
Qualitative Research

Lessons learned from community-based participatory research: establishing a partnership to support lesbian, gay, bisexual and transgender ageing in place

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Abstract

Background. Due to a history of oppression and lack of culturally competent services, lesbian, gay, bisexual and transgender (LGBT) seniors experience barriers to accessing social services. Tailoring an evidence-based ageing in place intervention to address the unique needs of LGBT seniors may decrease the isolation often faced by this population.

Objective. To describe practices used in the formation of a community-based participatory research (CBPR), partnership involving social workers, health services providers, researchers and community members who engaged to establish a LGBT ageing in place model called Seniors Using Supports To Age In Neighborhoods (SUSTAIN).

Methods. A case study approach was employed to describe the partnership development process by reflecting on past meeting minutes, progress reports and interviews with SUSTAIN's partners.

Results. Key partnering practices utilized by SUSTAIN included (i) development of a shared commitment and vision; (ii) identifying partners with intersecting spheres of influence in multiple communities of identity (ageing services, LGBT, health research); (iii) attending to power dynamics (e.g. equitable sharing of funds); and (iv) building community capacity through reciprocal learning. Although the partnership dissolved after 4 years, it served as a successful catalyst to establish community programming to support ageing in place for LGBT seniors.

Conclusion. Multi-sector stakeholder involvement with capacity to connect communities and use frameworks that formalize equity was key to establishing a high-trust CBPR partnership. However, lack of focus on external forces impacting each partner (e.g. individual organizational strategic planning, community funding agency perspectives) ultimately led to dissolution of the SUSTAIN partnership even though implementation of community programming was realized.

Key words: Ageing, at-risk groups, CBPR, geriatrics, gay, lesbian, bisexual, transgender (GLBT) issues, health disparities.

Introduction

In its ground-breaking 2011 report 'The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding', the Institute of Medicine stated that culturally competent health and social services for lesbian, gay, bisexual and transgender (LGBT) older adults are lacking nationwide (1). It is estimated that 5–10% of the older adult population (2–7 million) identify as LGBT (2). Older LGBT adults experience higher risk of disability, poor mental health, smoking and excessive drinking than their heterosexual counterparts (3,4), yet LGBT seniors are five times less apt to access public and community services due to fear of discrimination or harm (2). Compared with heterosexual seniors, LGBT seniors are more likely to live alone and are at higher risk for poverty, homelessness, social isolation and premature institutionalization (5). LGBT older adults consistently identify senior housing, transportation, legal services, social events and support groups as the most needed services (4). In a 2010 survey of older LGBT Coloradoans, two of the most important social service-related issues identified were 'increased support and services for LGBT elders' and 'access to LGBT-welcoming health care' (6).

A model that has been successfully used nationwide to help older adults access necessary resources and maintain independence, increase life satisfaction and sustain neighbourhood stability is the Naturally Occurring Retirement Community (NORC) (7,8). NORC programmes blend the principles of community organizing with strategic approaches to providing services by promoting proactive engagement of seniors in developing communities that will provide for their needs into the future (www.norcblueprint.org). Both 'Outing Age 2010' (2) and 'Healthy People 2020' (9) identified the promise of community partnerships as key to developing programmes and services that welcome, support and respect LGBT older adults. Frameworks to address health disparities that stress the importance of equitable partnerships between research and a vulnerable population include community-engaged research, participatory action research and community-based participatory research (CBPR) (10–12).

In the context of determining how to best address gaps in social supports and health disparities for a population of disenfranchised seniors, we formed a CBPR partnership called Seniors Using Supports To Age In Neighborhoods (SUSTAIN). The ultimate goal of SUSTAIN was to establish and adapt an LGBT focused NORC model in a Denver, Colorado neighbourhood. This paper describes how SUSTAIN was guided in its formation, growth and eventual dissolution by CBPR principles and shares transportable lessons that communities, service providers and researchers can use when forming strategic partnerships with vulnerable populations.

Methods

Community-based participatory research partnership description

SUSTAIN was funded in 2010 as a partnership between researchers at Kaiser Permanente Colorado, service providers at Jewish Family Service, and the Gay, Lesbian, Bisexual, and Transgender Community Center of Colorado (The Center). SUSTAIN grew to encompass multiple disciplines and community members with diverse expertise including several LGBT older adults (≥ 60 years); individuals representing social service agencies with expertise in healthy ageing, housing, care management and advocacy; The Center; an LGBT affirming church; two civic engagement

organizations; a regional Area Agency on Aging; a non-profit health care and research organization; a university researcher specializing in ageing and social networks; and a graduate school of social work intern. SUSTAIN held its meetings at The Center, and rotated meeting facilitation and minute-taking to assure all partners were fully included. While partners took the lead on specific tasks according to their expertise, all provided input.

Case study methods

A CBPR approach was used to guide the formation and work of the SUSTAIN partnership. This manuscript draws on information produced during the life of the SUSTAIN partnership, including (i) reports required by the funders jointly written by community and research partners, (ii) meeting minutes, (iii) a report from a multi-day intensive strategic planning process undertaken by the partnership and (iv) interviews with SUSTAIN partners. In one case, partner interviews were done by local media for an online newsletter story about SUSTAIN. Other informal interviews were conducted by one of the SUSTAIN partners to publish information in their church news bulletin. A third series of interviews was conducted by a Colorado Clinical Translational Sciences Institute (CCTSI) evaluator (KN) for a report on the partnership. The authors reviewed these data and reflected on their own experience as partners in constructing the descriptive analysis of the SUSTAIN journey. We explored how SUSTAIN embodied the core constructs of CBPR initially outlined by Israel *et al.* such as building on the strengths of the community; facilitating a collaborative exchange of skill, knowledge and resources; and explicitly attending to power and privilege dynamics by co-creating and adhering to core values, sharing decision making and leveraging the diversity of experience of all partners (13,14). In addition, we applied the cross-cutting constructs of the revised CBPR conceptual model of Belone *et al.* (15) (i.e. trust development, capacity, mutual learning and power dynamics) to guide our reflections on the partnering practices and lessons learned.

Results

Developing a collaborative and trusting partnership

SUSTAIN grew out of a shared concern among early partners that LGBT seniors had unique needs due to a history of oppression coupled with concerns that culturally competent services for LGBT seniors were lacking. It started with a straight ally to the LGBT community, the senior services director at a regional affiliate of Jewish Family Service, who had experience implementing NORCs in other communities in metropolitan Denver. She brought her vision to adapt the NORC model to LGBT seniors to both the Denver Office on Aging and the Denver Gay, Lesbian, Bisexual and Transgender Commission. By sharing this concept, collaborations were established such that the early group of SUSTAIN stakeholders bridged key areas in the LGBT, ageing and research spheres. For example, one member of the Denver Commission also served as a community-research liaison funded by the Community Engagement Core of the CCTSI. In turn, she reached out to a colleague with research experience on successful ageing in community. Another member of the Denver Commission, a health care provider at the city's safety net hospital, secured funding for a social work intern to conduct an initial community needs assessment and literature review. These efforts brought together a diverse team dedicated to the shared concern of addressing this nearly invisible segment of seniors.

SUSTAIN quickly identified a critical missing partner, The Center. This statewide, non-profit organization serves as a promoter of LGBT advocacy, education and social activities and houses the regional affiliate of Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders (SAGE). The community-research liaison, a frequent volunteer at The Center, met with the director to describe the project and invite The Center to join the partnership. Despite the existing positive relationship with the liaison and other SUSTAIN partners, the director expressed great scepticism about involving The Center in research and described past experiences with researchers who ‘used’ The Center and its resources; failed to include The Center in the research process; provided inadequate compensation; and did not offer authorship on publications.

Fortunately, we were able to address the relational mistrust because the CCTSI Partnership Development Grant was structured to emphasize equity not only financially (community partners were required to receive at least 50% of the funding) but also in terms of project design, implementation, assessment and dissemination. Research and community partners were required to jointly attend trainings on community-engaged research, collaboration, history and purpose of the institutional review board and determinants of health. This community-affirming grant structure gave the director the security she needed to engage The Center in SUSTAIN. One community partner expressed:

It was most gratifying as an older gay man to experience such support and affirmation from both our partners and members of the larger community. Being a CCTSI partner, in some ways added legitimacy to our sometimes discounted status in society. It is much appreciated.

CBPR was an ideal partnership development approach for several reasons. Foremost, the impetus for SUSTAIN came from community service providers and embedded community members. Their vision was to address health disparities using a NORC model for older LGBT adults in a Denver neighbourhood, focusing on this community as a specific unit of identity. The community members desired a research-based, needs assessment methodology because they saw local evidence development as critical to gaining the needed support for a successful and sustainable implementation. The CBPR principal of integrating knowledge and action for mutual benefit of all partners was evident by the joint publication of our findings (16,17) and the capacity eventually built within the community to provide services to LGBT seniors. Alignment of the partnership’s main goal with the principals and processes of CBPR was critical to SUSTAIN’s achievements. One research partner summed this up as:

I have learned what community-based participatory research can look like in its purest form...where a group of diverse, multi-disciplinary folks come together around a common interest/issue, and together, write a grant, plan the work, share all aspects of the work, and grow to respect what each person brings to the table, both personally and professionally.

Bonding and attending to power dynamics

The partnership development funding specifically encouraged the team to spend time building rapport. SUSTAIN spent the first few meetings focused on getting to know each other both professionally and personally—understanding not only each partner’s expertise and skills but also what life experiences had brought each partner to the table. An assignment prior to the first meeting asked: ‘What attracted you to the project?’ and ‘What “wildly audacious goal” do you have for this partnership?’. The two question exercise proved to be a non-threatening stepping stone to talk about experiences in the gay and straight communities, share coming out stories (as an LGBT individual or straight ally) and discuss generational differences in perspectives. In addition, a safe space was created to ask about labels and clarify myths and stereotypes. Discussions were sprinkled with communal laughter, as well as personal struggles and successes in owning one’s truth and respecting that of others, and proved to be profound in creating strong, trusting bonds. As one community partner reflected:

After the first couple of meetings I realized everyone was involved because they believed in the need to provide a safe, culturally competent, and socially rewarding environment for LGBT seniors. We are realizing the power of the partnership—that we each, as individuals and organizations, needed the expertise, skill, passion, and personal experiences of the other to make this work. This is true community-based participatory research, and it feels wonderful!.

From this platform, the important processes of defining a vision, mission, core values and partner roles, moved smoothly, quickly and fairly painlessly! Having a clear vision, mission and values in place (Table 1) provided immediate context for introducing the project to new partners. As one researcher said,

This is a phenomenal group of partners, whatever challenges come our way, the partnership figures out a way to solve them and move forward. Everyone pitches in. Two of our original participants left for other jobs. Their replacements are equally up to the job and are as well qualified as those who left. The commitment in this group is such that the new members were absorbed and welcomed with no problem.

Table 1. Seniors Using Supports To Age In Neighborhoods partnership vision, mission and core values

Vision	A community where LGBT seniors are able to age in a safe and trusting environment.	
Mission	Through the use of research methods, we will assess the needs, strengths and resources of the community. We will identify key stakeholders and build partnerships to enable us to define and move toward the creation of a safe and trusting environment for LGBT seniors.	
Core Values	LGBT	Clearly our focus.
	Active inclusion	This means that LGBT seniors are involved in our process and that we actively will seek racial and ethnic diversity.
	Choice	The model we implement will allow LGBT seniors to remain in their homes if they choose to do so.
	Neighbourhood	The model we implement will retain the character and integrity of the neighbourhoods we work in.
	Cultural competence	Whatever services and supports we identify will be competent to serve LGBT elders.
	RESPECT	Realize Every Single Person’s Experience Carries Truth; Realize Every Single Person’s Experience Can Teach. We honour and value the diversity we bring.
	Confidence	We will strive to create an atmosphere that earns the confidence of each partner, stakeholder and constituent.

Building capacity through mutual learning

Building capacity to successfully conduct the project was an important, shared commitment by all team members. Within the first year, community and research partners participated in learning sessions designed to facilitate shared language across the social work, community building and research disciplines. Community-based and research-based partners participated in a three-part seminar on the principals of CBPR and completed the Community Capacity Building Tool (http://www.phac-aspc.gc.ca/canada/regions/ab-nwt-tno/documents/CCBT_English_web_000.pdf). Community partners completed IRB and HIPAA training, so they could fully participate in the collection, analysis, interpretation and reporting of data. Research partners completed Project Visibility Training (<http://www.bouldercounty.org/family/seniors/pages/projvis.aspx>), a community-based training developed to increase the capacity of providers to offer ageing services that are informed, sensitive to and supportive of LGBT seniors.

Activities such as identifying critical partners and engaging in social network analysis were important to assuring connections to key stakeholder groups as well as identifying potential advocates to promote the partnership's activities. Early SUSTAIN meetings included a demonstration of the PARTNER tool (www.partnertool.net), a social network analysis programme that assists in identifying gaps and redundancy in the partnership and informs strategic planning. The team also received group training on the Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) evaluation framework (18). These joint learning sessions served to increase individual partners' self-efficacy in conducting CBPR as well as to expand SUSTAIN's network of allies and experts.

One of the core values identified early on by the partnership was Realize Every Single Person's Experience Carries Truth/Realize Every Single Person's Experience Can Teach (RESPECT). Identifying this value explicitly allowed all partners to simultaneously be both experts and students; thus, making it acceptable to ask questions without shame and increase our knowledge as a group. Partners expressed:

Our research partner has been a wealth of information. I have learned about other methods and means of research. I am actually going to be able to use one of the resources (RE-AIM) to help me organize and structure a totally different project. (Community Partner)

Since my full time world is research I don't believe I've learned too much more in terms of 'how to' in producing tangible products. However I have learned a LOT about the importance of having supportive and positive relationships. (Research Partner)

Research to address barriers to ageing in place

The partnership identified two main questions pertaining to LGBT seniors ability to age in place within this community: (i) what are the gaps/barriers and existing assets to support successful ageing (16) and (ii) are there culturally competent support services available (17)? The partnership conducted needs assessment activities, taking advantage of existing cultural and organizational events. Research and non-research partners participated in Denver's PrideFest by volunteering at several partner organization's booths, and conducting intercept surveys with older adult community members, to begin to identify health and service needs. In addition, one of the research partners participated in weekly meetings of a senior gay men's coffee group. Having initially disclosed SUSTAIN's mission and consistently showing-up for coffee and conversation, the researcher gained the men's friendship and trust. This was critical to the researcher's subsequent ability to conduct a focus group with these men to learn about their existing assets and challenges to ageing in their neighbourhood.

Implementation of knowledge gained and dissolution of the partnership

SUSTAIN carefully assembled itself over the course of a 2-year period, devoting time to building relationships, galvanized by a shared vision and mission, as well as norms, operating agreements and defined partner roles. Over the next several years, continued CBPR funding enabled the partnership to perform both a community member (16) and health and social service provider needs assessment (17), and local foundation funding was obtained to establish physical activity programming for LGBT seniors at The Center. The momentum from the partnership led to support from The Colorado Trust that enabled SUSTAIN to bring in new partners to conduct a strategic planning process. The group decided that developing culturally competent care management services would be the next step to best support LGBT seniors ageing in place. As the strategic plan blossomed (Table 2), controversy arose about whether one of the specific partners versus SUSTAIN itself should own and execute this work. Initial concerns were rooted in the fact that a local funding agency was interested in the concept but wanted an established organization to receive the funding. At the same time, SUSTAIN became aware that The Center's Board was in the midst of its own strategic planning process that included senior programming goals with significant overlap. As one SUSTAIN research partner stated,

We needed an exit strategy up front. We needed a way for people to comfortably say, 'Okay, I'm done', or 'I feel like I'm needing to be done'.

Ultimately, SUSTAIN decided to dissolve the partnership because others were better positioned to continue to build on the legacy of enhanced community supports and programmes to serve LGBT seniors. Efforts to promote LGBT seniors ageing in place have continued at The Center with establishment of the Care Link programme (<https://capitolhillcarelink.org/>) that coordinates care by referring individuals to community partners for help with services such as benefits counselling, in-home assistance and transportation in addition to providing community members with opportunities to participate in social, educational and volunteer activities. Another outcome that the SUSTAIN partnership played a role in bringing to fruition was the accreditation of The Center as a Silver Sneakers® site, which provides physical activity classes for LGBT seniors in a welcoming environment. In the words of one community partner,

SUSTAIN planted a seed [for the] senior LGBT focus that exists today.

Discussion

SUSTAIN applied the principles of CBPR to address health and social service needs in the isolated, marginalized community of LGBT seniors. Each of the organizations initially involved in this partnership had unique expertise but shared common values including openness to partnerships with community organizations and local agencies; belief that community member involvement in development and management of community initiatives was integral to sustainability; and understanding that an emphasis on culturally competent resources for all seniors was of the utmost importance. Similarly, the NORC model that SUSTAIN proposed to adapt for LGBT seniors had its foundations in community organizing but emphasized the importance of needs assessment and strategic planning, two areas integral to the research process. By understanding the multiple roles and overlapping identities of the partners, SUSTAIN was able to align areas of interest and develop a shared sense of community. This essential CBPR principal requires identifying and working

Table 2. Strategic plan blueprint for Seniors Using Supports To Age In Neighborhoods

Vision	A community where LGBT seniors are able to age in a safe and trusting environment		
Mission	Promoting the health and well-being of the Capitol Hill LGBT senior community in a safe and trusting environment		
Goal	Strategy	Activities	Indicators of success
Prevent people from having to move out of their community or home (allow ageing in place)	Further develop SUSTAIN governance and infrastructure	Develop operating principles and governing structure	Seven new committee members who are potential consumers recruited and become members
		Define criteria for SUSTAIN Advisory Committee membership Recruit consumers to serve on SUSTAIN Advisory Committee Recruit Advisory Committee members who meet defined criteria	Operating principles and governing structure written and approved by SUSTAIN Advisory Committee
	Develop short and long-term funding plan	Apply for funding to hire development consultant to create a short- and long-term sustainability plan Advisory Committee members 'network' with philanthropic organizations/individuals and opinion leaders	SUSTAIN Advisory Committee will have a development plan List of individuals and organizations that are aware of SUSTAIN
Empower senior LGBT community in Capitol Hill; use resilience framework in services	Identify community members at risk of not ageing in place	Create relationships to learn who individuals are who are at risk of not ageing in place	Number of identified consumers who take advantage of/participate in SUSTAIN
		Incorporate appropriate evaluation and assessment tools	Develop, utilize evaluation and assessment tool for client intake
		Develop marketing/outreach plan	Recruit Advisory Committee member with marketing expertise Develop 18-month marketing plan
Decrease isolation	Increase social activity	Identify current services for LGBT seniors in Capitol Hill	X% of identified seniors have heard about SUSTAIN and know about services
		Identify where LGBT seniors in Capitol Hill spend time/money	Reach target number of community business relationships
		Build relationships with community businesses/create incentives for them to participate	Increased attendance at social activities Reach target number of volunteers
		Ensure enough diverse social gatherings Recruit intergenerational volunteers Identify safe/trustworthy spaces, health care providers and businesses	

within existing communities of identity and discovering where they overlap (13).

Acknowledging intersecting spheres of influence allowed for quicker acceptance and trust among SUSTAIN partners and set the stage for the partnership's ability to connect the ageing, LGBT and research communities. Identifying these bridging individuals has been called out as an important facilitator of both individual and group dynamics in CBPR (15). A significant barrier SUSTAIN overcame in establishing the partnership was reluctance on the part of a key partner, The Center, to engage in a research endeavour due to prior experiences that felt exploitative. This barrier has been noted in CBPR partnerships involving other vulnerable communities (19). The fact that the researchers involved had existing ties to the LGBT community helped to allay The Center's anxiety; however, the funding mechanism, because of its emphasis on equity, was the critical link to obtain support and trust from The Center.

The strong focus on building trust that supported the partnership development and the ability to perform community needs assessments was critical to the early success of SUSTAIN. As others involved in CBPR projects have emphasized, a major strength underlying the high level of engagement of the partners was involving team members in reciprocal learning activities (20). Fostering an environment of openness and sharing early on (e.g. discussing 'coming out' stories and 'wildly audacious goals'), developing a mission and vision and identifying roles avoided the 'storming and

conforming' stages of group development that often need to be worked through for a team to move from 'forming' to 'performing' (21). While taking time to do this work may feel uncomfortable or too personal, as opposed to focusing immediately on tasks to produce outcomes, the time spent built a foundation of safety and reciprocity, a necessary context for successful CBPR (15). This high-trust environment also paid off later when turnover of some team members required indoctrinating replacements quickly (22).

Importantly, a vision strong enough to bring together a diverse group of stakeholders may not be adequate to support the partnership over time. Partners should revisit the strategic plan (vision, mission, goals, approaches and partner roles) on a regular basis and be prepared for the reality that organizations and individuals sometimes grow apart, particularly as partners change, funding priorities shift and institutions redirect focus. Early on, mechanisms should be created for partners to safely and constructively communicate the need to exit so that the impact on the integrity of the partnership can be minimized. Another key learning was to ensure that partners include and/or represent organizational decision makers and that their boards are supportive of partnership goals and stay informed of each major milestone accomplished. Others have also noted challenges in implementation related to change agents being external and having limited influence on management (23). Thus, regardless of the level of established trust, memorandums of understanding should be created for enhanced accountability.

Conclusion

In hindsight, the partnership was hindered by lack of attention to ensuring that the boards and higher-level leaders of the partner organizations and potential funders were aware of SUSTAIN's work. Although initially a reluctant partner, The Center eventually chose to fully embrace improving community access to new services for LGBT seniors. It was critical for SUSTAIN to understand that our success was serving as a catalyst but that The Center was best suited to obtain funding and develop the infrastructure for ongoing programming. Dissolving the partnership did not equate to failure. Rather, we believe the long-term success of this CBPR partnership should be measured by the capacity developed within the community and the successful implementation of community programming.

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