



Methodological factors conducting research with incarcerated persons with diabetes



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ABSTRACT

Objective: The aim of this study was to describe methodological issues specific to conducting research with incarcerated vulnerable populations who have diabetes.

Background: Much has been written about the ethical and logistical challenges of conducting research with vulnerable incarcerated populations. However, conducting research with incarcerated persons with diabetes is associated with additional issues related to research design, measurement, sampling and recruitment, and data collection procedures.

Method: A cross-sectional study examining the relationships of diabetes knowledge, illness representation and self-care behaviors with glycemic control in 124 incarcerated persons was conducted and serves as the basis for describing methodological factors for the conduct of research with an incarcerated population with diabetes.

Results: Within this incarcerated population with diabetes, sampling bias due to gender inequity, recruitment of participants not using insulin, self-reported vision impairment, and a lack of standardized instruments especially for measuring diabetes self-care were methodological challenges. Clinical factors that serve as potential barriers for study conduct were identified as risk for hypoglycemia due to insulin timing and other activities.

Conclusion: Conducting research with incarcerated persons diagnosed with diabetes requires attention to a set of methodological concerns above and beyond that of the ethical and legal regulations for protecting the rights of this vulnerable population. To increase opportunities for conducting rigorous as well as facility- and patient-friendly research, researchers need to blend their knowledge of diabetes with an understanding of prison rules and routines.

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1. Background

Incarcerated persons have a high burden of chronic illness, frequently experiencing multiple coexisting physical and mental health illnesses (Binswanger et al., 2012; Wang & Green, 2010; Wilper et al., 2009). Diabetes is one chronic illness that occurs in the prison population at similar prevalence to those living in the community (Binswanger, Krueger, & Steiner, 2009; Wilper et al., 2009). The American Diabetes Association (ADA; 2013) reports an estimated cost of diabetes mellitus in the community in 2012 as \$245 billion and that persons with diabetes have approximately two to three times greater medical expenditures compared to persons without diabetes. With an aging prison population and increased diagnosis of diabetes in younger persons, the burden of diabetes care in the prison is rising (ADA, 2014a). Evidence-based diabetes care strategies that have been tested in the correctional setting are needed to enhance health outcomes during incarceration and upon re-entry and reintegration into the community and to reduce associated cost.

Designed to help improve chronic disease health care outcomes, the National Commission on Correctional Health Care (NCCHC) has developed diabetes-specific disease management guidelines from nationally accepted guidelines of the American Diabetes Association (ADA, 2014b; NCCHC, 2014). However, there is very little research that examines diabetes-related health outcomes in this population or incarcerated patient characteristics that could affect glycemic control or the development of effective diabetes education programming. The lack of diabetes research involving incarcerated persons is in stark contrast to the abundant diabetes research conducted with community-dwelling adults.

The dearth of research in this area is likely the result of the general ethical and logistic challenges of conducting research with prisoners who are recognized as a vulnerable population. Challenges for conducting research with this population have been identified and discussed in the literature at length (Amory Carr, Amrhein, & Dery, 2011; Cislo & Trestman, 2013). Major challenges include ongoing stringent regulations for protection of prisoners and the conflicting agendas of corrections staff and academic researchers. The department of corrections staff focus on custody and security aspects of incarcerated patient care while researchers seek to conduct research to improve health outcomes and healthcare services (Cislo & Trestman, 2013).

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In addition to the issues and restrictions previously described, conducting research with incarcerated persons who have diabetes presents a different set of challenges for the research design, measurement, sampling and recruitment, and data collection procedures. These challenges were identified while conducting research to examine the relationships of illness representation, diabetes knowledge, and self-care behavior (SCB) with glycemic control in incarcerated persons with diabetes (Reagan, 2014). This research serves as the basis for describing methodological factors for the conduct of research with an incarcerated population with diabetes. Modifications aimed at reducing the challenges for conducting research with this vulnerable population are proposed.

2. Overview of the research study

Using a cross-sectional design, 124 incarcerated persons with diabetes were surveyed regarding diabetes knowledge, illness representation, and SCB. Measures included the Spoken Knowledge in Low Literacy in Diabetes Scale [SKILLD] for diabetes knowledge (Rothman et al., 2005), Brief Illness Perception Questionnaire [BIPQ] for illness representation (Broadbent, Petrie, Main, & Weinman, 2006) and the Self-Care Inventory Revised [SCI-R] for SCB (La Greca, 2004; Weinger, Butler, Welch, & La Greca, 2005). The ability of summary scores and items from these instruments to predict glycemic control (A1C) was evaluated using linear regression analyses. Covariates in these analyses included age, gender, education, incarceration length, health literacy, insulin use, medication count, and illness duration. A hybrid backward and forward variable selection strategy was used to identify a parsimonious multivariable model. Logarithmic transformation of A1C accounted for heteroscedasticity.

Participants (12.9% type 1 diabetes; 85% using insulin; 93.5% male; 40% Black; 37% White; 23% Latino; 77% high school education or less; mean age 47.3 years) had a mean hemoglobin A1C (A1C) of 8.2% ($SD \pm 1.96$). The final regression model was statistically significant ($F_{3, 124} = 9.51, p < 0.001, R^2 = 19.2\%$). Higher \log_{10} A1C was associated with lower personal control beliefs ($B = -0.007, t = -2.42, p < 0.05$), higher self-report of diabetes understanding ($B = 0.009, t = 3.12, p < 0.05$) and using on insulin ($B = 0.06, t = 2.45, p < 0.05$). Metabolic control was suboptimal for incarcerated participants in this study.

3. Methodological issues

3.1. Research design challenges

Variations in diabetes-related policies from institution to institution and national to international prison systems could make designing randomized control trials (RCTs) with adequate sample size problematic. RCTs are considered the gold standard for evaluating programs (National Institute Justice [NIJ], 2014) but very few have been conducted in the criminal justice system (CJS). Currently, the NIJ (2014) is challenging researchers to develop timely and effective RCTs that address relevant questions or problems in the CJS.

In the current study, a cross-sectional design was used. The policies for self-care behavior and the use of a blood glucose meter in the system studied were the same across all facilities. The care process utilized did not provide incarcerated patients with access to a blood glucose meter in their cell; they waited in line to self-check their blood glucose at prescheduled times in the presence of correctional nurses and had their insulin administered by correctional nurses. However, some participants were allowed to keep oral medications in their cell (KOP—keep on person), thus allowing some engagement in the SCB of medication taking. These policies were not problematic for the cross-sectional design of the current study. However researchers would need to consider the variation in procedures across patients if testing an intervention using an experimental or RCT design. For example, researchers examining the effects of an intervention on medication adherence should anticipate the need for a larger sample size or the use of a more complex study design to account for variations in medication administration. A

second design challenge lies in finding comparator groups for use in translational or patient-centered outcome research related to self-care management. Numerous research reviews such as Cochrane and systematic reviews draw on findings of completed research to compare the effectiveness of varied interventions for self-care management in community-dwelling persons with diabetes. However, findings from these reviews are not directly transferrable to the closed system environment of the prison. Cislo and Trestman (2013) cite the value of conducting a small pilot study first and working closely with the Department of Corrections (DOC) and other key stakeholders at every step of the way.

Another factor to consider when designing research with this population is the frequent movement or transfer of incarcerated persons between facilities for population management or release (Cislo & Trestman, 2013). Depending on the research design, facility transfer or release of research participants can impact multiple points in the research process. In this case example, four participants required the use of an interpreter to assist the researcher administer the Short Assessment of Health Literacy for Spanish Adults [SAHLSA-50] which was used to evaluate health literacy for Spanish reading participants (Lee, Bender, Ruiz, & Cho, 2006). When Spanish-reading participants were enrolled, a certified translator needed to be present to administer the SAHLSA. None of the four participants were released from prison system during the study period, but two were transferred between facilities. Frequent communication with the DOC administration was necessary to obtain help in locating these two participants.

Additionally, as a result of the frequent movement of incarcerated patients, studies with longitudinal or repeated measure designs can be difficult in this environment or, at a minimum, increase the costs of conducting the research. Such movement in an experimental or RCT could affect important variables of interest. The issue of frequent movement of potential can also present challenges for attrition and the length of time to complete the research, often taking months to years longer to complete a study (Cislo & Trestman, 2013; Trestman, 2006). These factors all need to be addressed when designing research proposals, and protocols.

3.2. Measurement challenges

Most instruments used for conducting diabetes behavioral research in the community have not been tested in prison populations. For this study, instruments that had face validity for, or characteristics relevant to the incarcerated population were used. However, there were still issues with lower than recommended levels of internal consistency. All survey instruments with the exception of the Rapid Estimate of Adult Literacy in Medicine [REALM] (Davis et al., 1993), a health literacy measurement, were verbally administered to the incarcerated participants because of the anticipated low literacy (Carson & Sabol, 2012). Only the SKILLD, designed for persons with low literacy, has been tested and used in prior research as a verbally administered survey for a community dwelling sample (Rothman et al., 2005).

Self-care behaviors (SCB) were measured for the current study. Although an important construct for diabetes behavioral research (AADE, 2014), instruments designed to measure SCB in research with community-dwelling adults do not translate well for measurement of self-care in the prison. As previously mentioned, all participants in this study, being from one correctional system, followed uniform policies related to blood glucose monitoring and insulin administration. However, personal factors such as low socioeconomic status influenced whether incarcerated patients had the potential to perform certain SCBs included on the Self-Care Inventory Revised Instrument (Weinger et al., 2005).

For example, in the current study, one of the SCBs examined was whether the incarcerated patient was reading food labels. This item was rated on a five-point Likert scale with “0” being never reads food labels and “5” being always reads food labels. In the prison, some patients with the financial means have the opportunity to purchase commissary foods. These individuals may be reading food labels at the commissary.

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