of this information should be available in hard copy there to make it more accessible to seniors themselves. Various related points were also discussed, including the benefits of having resources for caregivers on self-care and wellness on the site.

The second salient idea was that the website will not be very effective unless it is one component of a Hispanic Senior Center with casework and physical presence in the community. Ideally, there should be more trained bilingual social workers managing Hispanic family cases, networking with other social service agencies in New London, and referring these cases as needed. Participants also noted that the healthcare system is difficult to navigate because, at times, Hispanic patients need to be referred to specialists who may not have openings right away or to physicians who do not work with Medicare patients. In addition, language barriers between patients and providers can make this experience more challenging. While a website is helpful, it should be a back-up for face-to-face resources. The group discussed the challenges of providing such in-person resources, specifically finding and staffing a space and training a case manager to support seniors’ access to proper resources. During this portion of the discussion, participants became more animated in their gestures, indicating the significance of these issues since some of these women worked in healthcare in New London.

Focus Group 2: Women without College Education

Our second session also took place in the same conference room as the first and in June 2015. These participants had multiple nationalities and generational perspectives. Compared to the first focus group, the second one owned the space more as they left their seats, got food, walked around, chatted, and came in and out of the conversation. They were also relatively more animated in their kinesics. In addition, we witnessed instances of power dynamics between women at the table regarding their right to talk. For example, some participants frequently interrupted each other either to disagree or to make further comments on a particular point. Such interruptions were both verbal and kinesic, as the women tended be quite animated while making their points.
From the start, participants passionately emphasized that a website is not enough to address their aging issues. There are idiosyncratic, endemic, and negative issues affecting the New London community in general, and the Hispanic elders in particular. Our participants claimed that much of the elder population in New London does not feel safe because of violence, drugs, and other related issues in the community. Therefore, we will now have a section on safety on our website that we had not planned before. This group of women shared many personal stories that highlighted ways in which community well-being and individual well-being are intimately tied to healthy elders and healthy caretakers.

Participants provided examples of situations requiring support from a brick-and-mortar resource center advocating for case management, much like the suggestions made by the focus group of college-educated women. They considered that available information from the website must be supplemented with personal contact and problem solving.

Participants indicated their willingness to meet more often to discuss and address issues affecting their communities. Even after the event officially ended, all the women remained in the multipurpose room and continued the conversation. This group highlighted the need for culturally and linguistically accessible elder care in the New London Hispanic community. Our conversation also encouraged some participants to formulate and express initiatives about becoming paid care workers offering affordable service rates to community elders in general, and Hispanic elders in particular, especially when they heard other members sharing their paid care-service experiences.

**Focus Group 3: Men without College Education**

Our third focus group took place in November 2015 at the Provenance Center-Hispanic Alliance in downtown New London. Participants varied widely in age, ranging from early twenties to mid-sixties. The older men mostly dominated the conversation, although all participants were generally reserved in their verbal participation. The men did not appear to know each other, leaving a more than adequate amount of space between each other at the table. This general silence made us wonder if, in addition to the lack of familiarity of the setting and the participants, one of the reasons this group of men felt uncomfortable was related to the power structure of the
session: professional women moderating the conversation. Another reason could be our participants’ lack of familiarity with focus groups in general, not being used to talking in public or feeling comfortable when “being put on the spot” for comments and feedback (Alvesson, 2011; Sallee & Harris III, 2011).

After presenting the website to the group, the first important theme that emerged was the website content. The group unanimously agreed that the website is a good idea and noted that it is often difficult to access specific information for Hispanics in New London. Language barriers play a big role, and having the website in Spanish was crucial for them. Participants liked the section on self-care and resources for caregivers, but one man cautioned us against making the section too woman-centered, since he cares for his aging parents and could also benefit from self-care resources. Other participants agreed that perhaps there are more men in caregiving roles in the Hispanic community than is generally thought because of assumptions about machismo and masculinity in the Hispanic community. Men around the table displayed particular interest in this discussion not only through their comments but also by uncrossing their arms, sitting forward a bit more, and leaning into the table.

The second main idea that surged from the conversation was also in alignment with both women’s groups: the website is a good idea, but for it to be successful, it must be supported with a centralized location in the community where resources and information are accessible in person. Although participants thought a centralized location would be helpful, the larger issue at hand from their perspective is the general disorganization and lack of community among Hispanics in New London resulting from their vulnerable and highly fragmented social status. Participants thought that having a centralized location for information about aging could be a means of generating community unity among Hispanics.

The third main point of discussion concerned potential issues with the website. Men noted that in order for the website to be successful, there must also be an information campaign in the community so that people know about it. Ideally, this would coincide with the development of a resource center. Another issue that they brought up was the transitory nature of many non-profit social service organizations and the need constantly to update available resources in New London. This raised the
question of who would host the site and be responsible for updating the list of available services. Finally, participants suggested that the site be mobile-friendly, as many people only access the internet through their phones.

**Focus Group 4: Men with College Education**

Our last focus group also took place in November 2015 at the Provenance Center-Hispanic Alliance. Only one person arrived on time, so we had to start about an hour later to accommodate our participants’ work commitments. Meanwhile, we had snacks and were sociable with our participants who seemed eager to be part of a community conversation. They were very lively and talkative before, during, and after the focus group. One participant dominated the conversation, but most seemed to agree with his contributions and, even if they did not know each other, they were very amicable.

Participants agreed that the website would be a useful coordination tool to help connect multiple community entities including churches, health providers, schools, and social services agencies. They were emphatic about having an aggressive promotion campaign for our webpage through a variety of organizations in New London. Like the non-college educated focus group, they emphasized that community needs the webpage to be mobile friendly and accessible via social media. Participants also suggested the public library, the school system, social workers, counselors, housing projects, churches, casinos, broadcasting entities, and Facebook as possible website promoters. According to these participants, the library is a wonderful resource for families because programs can be developed in Spanish. Similarly, schools can promote the webpage in their newsletters.

There was enormous enthusiasm that the website would soon go live and have a “big” kick-off; this would be an opportunity to celebrate Hispanics and to raise awareness about aging and long term care for older persons. The name of the webpage should be very “catchy”, for example “Our Latin Help” or “Help NL,” with a clear message stating that this website is an information instrument for Hispanics who care for their older persons.

Similar to Focus Groups 2 and 3, these participants also brought up safety concerns in New London. But unlike the previous groups, Focus Group 4 went one step further and brainstormed solutions to address specifically
such concerns in our website. For instance, they suggested that our website should have information and advice on how to manage and prevent emergencies and crises; it should also contain contact information of different entities such as 911, the police department, the fire department, nearby hospitals, suicide hotlines, etc.

Participants shared that, although the webpage is an information instrument for the Hispanic community, many elderly Hispanics and their families lack access to computers and the internet, which could become a barrier to accessing this information. They repeatedly noted that this Hispanic community feels fragmented and invisible, and the desire for greater empowerment and visibility was voiced multiple times. Some suggested that if our webpage was widely used, it could produce a “domino effect” leading to the creation of additional information instruments in areas such as education and health services. There was unanimous agreement that information and social services are urgently needed among Hispanic families; the lack of services often leaves churches to assume social worker and case manager roles.

Participants were interested in knowing how the website would be administered and supported and whether the Hispanic community could better connect with Connecticut College students and with students from other institutions of higher education in New London. They wanted to know when the webpage would be ready and suggested another focus group for additional feedback (a beta test) before it went live. They were eager to have additional details on the website design, visual aids, and interactivity level. They said that all of the images must reflect the faces of the Hispanic community.

**Discussion**

We noticed common themes that our focus groups shared regardless of gender or educational level. First, participants welcomed our website and perceived it as a vehicle to help fill an information void for Hispanic caregivers in New London. This void is further exacerbated by the perception that many participants characterized the Hispanic community as fragmented, invisible, and disorganized; some participants - both men and women- emphasized the lack of community altogether. The notion of aggregated powerlessness adds to the burden of caring for a vulnerable
population group like elders. Also, the lack of an integrated community may leave elders at the mercy of their families’ willingness and, at times, constrained ability to care for them due to limited individual and community resources and to a lack of awareness of the existing supportive resources.

Second, our participants reiterated that, in order for this website to be useful and successful, it must be accessible. Accessibility in this context means that it should be in Spanish and English to eliminate language barriers. It also implies that it should be compatible with multiple electronic devices, not just with a computer. In addition to being useful, the website must be attractive, interactive, personable, and relatable. It needs to represent the Hispanic population of New London, not just a generic, hypothetical population.

Third, our website is not enough to address elder caregiving concerns and hence, it must not stand alone. It needs to be part of a greater long-term care information system, and the beginning of additional community-engagement initiatives. Our website must supplement person-to-person attention; case management was mentioned by our male and female focus groups, and an aging center was suggested and envisioned by the college-educated focus group of women.

One goal that we would like to accomplish is to strengthen the relationship between the Senior Center and the Hispanic community so that the center can also be part of the local community partners involved in this project, thus eliminating duplication of efforts (Andreasen & Kotler 2003; Rados, 1996; Sargeant & Jay, 2004,). In February 2016, new administrative officials were appointed to the senior center, and we think that this staff change can be positive for the Hispanic community and the website given their infrastructure, their mission, and the downtown location of the center.

Fourth, we witnessed an important moment in each of the focus groups when participants felt empowered to consider the website theirs, the community’s, instead of ours, the “outside” researchers’. Participants from both of the men’s focus groups seriously started thinking about how to best involve community partners to manage the website, how to successfully launch it and to divulge its existence and use, and how to take more effective community action in family caregiving.
Lastly, we repeatedly realized, especially after listening to our second focus group (women without a college degree), the importance of further contextualizing our website to the needs of the Hispanic population in New London. In addition to structural health care access inadequacies, our webpage contextualization will also address safety concerns that elders and their families face. While this issue was not part of our original project goal, we cannot overlook it now that we are aware of its existence as elders and the families and friends who care for them are not immune to safety concerns, which impact their well-being. Such ideas are confirmed by existing knowledge about health and well-being, particularly in issues of aging (Giraldez-Garcia et al., 2013; Steverink, Lindenberg, & Slaets, 2005).

**Challenges and Opportunities**

Three of the five main themes that emerged from our discussion (raising awareness, accessibility, and empowerment) are already strengths of our webpage. Participants’ feedback reassured us that the information instrument was culturally and linguistically accessible for Hispanic families, although some voices cautioned that internet availability and literacy were essential. Yet more work needs to be done to address the fourth theme, namely that the website becomes part of a broader information and support network on long-term care giving. Our New London partners (churches, health care organizations, social service agencies, and the Hispanic Alliance) agreed that a long-term care website is a significant contribution to a rapidly aging and large Hispanic population.

In this effort, we recognize major challenges, including community fragmentation and lack of sufficient resources supporting Hispanic families who care for their aging parents, relatives, and friends. It will be important that the community finds ways to voice their multiple, diverse needs and feedback both directly and indirectly through representative organizations. The website’s shift in ownership and the future network of long-term care support to the community will require deliberate coordinated initiatives among New London partners. In this process, it may be best to turn over leadership to organizations that provide direct services and advocate for the well-being of New London residents. At the same time, however, Connecticut College’s community-engagement programs can continue to offer opportunities for further work and assessment. Based on the enthusiasm of our participants, we believe that enough impetus exists to
begin a more systematic approach, allowing the creation of a long-term care support network in the future.

The fifth theme that emerged from our discussion refers to incorporating the safety issues affecting New London residents. These issues include a wide range of events from an older person’s fall, stroke, or heart attack to street violence and delinquency. Participants shared that exposure to these risks raises their vulnerability. Information on how to proceed and communicate with other residents is an important first step toward improving this risk management. We will further develop our website to include information on how to cover these types of risks in case of an emergency during the completion of Phase IV. The website must remain relevant and useful for our New London Hispanic community.

Finally, from a public policy perspective, we need to provide more customized long-term caregiving resources to Hispanics in New London who are experiencing the same issues that other communities nationwide are with their aging residents. Public policy changes require an additional level of community-based advocacy and action that are urgently needed in order to improve the well-being of aging minorities and their families. For example, our Hispanic community expressed a desire to address their caregiving needs beyond what our website can offer. There was agreement among participants that a case management center would be most appropriate. Our work as social scientists and drivers of social change can help lay out ways of action and find solutions to difficult problems. As we work in tandem with community partners, we will be in a better position to envision more ambitious projects such as the aforementioned case management center.

Conclusions

The New London Hispanic community will improve its well-being with better access to information on long-term care provision options for their families, elderly relatives, and friends. Our website will help fill part of the current information void in the community. In the medium- and long-term, however, a case management center with personalized help is ideal to best address information gaps, provide advice, make referrals and connect families with existing services. The consensus on both the relevance of the
website and the need for a case management center was felt strongly among male and female participants with various levels of education.

Participants’ responses to our research questions highlighted that our website is an important tool for Hispanic families because it has been conceived and developed with their needs and cultural identity in mind. Information should be supplemented with recommendations on preserving the safety of families and the provision of links to resources that can be used in crisis situations; website information should also be disseminated in hard-copy in a variety of institutions from schools to health-care centers; and Hispanic senior citizens in New London should be welcomed in social service agencies whose programs enhance their wellness.

Although we were aware of the social issues and occasional street violence in downtown New London, we were surprised by participants’ perceptions of unsafety and fragmentation. These perceptions reflect vulnerabilities and fear that are amplified among recent immigrants who, for example, feel unprotected given a rise in gang activity, drug trafficking, and possession. This adversity notwithstanding, participants showed empathy toward each other, commitment to address difficult situations, overall optimism and resilience. Despite expressed sentiments of disconnect, Hispanic families have the capacity to bond with one another and find ways to improve their living conditions.

One important implication of our research project is that addressing the needs of Hispanic families in New London will require additional public policy interventions. Policy interventions should include ways to seek caregiving support for families, aging parents, relatives, and friends. To help support the design of these interventions, college communities can often join efforts with social service agencies, community organizations, churches, and neighborhood representatives. Joint work can galvanize enough enthusiasm and commitment to meet the goal of providing in-situ, personal support to Hispanic families.

To encourage policy improvement, we feel a personal and professional responsibility to share our research with the New London community in addition to the academic community. In the near future, we will proactively share our work with key city officials and local agencies. We may not be
able to address all of the issues that our focus groups candidly shared, but we can start by being a louder voice and not just their ears.

References


