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Merging Person-Centered Care with Translational Research to Improve the Lives of Older Adults: Creating Community Based Nursing Research Networks

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Abstract

Translational research is a leading trend in science with the aim of bridging the research-practice gap in order to significantly speed the implementation of effective interventions in clinical practice. Integrating the values and preferences of older adults and their families in this process is critical to the success of translational research. Engaging communities in meaningful research is an important part of advancing translational science in which the older adult is a partner in developing solutions to the health needs of individuals within communities. This article describes one approach to developing an infrastructure to support patient-centered care within translational research, establishing a Community Based Nursing Research Network. Nurses throughout our communities are uniquely poised and prepared to assume leadership roles in community based research networks in order to support a true collaboration among stakeholders which prizes the voices of our older adults and integrates them into practice efforts.

Introduction

While researchers have made significant strides in the diagnosis, treatment, and prevention of serious health concerns, few of these advances have made their way into everyday practice. In fact, it takes an average of 17 years for only 14% of new scientific discoveries to be integrated into practice (Green, Ottoson, Garcia, & Hiatt, 2009). Leading funding agencies and clinicians have questioned the extent to which huge investments in health-related research produce changes in practice that actually improve the health of the general population. In response to this query, a new emphasis on translational research has emerged as a leading trend in science. Translational research bridges the gap between research and research application, stimulating an interactive feedback loop that allows research to inform practice and practice to inform research (Grady, 2010). Therefore, collaborations between nurse scientists and practicing nurses are critical to the success of the translational research process, and ultimately the successful infusion of research findings into the existing infrastructure of everyday nursing practice.

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Translational research challenges scientists to think beyond the laboratory into real world practice settings. Nurses have traditionally embraced this perspective as clinical experiences or problems are addressed through systematic investigation, and new practice initiatives are designed and implemented. Given our history, nurses are instrumental team members for advancing translational science. Perhaps more importantly, nurses have long recognized the importance of the patient/family's voice in developing strategies for achieving optimal health. Person-centered care does not simply address the impact of services on an individual; rather, it is concerned with the importance of the experience for the individual and family receiving those services (Frankl, 2005). The involvement of patients and families in health research has emerged as significant trend in outcomes research; for example, the Patient-Centered Outcomes Research Institute focuses on the meaningful involvement of patients and other stakeholders across all phases of research (see: <http://www.pcori.org/about-us/landing/>). Older adults have been the focus of many person-centered care initiatives, and with good reason. The potential for the voice of older adults to be lost, particularly given the vulnerability associated with multiple chronic conditions and cognitive impairments (Kitwood, 1997), necessitates a person-centered approach in the continuum of nursing care but also in nursing research.

Person-centered care is not solely about outcomes, but also about *process*. Techniques for systematically integrating values and preferences of older adults and their families into a plan of care that optimizes health through the delivery of the best of our science are sorely needed. Such an approach merges person-centered care and translational science, shaping a new paradigm for improving health. The purpose of this article is to describe one approach for developing an infrastructure to support person-centered care through community engagement research by capitalizing on the unique strengths of nurses as community partners and research project leaders. Community Based Nursing Research Networks can serve as a foundation for gerontological nursing research focused on person-centered care, while building and supporting a strong research role for practicing nurses in clinical and community sites.

In the following sections, community-engaged research is first described, followed by discussion of the important role of the gerontological nurse in Community Based Nursing Research Networks. We then describe our experience at the Penn State College of Nursing as one example of promoting the role of practicing gerontological nurses in developing the evidence for person-centered care for older adults.

Community-Engaged Research

Community-engaged research has emerged as a critical component to fill a significant void in translational science: creating systems and processes for infusing new knowledge in order to improve the health of communities much sooner than the traditional 17-year pipeline to practice. Engaging communities in meaningful research has well-documented benefits including improving the relevance of research questions based on community needs, including more diverse and representative samples, and improving the speed and extent to which research findings are put into practice within communities (Israel, Schulz, Parker, & Becker, 1998; Minkler, Blackwell, Thompson, & Tamir, 2003; Viswanathan et al., 2004).

Community-engaged research brings together academic researchers and communities in a collaborative partnership for research, rather than the traditional approach to research in which investigators control all aspects of a project. The perspective of community members throughout all phases of research is essential for providing additional insight into understanding health problems, guiding recruitment strategies, improving the reliability and validity of measures, ensuring relevance of research methods and intervention strategies, identifying meaningful paths for dissemination, and maximizing the potential for translation into practice (Cargo & Mercer, 2008; Isler & Corbie-Smith, 2012; Minkler, 2005).

A community-engaged approach to research provides a unique opportunity to integrate patient-centered care into home- and community-based settings for older adults by providing structured venues for older adults to assume a more active role. Ideally, the voice of community-dwelling older adults and their families would be heard in the identification of prioritized needs for enhanced health care and supportive services, meaningful goals for work, volunteer, or social integration opportunities, and intervention plans which reflect community needs and values (Ruggiano & Edvardsson, 2013). There is growing evidence that supports the utility of community-engaged methods for producing meaningful outcomes for older adults. For example, the Beat the Blues intervention for depression was tailored specifically for older African Americans and implemented in partnership with a community-based senior center (Gitlin et al., 2012). Following the four-month multi-component, home-based intervention, participants in the intervention group were more likely than controls to enter remission. They also demonstrated clinical meaningful reductions in depression severity, as well as improved mood, quality of life, and depression knowledge (Gitlin et al., 2013). From development of the intervention through connecting with a difficult to reach target group for intervention delivery, community-engaged research methods were crucial to Beat the Blues' success.

Nursing's Potential in Community-Engaged Research

In order to facilitate person-centered care and associated positive outcomes, engaging communities in research must also include the engagement of nurses working within those communities. Nurses who care for older adults across settings understand the needs of their patients, are trusted and respected members of their communities, and understand the community's culture and context. Therefore, gerontological nurses have critical roles to play in both developing the evidence for person-centered care as well as the translation of this evidence within community-engaged research initiatives. A Community Based Nursing Research Network capitalizing on nursing's role in communities is proposed as a viable strategy for addressing the need for sustainable community engagement that amplifies the voice of older adults and their families who live their health experiences in a given community.

Nurses are highly respected community members who know the local health care delivery system, inherent gaps in services, and critical attributes of the community as a collective system. Community engagement is not new to nursing—the discipline has been built upon a strong tradition in promoting public health. Consider the historical roots of nursing. Florence Nightingale aptly pointed out the significance of environment on health and worked to

improve the sanitary conditions within the communities of the Crimean War (Nightingale, 1859). Later in 1906, Lillian Wald coined the phrase “public health nurse” through her work with the Henry Street Settlement in New York City, where she worked tirelessly to improve the community conditions that contributed to poor health outcomes in the vulnerable poor (Fee & Bu, 2010). As ethnographic studies of communities emerged in the 1970’s–1990’s, the powerful influence of community structures and functions on health were highlighted and the importance of local knowledge, that is, the knowledge and experience of those experiencing health in a given community, was acknowledged (Kulbok, Thatcher, Park, & Meszaros, 2012). Steeped in a rich tradition of collaboration with community members, the role of nurses in community health work is described by Meadows (2009) as working with “diverse partners and providers to address complex challenges in the community. Nowhere is this more evident than in current efforts ... to help the elderly effectively manage their chronic health problems and remain at home” (p.19). Clearly, nursing is central to *interdisciplinary* or even *transdisciplinary* efforts to engage communities in research designed to improve health outcomes.

While community-engaged research involves community members in the research process, including nurses in these initiatives is crucial to changing gerontological nursing practice. Practicing nurses have an important role to play in developing evidence for better care as well as determining the best ways for disseminating and implementing this evidence across care settings. Nurses providing care to elders as well as mentoring new nurses are a pivotal link between the needs of older adults and the context of the healthcare delivery system.

Establishing Community Based Research Networks

Principles of Community Engagement were developed collaboratively by the Clinical and Translational Science Awards Consortium’s Community Engagement Key Function Committee to assist in the planning, design, implementation, and evaluation of community engagement efforts in order to form effective partnerships (National Institutes of Health, 2011). At the Pennsylvania State University College of Nursing (PSU CON), we have embraced these principles to guide the development of a sustainable Community Based Nursing Research Network (CBNRN), responsive to the needs of older adults and organized to address: 1) what to consider prior to beginning engagement; 2) what is necessary for engagement to occur; and, 3) what to consider for engagement to be successful. In the following sections, discrete strategies for establishing the CBNRN’s focus on situating nurses as instrumental partners in collaboration with older adults and their families are described within each category. The network-building project currently underway at the PSU CON is introduced as an exemplar of enacting these strategies and following established community engagement principles in order to build nursing research capacity, deeply embedded within diverse communities across a statewide geographic area. While our CBNRN capitalizes on the strengths of PSU, such a network need not be exclusive to academic institutions. The Principles of Community Engagement can be applied to building similar networks outside of the university setting; however, such links with nurse scientists and others with research expertise are foundational to the community-engaged research process.

Nurses throughout our communities, including nurse clinicians, educators, and administrators, are all valuable potential partners for community-engaged research. A background in research methods is not a necessity. With shared goals of improving the health and well-being of older adults as well as partnering with elders in the community to include their voice in patient-centered research and practice, the competencies necessary to collaborate with a research team can be built within an academic-community partnership. A true partnership involves recognizing and utilizing the strengths of all members. Nurse scientists can guide and mentor other nurses in the research process, while nurses involved within their communities contribute their own unique expertise and community connections. Throughout this process, nurses within community settings become Community Nurse Partners, prepared to extend the CBNRN to organizations and individuals with ties to the target group, older adults, and with the critical knowledge to share regarding communities needs and priorities.

What to Consider Prior to Beginning Engagement

Before setting out to establish a CBNRN with a specific focus on nurses as leaders, an assessment of available nursing leadership resources is essential. Available networks rich in nursing resources may include schools of nursing, visiting nurse organizations, healthcare systems, or professional organizations. Nurses within these organizations are a unique and valuable initial contact for community research collaboration; they are part of an intricate network of community health resources, covering all life stages, levels of care, and community demographics. The evaluation of available assets sets the scene for positioning nurses as leaders in engaging community-based organizations and individuals in the development of a patient-centered CBNRN. Given our rich history in understanding public health, nurses are optimal leaders in the CBNRN movement.

Assessing available assets, whether at the level of one community or across a large geographic area, is critical, but nurses identified as potential Community Nurse Partners must be interested in collaborating. Without an understanding of the community-engaged research process or the CBNRN itself, it will be challenging to engage busy nurses in such an undertaking. Therefore, the next steps must involve clearly articulating the goals of the CBNRN, building interest and excitement, and developing a true sense of camaraderie and shared vision for the CBNRN. Effective partnerships must be mutually created. In order to stimulate interest in the development of a CBNRN, consider hosting a networking event to engage potential Community Nurse Partners in community-engaged research. This type of an event is not a typical continuing education offering, it is a *networking* event with essential education infused in short segments. At its conclusion, participating nurses should be able to describe the purpose of the CBNRN, have a basic understanding of the value of Community Nurse Partners within communities, and be able to share initial ideas regarding how their own interests and expertise can contribute to the CBNRN.

Inviting nurse leaders to interact with researchers who are involved with community based research exposes new opportunities for future interactions. It is important that the introductory event be stimulating and engaging, highlighting the potential for community-engaged research to impact local communities. At the same time, it is critical to focus

attention on the interests and community-based concerns of the nurse participants. Openness and flexibility which allows everyone's voice to be heard will inspire interest as well as foster the creative space necessary to address the complexities of forming these collaborations. In short, balance the importance of local knowledge with the expertise of researchers.

In preparation for leadership roles in community-engaged research, many nurses will require focused education in research processes and procedures. But, beyond the mechanics of research, these partners will be instrumental in identifying and building relationships with community stakeholders. In order to establish the expertise needed to facilitate community engagement, more advanced preparation is needed. Understanding the Community Nurse Partner's role in community based participatory research provides a framework for addressing collaborative engagement (for example, see Allen, Culhane-Pera, Pergament, & Call, 2010). Community based participatory research is a standard technique for engaging communities that accentuates the community nurse's role in the process. Emergent Community Nurse Partners must be adept at non-hierarchical approaches to group processes, strategies for working through conflict and reaching consensus, and team leadership/facilitation skills. These skills can be taught, but more importantly, they must be modeled and reinforced over time. This raises another consideration in the pre-launch phase: developing a mentorship model.

Thoughtful investment in initial preparation of nurse leaders for CBNRN builds commitment and generates a sense of expertise. Careful consideration of potential Community Nurse Partners is recommended to tap into available resources or networks. For example, as a land grant university, the significant thrust of the mission of PSU CON is to enhance the health of citizens of the Commonwealth. The PSU CON is organized with centralized administrative accountability for pre-licensure and graduate programs at 12 campus locations across the state. The PSU CON faculty includes a large group of masters- and doctorally-prepared nurses with deep ties to their communities across the state, extensive expertise in their clinical areas, and understanding of the care delivery system in their respective communities. The College is also fortunate to have a Hartford Center of Geriatric Nursing Excellence, a unit that promotes high quality care of older adults through education and awareness. In addition to these resources, PSU CON is involved with University's Clinical and Translational Science Institute, particularly with the Community Engagement Research Core. Collectively, the system presents a wealth of opportunity for grooming active nursing partners in the CBNRN project.

Seizing this opportunity, a networking event was sponsored by the Penn State Center for Nursing Research. An open invitation was sent to faculty inviting them to meet academic researchers and explore the potential for collaborative engagement. Educational segments (e.g., the cycles of translational research from bench to population) were kept brief, no longer than 15 minutes. Facilitation of the event focused on collaboration as equal partners, highlighting the importance of the local community knowledge held by the faculty members. At the closing of the day, the collective group discussed the skills needed by non-research faculty in order to promote stronger research collaboration. This discussion was used to refine the curriculum of the training sessions for our Community Nurse Partners,

highlighting the need for topics such as ethical issues faced in research, principles of recruitment, training on the protection of human research subjects, and writing for publication (see Table 1). As senior researchers interacted with faculty participants, the seeds of mentoring relationships were sown as relationships were initiated.

What is Necessary for Engagement to Occur

The identification and preparation of nurses for roles as Community Nurse Partners sets the scene for the next phase of developing a CBNRN: preparing these nurse leaders to develop and engage in community-engaged research partnerships. Developing the skills necessary to collaboratively lead a community based research project will require a certain level of formal training as well as adaptive mentorship which is focused on the relationships and needs within the communities of interest. One valuable benefit to engaging advanced practice nurses and clinical faculty as Community Nurse Partners is the foundation of knowledge which CBNRN-specific training can build upon. Although these nurse leaders may have minimal experience with nursing research, they have had relevant coursework and are certainly familiar with the role of evidence-based practice and the importance of the translation of research findings into clinical arenas. Depending upon the familiarity and expertise of the group, tailoring of content may be important. This does not imply that Community Nurse Partner groups must be homogenous; indeed, differences in experience and expertise should be viewed as highly valuable to the partnership. Table 1 provides a basic guide to curriculum which the PSU CON has identified as necessary for our group of Community Nurse Partners in order to adequately prime them to engage community members in research endeavors. The Wellesley Institute in Toronto has made publically available its community based research and capacity-building workshop materials (See Table 2). This extensive repository of twenty workshops ranging in topics from *Introduction to Community Based Research* to *Writing Effective Letters of Intent* to *The Fine Art of Volunteer Management* is available free for download, copy, and distribution, can be a valuable resource for developing a training program specific to your particular Community Nurse Partner needs.

As nurses transition toward implementing the collaborative strategies of community engagement, an experienced mentor can guide the developmental process and provide ongoing support. Consider framing mentorship as another opportunity for collaboration; mentors need not be nurses or academic researchers. Rather, search for experienced leaders in collaborative projects in targeted communities, organizations, clinical settings, or academic units. Invite potential mentors to interact with the nurse leaders during initial training sessions to establish relationships and determine the best match for the mentor-mentee dyad. If possible, the identified mentor group may have special concurrent sessions to highlight their roles in guiding the development of collaborative leaders.

Once Community Nurse Partners are prepared to launch their role as collaborative leaders within a CBNRN, the next step is to identify stakeholders in individual communities. Realistically, this process does not happen in a stepwise fashion, but likely has been paralleling the process of establishing the Community Nurse Partner infrastructure. Characteristics such as culture, economic conditions, social networks, political structures,

demographics, and previous efforts to engage community members in research-related projects are all important to consider (National Institutes of Health, 2011). A number of tools are available to guide community assessments (see Table 2 for related online resources). For example, the Department of Health and Human Services and the Administration for Children and Families offers a step-by-step approach and Rotary International provides a set of guidelines and tools to assess a community's strengths and weaknesses, ranging from survey development tips to community mapping. In addition, the Patient Protection and Affordable Care Act ("Patient Protection and Affordable Care Act," 2010), added new requirements for all non-profit hospitals to conduct a community health needs assessments and adopt an implementation strategy addressing these needs at least once every three years in order to maintain their tax-exempt status. These assessments can be valuable resources for CBNRN to target initial efforts matched to community health needs. Formal competency development with the Community Nurse Partners may also culminate in community assessments, conducted as a group or individual project, specific to a community of interest.

Given our interest in promoting the health of older adults, stakeholders relevant to services for older adults and their families are targeted within the PSU CON CBNRN. Again, local knowledge is critical to determining how the system works in a given community. As stakeholders are identified, consider the breadth and depth of the range of services targeting older adults in that community. Nurse leaders invested in the community will be able to relate instrumental partners in the care of older adults. For example, the Area Agency on Aging, adult day service providers, long term or acute care systems, rehabilitation providers, and home care service providers typically rise to top of mind. Thinking beyond this high impact group in the service continuum, consider pharmacies, transportation services, fitness centers or programs for seniors (including the YMCA/YWCA), hospice providers, faith-based groups, senior housing, support groups, patient advocacy groups, and older adults consumers themselves.

Reaching out to community organizations and leaders is a process rather than an event. Establishing relationships and building trust takes time, even when goals are shared. Prior to consideration of a research project, meetings with community groups should focus on building the partnership itself. Community engagement begins with relationship building and leads to research development that involves all stakeholders. The Tufts Clinical and Translational Science Institute developed a curriculum guide for community partners called Building Your Capacity (BYC; see Table 2). The BYC program was developed specifically for community organizations interested in increasing their capacity to participate in community-engaged research and was developed in collaboration between Tufts, Harvard, and Boston Universities along with two community partners in the Boston area. Rather than a prescriptive training program, the BYC program is a guide which can be used to implement a research capacity-building program with community organizations and health centers and is intended to be tailored to specific audiences based on needs.

What to Consider for Successful Engagement

Developing a promising infrastructure for community-engaged research, research competencies among Community Nurse Partners, and capacity within community organizations is the critical first step to support person-centered care through community engagement. However, it truly is only the first step. Through the strategies described, resources are developed for meaningful collaboration, but they must be mobilized and supported in order to bring about change. Benefits to all stakeholders must exceed the effort required to participate. And the effort expended by all partners in the CBNRN is substantial, including time and financial resources as well as the less quantifiable effort associated with navigating new relationships and the art of compromise (Staley, 2009). Benefits may include opportunities for networking, access to information and resources, personal recognition, learning, solutions for community problems, improved relationships among stakeholders, and increased problem-solving capacity (Butterfoss, 2006). Sustaining a CBNRN requires seeing through promises of benefits, and being creative regarding what might be most important to different constituents. Scientific research requires financial resources and such funding is typically project-based and time-limited. The CBNRN must withstand the ebb and flow of research funding in order to achieve long-term success.

Conclusion

Maximizing opportunities for older adults, their families, and the community agencies which serve them requires both expertise and relationships. The inception of the PSU CON CBNRN is focused on building capacity by engaging untapped human resources in the CON clinical nursing faculty and community partners in foundational training and coalition building activities. CBNRNs are a sustainable solution to factors inhibiting the rapid infusion of effective strategies to improve health in a collaborative manner including the lack of human resources prepared to engage in collaborative research in small communities and engagement of stakeholders as full partners in the research enterprise in order to address issues relevant to their constituent group.

Gerontological nurses throughout our communities are uniquely prepared to assume leadership roles in creating CBNRNs for translational research that incorporates person-centered care and ensures the voices of older adults are heard, valued, and included in the development of meaningful programs to address health-related needs. Translational research has direct clinical nursing implications since it bridges the gap between research and practice, and community based research has the potential to address several critical and common gaps in the care continuum such as transitions between care settings. Nurses working throughout their communities in various roles are all well-situated to partner with a CBNRN, extending their role as patient and family advocates to a new arena with significant implications for changing clinical practice. The trend toward translational research opens new doors for community based nurse clinicians and educators to assume a role in bringing evidence-based practice to a variety of settings while respecting the voice of the older adult consumer. Beyond health care, the potential of CBNRNs reaches into the social determinants of health that nurses know matter.

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Table 1**PSU CON Curriculum Model for Preparing Nurse Leaders in CBNRNs**

Foundational Research Training

- Overview of the role of the research nurse
- Understanding research protocols
- Principles of recruitment
- Applied ethics and required human subject protection training
- Processes of informed consent
- Data collection/specification of protocols/data management

Team Science

- Roles
- Functions
- Communication
- Contributions

Community Coalition Building

- Identifying stakeholders
- Building coalitions
- Best practices for sustaining/maintaining established coalitions

Dissemination

- Guidelines for determining authorship
 - Manuscript development/publication tips
 - Diversified venues for dissemination to consumers and community-at-large
-

Table 2**Online Resources for Building CBRNs**

Wellesley Institute Community- Based Research Workshops	http://www.wellesleyinstitute.com/publication/cbr-workshop-materials-now-available/
U.S. Department of Health & Human Services CCF/SCF Tools for Conducting a Community Assessment	http://www.acf.hhs.gov/programs/ocs/resource/conducting-a-community-assessment-1
Rotary International Community Assessment Tools	https://www.rotary.org/en/document/578
Building Your Capacity: Advancing Research through Community Engagement Curriculum Guide 2012	http://www.tuftsctsi.org/~media/Files/CTSI/Library%20Files/Building%20Your%20Capacity%20Curriculum%202012.ashx