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Challenges in community-based research with Latino migrant farmworker children and families

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Migrant and seasonal farmworker labor supports the U.S. fruit and agricultural industry with estimates of the workforce standing at one to three million (documented and undocumented) and 72% being foreign-born (68% with nativity in Mexico [U.S. Department of Agriculture, 2013; National Center for Farmworker Health, 2012]). Of these workers, 58% are married, 51% of those married are parents, and 69% have more than one child with an average of two children per family (U.S. Department of Labor, 2004). The exact number of children who travel with their families is unknown, but enumeration studies conducted in Michigan and Oregon show that there are approximately 14,800 youth under the age of 19 in Michigan (66% age 12 and under) and 55,000 in Oregon (72% age 12 years and under) (Larson, 2013a, 2013b).

Recommendations from the American Academy of Pediatrics emphasize research as an agent of change to improve the health of children, especially community-based research (Duggan, Jarvis, Derauf, Aligne, & Kaczorowski, 2005). Community-based research can address health disparities in vulnerable populations, such as migrant farmworker children, and considers social context with ecological factors that influence individual health and health behaviors. When a vulnerable group is the target enrollment population, an ethical researcher remembers that there is a difference in the conduct of research *with* any vulnerable population, compared to *on* a vulnerable population. The semantic of these two words (*with* compared to *on*) may imply partnership compared to exploitation. Migrant children may experience a broad range of health problems (e.g., exposure to pesticides), as well as psychosocial issues related to their itinerant lifestyle including being apart from extended family, disruption in school attendance, living in temporary housing in agricultural work camps, adapting to a new culture, and facing stigmas of non-citizenship (Council on Community Pediatrics, 2013). Community-based research may help address resulting health

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disparities; however, the conduct of community-based research with a migrant population has its challenges.

A review of the literature and shared anecdotal experiences by researchers who study migrant farmworker children and their families reveals common difficulties and challenges. Lessons learned will be shared here. Any researcher who engages in community-based research with the migrant farmworker as its research participants must first acknowledge that entry into the community comes with “baggage,” both positive and negative that includes the community’s previous experience with researchers and the research process (Wallerstein & Duran, 2006). These past experiences can encourage participants to enroll in studies acknowledging the benefits to self, neighborhood, and society. Or, dissuade them.

In community-based research, there is naturally a relationship between researcher and partners. Community stakeholders may have a vested interest in the success of the project and direction of results, and may become disenfranchised when outcomes are unexpected. Researcher bias must be minimized and objectivity maintained. Gatekeepers will have access to the community and its agencies, and need to be identified for participant recruitment. Letters of access from agencies may or may not satisfy the Institutional Review Boards for the Protection of Human Subjects and a Federalwide Assurance (FWA) Form may need to be completed. The FWA is an institutional commitment to comply with the Health and Human Services, Office of Human Research Protection of Human Subjects regulation 45 CFR part 46 (US Department of Health and Human Services, 2011). It may be best for the researcher to complete the form together with the responsible community agent.

In accordance with regulations on the protection of human subjects with regard to consent forms, as well as all other research documents viewed by participants, translation into Spanish or Spanish dialects is necessary. However, some indigenous languages spoken by migrants may not have a well-recognized written language. Some institutions require the translator to be certified by either a university program or professional organization. Translating a document into another language is not only done word by word, but the intent and cultural sensitivities need to be reflected as well (Hendrickson, 2003). All translated documents then need to be translated back into the original language, compared for differences, and corrections made. Survey questions with audio-enhanced voice files on tablets have demonstrated good data quality, and using voice files to ‘speak’ to participants decreases the number of bilingual research team members needed at data collection sites (Kilanowski & Trapl, 2010; Kilanowski, Trapl, & Kofron, 2013). Depending on the sensitivity of the data collected, an additional consideration with consent forms is obtaining a Certificate of Confidentiality (COC). A COC is an additional form that protects participants’ anonymity by preventing any research data or records from being subpoenaed. A COC is issued when two criteria are satisfied: (1) research is of a sensitive topic and (2) protection is needed to achieve the objectives of the research (U.S. Department of Health and Human Services, 2014). In the current climate of immigration policies, migrant parents who consider enrolling their children of U.S. citizenship in a research intervention may be reluctant to do so for fear of their entry status into the country being discovered. A third consideration, transportation of confidential data, should also be an important issue for researchers since data that are collected in remote areas is brought back to the university.

Inquiring into data transportation policies of the Institutional Review Boards at the university is necessary.

Methodological questions on research design may arise in the initial phases of the research project. In the vulnerable population of migrants using a randomized sample framework to classify one group not to receive the health intervention may be difficult, in both a practical sense because of the physical distribution of potential participants, but also in a moral sense because there is such a great need for health promotion activities.

The selection of study personnel should be carefully contemplated as establishing trust in any community research endeavor is essential for achievement of study aims. Community trust towards unknown personnel may be achieved by them first serving as a volunteer in community activities where relationships can be established, but this can be time-consuming. For the process of data collection and for the delivery of the intervention, it may be valuable to investigate if there are lay community outreach workers that are available to be employed (Amendola, 2013; Sanchez, De La Rosa, & Serna, 2013). Employing individuals for the research team who are already known to the community facilitates trust between researchers and participants, which can only aid in recruitment, enrollment, and retention. Also to be considered when true community-based research is undertaken is the need for full engagement in the research process by the participants, in this case, the children's parents. However, immigration policy may impede full engagement due to fear of bringing attention to themselves or family members. There is a fear of deportation and potential family separation. Reassurance that participants' names will not be transparent and legal status of entry into the U.S. will not be asked may arrest this fear. However, multi-phase or longitudinal research design may make this totally unanimity impossible.

Challenges in the logistics of data collection can delay initiation of the research project; so ample time needs to be allocated for development of protocols and procedures. For example, research locations in migrant agricultural work camps, harvest fields, and student summer Migrant Education Programs may be distant from the academic work site. [The Migrant Education Program is a federally funded education program for qualifying migrant children to ensure that children are not penalized by disparities in curriculum, graduation requirement, or academic content due to movement among the states for parental employment (U.S. Department of Education, 2013).] Research team members need to be willing and able to travel to data collection and intervention sites (McCoy, Hlaing, Ergon-Rowe, Samuels, & Malow, 2009). Study materials, mileage costs, and even motel and meal costs may need to be included in the budget. Correct directions to the research site are a necessity and paper maps may be needed as in some rural areas global positioning systems may not be operational.

A flexible schedule is critical for data collectors, as migrant children and parents may not be available during standard working hours: their picking day schedule can easily extend past sunset. Migrant parents who want to participate in health promotion interventions may not have the time after returning from the fields because they still need to wash, cook the evening meal, and attend to their children's needs (Kilanowski, 2012). As for reimbursing participants for their time, gift cards may be given per institutional policy; however some

remote areas may not have local stores that accept gift cards. Reimbursing with cash may be preferable to some participants, but frowned upon by universities. Look for national retail chains with a variety of store merchandise for gift cards.

Working with a mobile population can be problematic. Migrant families move frequently within the same town in one season, or move from state to state as they follow the migrant stream and the maturation of crops that need to be hand-harvested. Weather also affects when migrant families move as the hand-harvest of produce depends on ripening, which is dependent on water, sunlight, and temperature conditions. Retaining participants with a multi-session intervention can be difficult and with a longitudinal study retention can be even more arduous: expect attrition and statistically account for attrition when planning sample size. Distributing post cards with toll free contact information on the study and obtaining contact information on participants' friends and relatives may be helpful (McCoy et al., 2009). In addition, McCoy and colleagues (2009) suggests obtaining participant's nicknames to assist in locating missing participants as fellow workers may not be knowledgeable about a person's real name. When working with migrant children in the summer Migrant Education Program researchers experienced problems obtaining paired pre and post-tests of measurements because state labor laws permit middle school children to pick crops in the fields so they can contribute to their family's income or to their own personal savings (Kilanowski & Li, Epub ahead of print 2013). Students would enter the summer education program and attendance would wax and wane depending on weather and maturation of crops. Additionally, if their parents move to another farm to hand-pick produce, missing student data results. If the final study enrollment yields a small sample size with an accompanying lack of power and no statistical significance, important information on this vulnerable group may not be disseminated because of difficulties in getting the research published.

Nursing research interventions need to consider the built environment that may not be conducive to certain health promotion interventions, such as those seeking to increase migrant participants' physical activity (Lee, Mirsa, & Kaster, 2012). For example, one migrant mother was encouraged to increase her activity level by walking, but she replied that when she started the routine of walking along the country roads near the agricultural work camp, the men in the migrant camp laughed at her (Kilanowski & Li, 2013). Children living in agricultural work camps typically live far from public school playgrounds and migrant camps are often located off remote and dirt roads. Access to safe walkways may not be realistic or convenient. Community physical resources need to be assessed before designing interventions.

Cultural considerations of research design and interventions are imperative to promote effectiveness (Leininger & McFarland, 2002). In the Latino culture, the concepts of *machismo* (distinction between sexes with males enjoying rights and privileges denied to females), *familia* (the extended family plays a major role in life with strong bonds), *respeto* (respect for the elderly and authority), faith (most Latinos are Catholic), and a collective social orientation (interdependence with a strong group identity) need to be considered when designing the intervention (Carteret, 2011; Enriquez & Pajewski, 1996). In a qualitative study that examined mental health therapy mandated by the school or judicial system,

researchers found there is a need for clinicians to validate migrant parents' efforts in raising children within the context of their cultural standards (Ahn, Miller, Want, & Laszloffy, 2014).

Researchers may also need to acknowledge power differentials and an oppressive hierarchy within a school or health care system and to consider these factors in research protocols (Ahn, Miller, Want, & Laszloffy, 2014). Latino children and parents may be less assertive in expressing themselves to their peers and other adults and show passivity to authority figures. Noteworthy, health literacy may require that migrant families be given detailed written information within their reading ability. Lastly, child care may need to be incorporated into the research design and planning. In previous research, personnel often budgeted for and provided recreational activities to accompanying young children, such as coloring books, watercolor paints, and playground balls (Kilanowski & Li, 2013).

While this article serves to inform nurse researchers who conduct or will conduct studies with migrant children, the application of lessons learned to nurse practitioners will be briefly addressed. Leininger and McFarland (2002) present a theoretical framework for a clinical practice of cultural sensitive care. When nurse practitioners care for migrant children and families their cultural, social, and environmental characteristics should always be considered. Within a clinical setting, appropriate translators (not older children) are needed to adequately communicate health promotion and episodic care instructions. Printed materials need to be evaluated for reading levels. The lack of electronic records from previous health care providers may make continuity of care challenging, and may lead to unnecessary duplication of diagnostic tests. A work-a-round may be presenting parents with paper copies of progress reports of care rendered at that location. State insurance policies, if purchased by parents, may not be portable across state lines when the families migrate. And lastly, clinic hours need to be flexible and consider the long working day of the migrant parents who often pick crops from sunrise to sunset.

Researchers who engage in community-based research may hope that their discoveries can be a force of change in the community (Wallerstein & Duran, 2006). Community-based research may also serve as a vehicle for education, programming, and a platform for community empowerment with self-evaluation and analysis. But researchers remain concerned about sustainability of change and improvement. Wallerstein and Duran (2006 & 2010) concluded that community-based research must be conducted with integrity and humility with the ultimate goal of reducing health disparities. Research can improve health equity as it represents the intersection of research science and clinical practice. Challenges in research should not deter the investigator from including migrant farmworker children in a sample, but rather be content with communicating the needs of vulnerable children to the public (Wallerstein & Duran, 2010).

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