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The Capacity to Give Informed Consent in a Homeless Population with Developmental Disabilities

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Abstract

This study examined homeless persons with developmental disabilities and their ability to understand the informed consent process for research using a capacity-to-consent screener. Bivariate associations with the inability to pass the screener on the first attempt were noted with three factors: an eighth grade or less in education, chronic homelessness, and mental retardation diagnosis. With multiple regression, the only outcome associated with inability to pass the screener on the first attempt was an eighth grade or less education. This study indicates the need for consideration of developmental disabilities when homeless and mental health providers are working with the homeless community.

Keywords

Developmental disabilities; Homelessness; Capacity to consent; Informed consent

Introduction

Although not considered a vulnerable population according to the regulations for federally funded human research protocols, susceptibilities associated with developmental disabilities require special considerations in research (Freedman 2001; Iacono and Murray 2003). Research supports the fragile understanding of the informed consent process and purposes of research among those with moderate and severe developmental disabilities (Gunn et al. 1999; Morris et al. 1993). For those potential research participants with more severe disabilities, informed consent may be required by the persons' guardians or proxies (Wiles et al. 2005). This paper examines the capacity to give informed consent to research in a sample of developmentally disabled homeless persons.

While there is little controversy over the need to closely monitor recruitment of research participants with more severe developmental disabilities, the symptoms of which are easily distinguishable, there has been little examination of the capacity to give consent in those with less severe disabilities. Morris and colleagues (1993) found that while the majority of those with moderate mental retardation could not give informed consent, about half of those with mild mental retardation also could not. Inability to give consent is important because among those who are chronically homeless, prevalence rates of mental retardation is

estimated at 22% (Stratigos and Katsambas 2003; U.S. Conference of Mayors 1998). It is logical to surmise that a significant proportion of those experiencing homelessness have milder developmental disabilities, otherwise their ability to survive on the streets would likely be severely compromised. Persons with more severe disabilities would be recognized by social service providers and intervention would be provided to get them off the streets due to their obvious vulnerability to dangers if they remain on the streets (Stavarakaki 2002). Those with milder developmental disabilities may be able to mask their disabilities through adoption of street-savvy behaviors or by withdrawing; thus potentially being overlooked by those who may be able to provide them with needed services (Goffman 1963; Petersilia 2000; Morton and Pollio 2009).

This masking phenomenon may dually influence capacity to give informed consent warranting concern for conducting research with homeless persons. While researchers frequently assess psychiatric and substance use disorders among their low-income or homeless samples (Cottler et al. 1998, 2001; Morse et al. 2006), there is oftentimes little or no inquiry into developmental disabilities. Rarely is the receipt of special education services while in school even queried in homelessness research. Researchers and practitioners focusing on this population are trained to be more familiar with the prevalence of psychiatric disorders and substance abuse as antecedents to, and contributors of, chronic homelessness (Klinkenberg and Sacks 2004). Additionally, during the informed consent process, if memory impairments are noted, they may easily be attributed to psychiatric symptoms or intoxication, which are frequently co-morbid with the developmental disability, rather than the primary cause of cognitive limitations for the individual (Christian and Poling 1997; Halpern et al. 1986).

The concern that vulnerable people, such as the developmentally disabled, are not exploited or harmed through research is soundly based on historical precedent. These events include the Nazi experiments on the disabled (among others) that led to the development of the Nuremberg Code, which set forth principles of protection of the rights and well-being of research participants (Nuremberg Codes 1949). In the United States, the Willowbrook State School experiments were conducted from the 1950s to the 1970s, in which mentally retarded children were injected with various strains of the hepatitis virus so that researchers could study the progression of the disease. Though guardians gave consent for this research, it is unclear if they understood the true study procedures or purpose (Freedman 2001).

Similar human subjects' atrocities were experienced by rural African American men in the Tuskegee Syphilis Study conducted from 1932 to 1972, where progression of syphilis was studied and treatment withheld despite the availability of penicillin treatment (Jones 1993). Though in the Tuskegee Study, the developmental disability diagnoses of the men were not a concern to the researchers, these men largely lacked formal education, lived in poverty, and were African American in the rural South, all factors that contributed to their vulnerability and exploitation.

Those with developmental disabilities, especially milder ones, would seem to have the capacity to give consent as long as researchers simplify language, provide cognitive aids to increase understanding of written language (e.g., reading the consent aloud; using pictures,

etc.), and have lengthier discussions about the study and the informed consent process (Gunn et al. 1999). In the present study, we simplified the informed consent process as much as feasible without compromising content, to ensure that barriers to comprehension of the process and study procedures were minimized.

This study sought to answer the following five research questions: (1) Do homeless persons with developmental disabilities have the capacity to give informed consent? (2) Is their ability to give informed consent increased if a brochure on the research process is read to them prior to receiving the informed consent screener? (3) Does lower educational attainment negatively influence their ability to give informed consent? (4) Does chronic homelessness negatively influence their ability to give informed consent? (5) Does the increased severity of the developmental disability negatively influence the ability to give informed consent? To our knowledge, this is the first study to examine these questions in an urban population of predominately African American homeless persons.

Methods

Sample

This cross-sectional, exploratory study consists of semi-structured interviews ($n = 62$) from a purposive and snowball sampling of developmentally disabled persons on the streets of targeted urban areas of St. Louis, Missouri. Initially, we used key informants to identify a pool of homeless persons who were potentially interested and eligible for the current study. These key informants had been previous participants in another study conducted by the lead author of the present study, on developmentally disabled homeless persons (Morton and Pollio 2009). Three of these key informants were located, and they eagerly referred a number of respondents to the current study. When these referrals were exhausted, we then employed street outreach strategies to locate potential respondents in two St. Louis City public parks with a high density of homeless persons and also at a nearby soup kitchen for the homeless. We also used respondent intercept outreach methods in these same areas commonly known in the community as places where the homeless congregate. Approximately 60% of the sample was derived from street outreach, with the remainder captured through snowball or respondent-driven sampling.

Both the first author and a trained Master-level research assistant went out as a single study outreach pair to recruit and enroll participants for this project. Although they entered the streets as a pair, the interviewers were responsible for conducting the interviews separately, yet in viewing distance of the other interviewer. Though confidentiality was maintained throughout the research process, it was important for each interviewer to know who the other was interviewing to avoid duplication of respondents for interviews. As an example, one early respondent did attempt to disguise himself and obtain an interview with the other interviewer.

The respondents gave self-reports of any developmental disabilities. Once we identified a potential participant, one of the two interviewers explained that we were seeking to interview homeless persons who had been in special education to learn more about research participants' ability to understand the informed consent process and the purposes of a

research study. Eligibility criteria included: (1) being age 18 years or older; (2) having received special education services during their educational career; and (3) being currently homeless (i.e., staying outdoors, in a shelter, temporarily doubled up in another's residence, or staying in a place not meant for human habitation). At the point of learning that the research project was for those who had been in special education, some potential subjects self-selected out of study participation.

The interview began with the interviewer explaining the purpose of the study and the informed consent process. Additionally, for every odd-numbered participant, we read and distributed a brochure designed specifically to explain the research process to persons with developmental disabilities. We then read the capacity-to-consent screener to the respondent. We gave respondents three attempt opportunities to answer at least eight questions correctly. If respondents were unable to meet this threshold, their participation terminated at this point. Interviews lasted between 30 and 45 min on average. A few lengthier interviews (i.e., lasting 60 or more min) were attributed to respondents having severe cognitive limitations. Respondents received \$10 in bus tickets for their participation. Though we did not offer any formal treatment services after the interview, we referred those who asked for further assistance or who appeared especially fragile to case management services offered by the Missouri Department of Mental Health. We also informed them about available substance abuse treatment, homeless services offered by various non-profit agencies, and gave instructions on how to obtain a voucher for a Missouri identification card.

Instrument

We collected demographic data on age, education level, employment status, developmental disability diagnosis, current living situation, and length of time homeless. We also obtained data using a ten-item capacity-to-consent screening tool that was derived from the Zayas et al. (2005) screening tool intended for use with people with psychiatric disorders and tailored for use with racial/ethnic minorities. Since the majority of the homeless in St. Louis are African American (as is reflective in the current study), we concluded that this screening instrument was particularly appropriate and could also be tailored for use with developmentally disabled homeless persons. We tailored the first six questions to the specifics of this study. For instance, after we completed the informed consent process detailing the study's intent, risks and benefits, and protections, we asked respondents to verbally describe for us the purpose of the present study, why they were asked to participate (e.g., they were in special education), and what they understood the risks and benefits to be for participating in the study. The next four questions pertaining to participants' rights to terminate participation, to refuse to answer questions, and their understanding that that they would not lose services by participating in the study were maintained from the original instrument. The protocol allowed for three attempts to answer eight out of these ten questions correctly. If respondents were unable to answer at least eight questions correctly in a maximum of three attempts, we then offered remuneration, as well as any referral information as needed, and we concluded their study participation at that point. Otherwise, we then filtered participants to the second phase of the study involving several additional interview questions about their level of community participation and integration. While this

second phase was a parallel aim of the overall study, it is not the focus of the current analysis reported herein.

Measures

Dependent Variable—The dependent variable was whether or not the respondent correctly responded to the screening tool on the first attempt. The dependent variable was dichotomized as follows: Able to pass on first attempt? (1 = yes; 0 = no).

Independent Variables—We analyzed educational attainment for associations with the dependent variable. Respondents were asked: “What is the highest grade of school that you completed?” The response (e.g., 6th grade) was then coded by the interviewer into one of the following categories: no formal education; 8th grade or less (e.g., this would be coded for 6th grade completion); less than high school diploma; GED; high school graduation; trade or technical school; some college; college graduation; or graduate work (beyond undergraduate). Therefore the categories were mutually exclusive, as only the respondents’ highest grade completed was recorded and no respondent was placed in more than one category. We categorized age ranges as 20 to 29-years-old; 30 to 39-years-old; and age 40 and over.

We defined the independent variable, chronic homelessness (dichotomized as 1 = yes; 0 = no), as six or more months of being consecutively homeless from the time of the interview, with no permanent address during that time period. We categorized current habitation as being temporarily doubled up with other(s); or residing in a halfway house; emergency shelter; or on the streets (each of which was dichotomized as 1 = yes; 2 = no). Temporarily doubled up with others was operationalized as staying with others for 2 weeks or less and that residence was not considered the respondent’s permanent address.

We also examined the effect of a developmental disability diagnosis (1 = yes; 2 = no) on the respondents’ capacity to consent. We expected that having a self-reported severe developmental disability (e.g., mental retardation) would adversely affect capacity to consent. The interviewers deduced that those with self-reported mental retardation were for the most part mildly mentally retarded as they were in fact able to successfully navigate the homeless community.

Data Analyses

Univariate analyses (e.g., frequencies; means, standard deviations) described the sample. Chi-square analyses bivariate assessed the respondents’ inability to answer the capacity-to-consent screening tool on the first attempt based on the brochure being explained and given to them, education level, chronic homelessness, and reported developmental disability diagnosis. We employed multiple logistic regression procedures to model capacity to consent by independent variables that were either bivariate significant or showed near significant trends.

Human Subjects Approval

The Washington University Institutional Review Board approved all study procedures.

Results

Sample Description

Table 1 shows that the sample ($n = 62$) ranged in ages from 20 to 64 years. The mean age of the sample was 36.21 years ($SD = 11.58$), with about a third of the sample being younger than age 30 and 40% being age 40 or older. The majority were male (75.8%), African American (93.5%), and with less than a high school education (66.1%). The categories of no formal education, trade or technical school, college graduation, and graduate work were not endorsed by any respondents. Nearly 1 in 5 was working full or part-time (17.8%), over half of the sample (54.8%) reported that they were not working, but were actively looking for work. Regarding current habitation, nearly 60% of the sample ($n = 37$) was currently living on the streets or in places not meant for human habitation. The remainder reported staying at an emergency homeless shelter ($n = 19$), in someone else's home or apartment ($n = 2$), or in a hotel or single-occupancy room, a boarding house or halfway house ($n = 3$). About 40% of respondents ($n = 27$) were considered chronically homeless (i.e., 6 months or more consecutively homeless), with the average duration of being homeless being approximately 1 year (mean = 50.82 weeks; $SD = 80.74$). Notably, some of the participants reported having a homeless companion, who in some instances appeared to take on a caretaker-type role.

The most prominent developmental disability reported was a learning disability (79%), and to a much lower proportion, mental retardation (12.9%). Multiple developmental disabilities were reported by 8% of the participants ($n = 5$). For the purposes of this study, we considered a behavioral disorder as a developmental disability in ($n = 7$; 11%), since it can trigger receipt of special education services. Though a behavioral disorder is not consistently considered a developmental disability, only two participants reported a behavioral disorder as their sole developmental disability, while five participants reported the behavioral disorder co-occurred in the context of another developmental disability. Multiple developmental diagnoses were examined separately in bivariate analyses. Only mental retardation was examined in the regression analyses, and the eight respondents reporting this diagnosis reported no other. Over half of the sample was able to pass the capacity-to-consent screening tool on the first attempt (56.5%), with 40.3% of the sample passing on the second or third attempt, while only 3.2% were unable to pass the screening tool at all.

Bivariate Relationships

There were no significant bivariate association between participants receiving a brochure and their capacity to consent. However, inability to consent on the first attempt was significantly associated with having the lowest level of formal education (i.e., 8th grade or lower attainment), (75 vs. 36.7%; $\chi^2 = 4.28$; $df = 1$; $P = .04$), being chronically homeless (61.5 vs. 31.4%; $\chi^2 = 4.3$; $df = 1$; $P = .04$), and having mental retardation (87.5 vs. 36.7%; $\chi^2 = 5.28$; $df = 1$; $P = .02$). There was a trend toward significance for participants with a self-reported learning disability (versus those without) to pass the informed consent screening tool on the first attempt (62.5 vs. 22.2%; $\chi^2 = 3.49$; $df = 1$; $P = .06$). In the two instances where respondents were unable to pass, one had participated in a previous project (Morton and Pollio 2009) and was documented to have both mild mental retardation and a co-morbid severe brain injury, which severely compromised his memory and ability for self-expression,

and often caused him frustration. The other respondent also appeared to have a more severe developmental disability than most study participants.

Multiple Logistic Regression

We entered statistically significant bivariate predictors (i.e., mental retardation, chronic homelessness, and eighth grade or less in education) into a multiple logistic model to determine their influence on being unable to consent on the first attempt (Overall model: $\chi^2 = 16.82$, $df = 3$, $N = 57$, $P = .001$). In the final model, while there was a near significant trend for mental retardation (CI [95%] = .011, 1.02; $P = .053$), having an 8th grade or lower education persisted as an independent predictor of the respondents' inability to consent on the first attempt (CI [95%] = 1.26, 27.43; $P = .02$), (Table 2).

Discussion

This study was consistent with the findings of Morris and colleagues (1993) that nearly half of their sample with mild developmental disabilities was unable to give informed consent for research participation on the first attempt. Whereas the Morris et al. (1993) study sample was patients in a residential setting, the current study goes a step further by examining the capacity to consent among homeless individuals who were primarily living on the street. Though most of the participants in this current study nodded their heads and/or voluntarily stated that they understood when we read the Informed Consent Form to them and explained the study's purpose, 43.5% were not able to pass the capacity-to-consent screening tool on the first attempt. This finding demonstrates the need for extra vigilance on the researchers' part when they are seeking informed consent from those with known or suspected developmental disabilities. Incapability to give informed consent will likely affect the reliability of findings due to the probability that participants may not understand some survey or assessment questions, while concomitantly not asking the interviewer for clarification.

We also found that those with low educational attainment (i.e., had an eighth grade or lower education) are less likely to be able to give informed consent on the first attempt. Though a developmental disability may compromise understanding, special education should enhance the ability to learn and to familiarize students with skills that allow them to concentrate on tasks. In addition to the obvious positive consequences of educational attainment such as the probability of future stable employment, education improves students' skills for self-sufficiency in accomplishing daily activities. Yet, it is troubling that nearly 18% of this sample had such low educational attainment. However, given the public education climate in St. Louis that, with some exception, has historically received poor quality ratings and is largely racially segregated, this rate can be placed more in context (e.g., Portz et al. 1999; Wells and Crain 1997).

The lack of association of the brochure on the research process and informed consent (specifically written to improve developmentally disabled respondents' comprehension) with passing the informed consent screening tool on the first attempt is troubling. It was noted by the interviewers that while reading the brochure to respondents, some appeared to become distracted and bored (e.g., looking around, fidgeting, and yawning). This may be

attributed to the interviewers having already informed the respondents of the important aspects of the informed consent process and of the study's purpose. Feasibly, distractibility and the lengthening of the survey process attributed to the respondents actually forgetting the high points of the informed consent process and the study's purpose. Deletion of the brochure and mentioning only the important aspects of the informed consent process and the study's purpose may be more appropriate for persons with developmental disabilities who may have short attention spans and affected comprehension abilities.

These data also support the need for an informed consent process that is sensitive to the literacy challenges and cognitive limitations of potential study participants. Researchers should simply explain a study's purpose in uncomplicated language, thus increasing the likelihood of comprehension. Those with cognitive impairments due to psychiatric illness and substance use disorders would also benefit from such a simplified, yet sensitive, informed consent process.

This paper issues a call to homelessness researchers to query participants regarding the developmental status of potential participants in order to insure that consent for research participation is truly informed. Such queries will aid in appropriately developing and tailoring programs and policies with the highest benefit potential, while also ensuring that participants will receive needed case management services and entitlements such as Social Security based on their disability. Research would also benefit from recognizing that many homeless persons with developmental disabilities also have co-occurring substance use disorders and/or psychiatric disorders, thus further limiting their ability to give informed consent.

These findings are presented in the context of a few important study limitations. Specifically, this study is limited by its small sample size (thus restricting robustness in the statistical analyses), and in its cross-sectional design (permitting only speculation about causality). This study also did not test the reliability of the modified informed consent screener prior to implementation. It became apparent during interviews that one of the questions (Question #4: "Tell me at least three things you will be asked to do in this study.") sometimes required clarification, which may be due to the question's lack of specificity rather than the participant's inherent ability to comprehend.

Gonzalez and Rosenheck (2002) found prevalence rates of mental illness and substance abuse co-morbidity up to 70% among homeless persons, with 62% having poorer outcomes. It is likely that the prevalence of co-occurring psychiatric and substance use disorder was comparable in the current study. An assessment of mental illness and substance use disorders and potential interactions of these disorders with developmental disability would have greatly increased the significance and the generalizability of our study. However, our study was limited in not only its size, but also in scope, thus precluding even a brief self-report assessment of these co-occurring disorders and subsequent testing of their associations and probabilities. Future research with homeless persons with developmental disabilities would benefit from the inclusion of measures of mental illness and substance use disorders.

Due to time, cost, and scope limitations of the study, it was more feasible to rely on self-reported developmental disabilities (rather than more objective measures) to determine eligibility. This limitation may have resulted in over-reporting and/or misreporting of learning disabilities, which are less stigmatizing than reporting about mental retardation. In some instances, participants may have falsified a developmental disability in order to qualify for study inclusion. Given previous experience with this population and the rigor of the study recruitment and enrollment procedures employed, it is believed that if such deception occurred, it occurred with a minority of participants. Validating self-reports of developmental disabilities through school records, as done in a previous study (Morton and Pollio 2009), while perhaps ideal, was not feasible given the cost and time constraints associated with gaining participants' permission for release of school records and actually obtaining the records, and the potential loss of some of the more transient participants. Future research with this population should consider the administration of the Folstein Mini-Mental State Exam (MMSE) that assesses performance across a number of domains (Folstein et al. 1975). The Abbreviated Halstead-Reitan Impairment Index derives and average impairment rating based on the patient's aphasia screening test, block design, digit symbol, and trial A and B performance, and correctly classifies (impaired/not impaired) with 84% accuracy (McNamara et al. 1994). Both the MMSE and Abbreviated Halstead-Reitan screeners have been successful in measuring the cognitive abilities of persons who are homeless (Buhrich et al. 2000; Gonzalez et al. 2001). Use of such screening tools would lead to reliable accuracy of cognitive impairments, while being brief enough for the relatively short attention spans of some of the participants.

Implications and Future Research

People with milder developmental disabilities appear to be able to participate in research, as long as there is an understanding by the interviewer that they may require extra attention during the informed consent process (and throughout the study) to ensure comprehension and ongoing consent. Though substance disorders and mental illness are important dynamics facing this population, a masked developmental disability may impede effective prevention intervention efforts for substance use and mental health programs. A less rigid conceptualization of homelessness, which increases inclusion to those who are developmentally disabled, will benefit research and community mental health practice.

Research into the prevalence (epidemiology) of developmental disabilities among the homeless is warranted. Such research should seek to verify self-reported diagnoses through school records or direct assessment of developmental disabilities. The cost and time barriers inherent in research efforts with homeless samples is obvious. Obtaining verification of the developmental disability through school records or assessment increases the burden of the assessment process (with persons with short attention spans). Further, obtaining school records can take weeks, which would logically mean loss of many transient participants. If respondents are local, school districts will often expedite the specific information desired if the participant is present (e.g., Morton and Pollio 2009). In the Morton and Pollio (2009) study, bio-psychosocial assessments were conducted with all homeless persons reporting a developmental disability, then school records were obtained. If these records did not show a developmental disability diagnosis, their self-report assessments were not utilized in data

collection and analyses. However, these assessments could be used for comparison purposes, but it must be considered that the person without a diagnosis actually has one that was not noted by the school. Coordination between researchers, community organizations, state mental health offices, and school districts could lead to a reduction in the costs and time associated with validating developmental disability diagnoses from records.

It is also important to determine the mental illness and substance use disorders that may be comorbid in this population. Disentangling cognitive impairments attributable to psychiatric illness, substance disorders, and developmental disabilities, and those that are comorbid will assist community mental health in improving treatment to the homeless population (Hackerman et al. 2006). For example, these programs include substance abuse, HIV/AIDS prevention, and support groups for people with developmental disabilities. Longitudinal research should also be considered in order to permit an understanding of the long-term outcomes for the homeless with developmental disabilities.

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Table 1

Sample socio-demographic characteristics

	<i>n</i>	%
Gender		
Male	46	74.2
Female	16	25.8
Race		
African American	58	93.5
Caucasian	4	6.5
Age range		
20 to 29-years-old	23	37.1
30 to 39-years-old	14	22.5
40 to 64-years-old	25	40.3
Mean age (SD)		
Mean = 36.21 (SD = 11.58); Median = 35.50; Mode = 42	62	
Educational attainment ^a		
8th grade or less	11	17.7
Less than high school	30	48.4
GED (high school equivalency diploma)	2	3.2
High school diploma	15	24.2
Some college	3	4.8
Current habitation		
Temporarily doubled up with other(s)	2	3.2
Halfway house	3	4.8
Shelter	19	30.6
On the streets	37	59.7
Mean Length of time homeless (in weeks)		
Mean = 50.82 (SD = 80.74); Median = 12; Mode = 4)	61	
Chronic homelessness (6 months or more homeless)	27	43.5
Developmental disability diagnosis (may be more than one diagnosis per person)		
Learning disability	49	79
Mental retardation	8	12.9
Autism	1	1.6
ADHD	2	3.2
Behavioral disorder	7	11.3
Number of attempts needed to obtain informed consent		
1	35	56.5
2	22	35.5
3	3	4.8
4 (Informed consent not obtained)	2	3.2
Employment		
Full-time	4	6.5

	<i>n</i>	%
Part-time	7	11.3
Not working, but actively looking	34	54.8
Not working, and not looking	14	22.6
Retired	1	1.6

^aThe following categories for education while queried, were not endorsed by any respondents: no formal education, trade or technical school, college graduation, and graduate work

Table 2

Regression of inability to give informed consent on first attempt on eighth grade education or less, chronic homelessness, and mental retardation

Independent variable	<i>b</i>	χ^2	Odds ratio	95% CI
Intercept	1.96	3.07	–	–
Eighth grade education	1.77	5.07	5.87	1.26–27.43*
Chronic homelessness	–1.06	2.79	.35	.10–1.20
Mental retardation	–2.24	3.76	.11	.01–1.03

$N = 62$; pseudo $R^2 = .34$;

* $P < .05$