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Cynthia Nickless

Clinical Psychology- Gallaudet University

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PROGRAM OUTCOME RESEARCH IN RESIDENTIAL PROGRAMS FOR DEAF MENTALLY ILL ADULTS

CYNTHIA NICKLESS

Clinical Psychology

Gallaudet University

Abstract

A brief description is presented of a recent research investigation of program outcome in a deaf, mentally ill adult population. General benefits and limitations of outcome research are discussed. Special emphasis is given to the unique circumstances and methodological considerations that exist when conducting outcome research on a deaf, psychiatric population. Lastly, suggestions for similar research endeavors are presented.

Little research currently exists providing descriptive and outcome statistics for deaf mentally ill persons. Estimates suggest that approximately 3,500 chronically mentally ill deaf individuals and 212,000 hard of hearing mentally ill individuals exist in our country. When considering that only 15% of these individuals are estimated to be inpatients in psychiatric facilities (Shadish, 1989), it is probable that approximately 3,000 deaf mentally ill and approximately 180,200 hard-of-hearing mentally ill are living in our communities. Of this total, less than 2% are said to be receiving mental health services (Gerstein, 1988). This low service utilization is likely due to the paucity of mental health services available to the deaf mentally ill, as well as the lack of clinical staff skilled to work with this population (Vernon & Andrews, 1990; Steinburg, 1991).

For the small percentage of deaf mentally ill individuals who do receive mental health services, little data are available on their sociodemographic

profile and on their level of benefit from services provided. For this reason a research project was instigated to investigate those client variables which are predictive of differential program outcome for deaf mentally ill clients in a private, nonprofit residential program. This collaborative research project was created between the Clinical Psychology program at Gallaudet University and Deaf-REACH¹.

Deaf-REACH is a private, non-profit community agency in Washington, D.C. for deaf persons with serious mental illness. Deaf-REACH's continuum of housing services began in 1973 with the establishment of the first nationally recognized model home for mentally ill deaf individuals. This multi-level agency includes community residences, a community service center, a clubhouse, and an independent living skills program.

Research was conducted on agency grounds and included a comprehensive file review of 23 adult residents as well as staff ratings of client progress. Data were collected on 37 client variables for each subject and culled solely from client files. After data collection was completed, staff raters participated in a rating session of subject progress. Three levels of client progress were employed: improved, maintained, and deteriorated. Client outcome was rated in three distinct behavioral domains: socialization, self-care, and vocation. This tripartite differentiation of outcome has been used in previous studies and

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provides a clearer picture of program outcome than bipartite models (Owen, 1984).

Results indicated that a number of client variables were significantly correlated with program outcome. Examples of client variables that correlated significantly with outcome include a history of suicide attempts, a history of substance abuse, a diagnosis of mental retardation, and the nature/frequency of family contact with the client².

The Benefits of Outcome Research

Existing outcome studies have shown that numerous benefits are derived from this type of investigation. Reported benefits include the provision of reliable data for assessment of program effectiveness, justification of differential treatment for specific subgroups of clients, guidance in clinical treatment planning, and the encouragement of continued financial support for psychosocial rehabilitative programs for the mentally ill (Mendel, 1986; Mirin and Namerow, 1991).

As a result of the deinstitutionalization movement, numerous community support programs have emerged promising an enhanced quality of life for its consumers. Unfortunately, these programs are often instituted both in the private and public-sector, without accompanying research endeavors aimed at determination of program effectiveness. Both consumers and mental health professionals associated with these programs seldom have the opportunity to have their beliefs in program effectiveness verified via research findings. For this reason, outcome research is especially crucial as it provides a reliable and valid vehicle for establishment of program effectiveness.

Outcome research has the potential to identify those diagnostic subgroups, with varying symptomatology, that may respond differentially to specific treatment modalities. For example, a study that investigated outcome of "Kraepelinian" schizophrenics versus chronic schizophrenics found that the former group was less responsive to haloperidol and exhibited more severe negative and positive symptomatology (Keefe et al 1987). Not only did this outcome study suggest that "Kraepelinian" schizophrenics may represent a diagnostic subgroup, but it also suggested that they may require a unique treatment strategy.

Outcome studies can provide data augmenting the clinical treatment planning process. When specific client characteristics are associated with varying levels of program success, clinical staff are able to formulate client treatment plans accordingly. The program may decide to treat only those clients who exhibit profiles typically associated with program success. More likely, however, programs serving the mentally ill will strategically place new clients in differing treatment modalities based on the client's presenting profile. This can result in maximization of program effectiveness and minimization of program failure.

Lastly is the issue of rising health care costs and its relationship to program effectiveness. Federally funded programs, by necessity, must provide evidence of program effectiveness in order to elicit continued funding. In addition, the emphasis on cost-containment made by health policy planners and third-party payers requires that programs in the private-sector also have data regarding program effectiveness. Outcome studies conducted in both public and private-sector programs have the ability to demonstrate program effectiveness, thus validating the productive utilization of funding sources.

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The Limitations of Outcome Research

Literature on the subject of treatment outcome collectively agrees on one point; treatment outcome research is critical yet problematic (Bryer, 1990; Curry, 1991; Mendel, 1986; Mirin & Namerow, 1991). The methodological, financial, and resource limitations accompanying outcome research often preclude such investigation. These general research limitations are further complicated when a deaf mentally ill subject population is employed.

General methodological impediments include misdiagnosis of patients assessed, chronicity of many psychiatric disorders with accompanying cycles of exacerbation and remission, ambiguous definitions of treatment, methodological limitations imposed when utilizing a large number of client variables, rater subjectivity, unreliability of measures used, lack of control groups or comparison groups, and complexity of the mental health care system. Of these methodological hurdles, three have particular relevance to outcome research on a deaf population; misdiagnosis, treatment ambiguity, and unreliability of research measures.

There is much opportunity for misdiagnosis of psychopathology in deaf mentally ill individuals (Steinburg, 1991). Though efforts are being made to revise existing diagnostic and assessment measures for deaf persons, past misdiagnoses of clinical disorders may remain in client files. The validity of outcome research that employs the use of file review is questionable when utilizing client data that may include inaccurate diagnoses of psychopathology.

When assessing treatment outcome, definitions of diverse treatments must be clear and distinct. Existing treatment models employed for the deaf mentally ill are often adaptations of models previously proved effective with hearing counterparts. Unfortunately, many of these models have not been scientifically investigated as

to their appropriateness with a deaf population prior to implementation. Though results of treatment outcome research with deaf mentally ill populations may indicate that particular treatments are more suitable for specific client subgroups, the treatments themselves may be poorly defined and exhibit considerable overlap. The researcher is then unable to determine if it is the treatment itself which is correlated with positive outcome, or some extraneous and uncontrolled variable.

Research measures established using hearing populations are often inappropriate for use with deaf individuals. Reliability and validity of these measures diminish when they do not account for linguistic and cultural differences inherent to deaf subject populations. Researchers will find that many measures must be revised or adapted for use with this population. Though allowing for immediate use of the measure in the research project, hasty revisions may negatively impact the tool's validity and reliability, resulting in inaccurate research findings. Lastly are the issues of financial and inter-agency resource limitations that often preclude outcome research on the seriously mentally ill, independent of hearing status. Financial limitations often prevent community-based mental health facilities from conducting outcome research (Curry, 1991). Research, though desirable, is logically one of the first areas to be eliminated in the prevailing era of budget constraint. In response to a report by the National Institute of Mental Health (1991), a national plan for improvement of services for the seriously mentally ill was proposed, emphasizing the need for research in community treatment programs. As more federal and private funds are made available, an increase in outcome studies can occur in agencies that previously could not financially support such investigations.

Other inter-agency resource limitations that prevent outcome research from being conducted include agency time constraints, staff availability,

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accurate and complete client files, space limitations, and computer resources necessary for the compilation of data and execution of statistical analyses.

Additional Concerns When Conducting Outcome Research with Deaf Mentally Ill Populations

The researcher who conducts outcome studies with a deaf mentally ill population must address a number of unique methodological, professional and ethical issues specific to research conducted with this subject population. The experience of conducting the collaborative outcome research project at a community-based rehabilitation program for the deaf mentally ill allowed the author to identify the following outcome research concerns: lack of outcome research in the field of deafness and mental illness, communication obstacles between individuals involved in the research, reduced statistical power of research results based on a high number of client variables, confounding variable of deafness, and limited generalizability of research results. In addition, a number of ethical issues were identified and are discussed at the end of this section.

The scarcity of research on deaf mentally ill populations necessitates that pioneering efforts be made in this area. However, early investigations are limited by the paucity of existing demographic data or related literature. Thus the researcher is left to develop hypotheses void of the guiding influence of existing empirical findings. These seminal research hypotheses tend to be global and nonspecific, increasing the likelihood of methodological error and the reduced reliability of research results.

Communication is a key issue when conducting outcome research with deaf populations. Although the investigation did not require client contact, it

did require the researcher to communicate with both hearing and deaf staff. Lengthy instructions were given during staff rating sessions of subject progress. It is imperative in all research involving deaf individuals that instructions be consistently understood by staff regardless of hearing status. Sign language interpreters can be used to facilitate communication. The same interpreter(s) should be used across rating sessions in an attempt to obtain the highest level of consistency in communication possible. These interpreters must be briefed on the experimental design as well as instructed in how to minimize experimental error. Consistent instructions are vital in maintaining experimental control.

The exploration of a large number of client variables reduces the statistical power of the research findings. In the author's pilot investigation, 37 client variables were correlated with ratings of client progress in the program. Though significant results were found, caution must be exercised in the interpretation of these results as significance may be a product of multiple statistical manipulations versus true significant relationships. Not always optimal, pilot studies include multiple variables with the hope of forming more specific hypotheses.

The researcher must be careful not to automatically attribute significant findings to the variable of deafness. For example, though deaf mentally ill clients may be significantly more likely to have an additional diagnosis of mental retardation, this does not indicate that mental retardation is causally linked to the deafness. Deaf mentally ill individuals may be more prone to being misdiagnosed as mentally retarded based on the current lack of adequate assessment measures for this population. More than just an audiological deficit, the variable of client deafness is immensely complex, incorporating educational, cultural, emotional, and psychological factors.

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The results of any outcome study on the deaf mentally ill are restricted in terms of their generalizability to other similar populations. Research results cannot then be assumed to apply to other mentally ill populations that are not deaf or have other unrelated disabilities.

Ethical considerations abound when conducting research with a deaf mentally ill population. The researcher conducting an outcome investigation with this population will undoubtedly find him/herself confronted with one or more of the following ethical dilemmas: over-utilization of this clinical group for research purposes, confidentiality of subjects, informed consent, and additional limitations enforced by institutional review boards.

Deaf mentally ill residents are an especially vulnerable population based on their communication and psychological limitations as well as their central location. For this reason, researchers may be more prone to conduct research with this group as they do not pose the usual limitations of subject resistance and inaccessibility. Availability does not justify repeated research on the same subject population.

Confidentiality of deaf mentally ill research subjects can be difficult to ensure considering the population's small size and high utilization of identical services. Readers of published research results will often be professionals and/or other members of the deaf community that have had contact with subjects, either professionally or personally, and thus can identify individuals easily via descriptive data. For this reason, all attempts must be taken to avoid identification of subjects in publication or communication of research results.

Deaf mentally ill subjects have the right to informed consent prior to their participation in any scientific investigation that requires subject contact. The researcher may find that obtaining informed consent with deaf mentally ill subjects requires more than the usual consent form. As with other mentally ill individuals, consent forms will require

further explanation. Interpreters must be used if the researcher is not fluent in sign language and all measures must be taken to ensure that subjects are aware of what is being asked of them and their rights as research participants.

A rigorous scientific review of the research proposal should be conducted by an established institutional review board that is skilled in the area of deaf culture. This reduces unethical research practices with this population as well as sets a high standard for future research in this area. Review boards will often require that the researcher be knowledgeable about deaf culture as well as a skilled signer. If this is not the case, the researcher should then be asked to consult with a professional in the area of deafness who can oversee the research process. Therefore, the researcher must expend additional energy and finances for such consultation in effort to meet ethical requirements.

Suggestions for Future Research

Additional outcome studies with deaf mentally ill individuals are vitally needed. Findings from additional studies can either corroborate or refute previous findings, assisting in the acquisition of substantiated hypotheses. Further research should focus on collaboration, communication, accessibility of results, and immediate application.

Research liaisons between residential treatment centers and universities are optimal as they provide valuable research that either institution in isolation cannot effectively execute (Curry, 1991). Collaboration provides an optimal vehicle for outcome research to be conducted without taxing agency resources. Not only can university and agency settings form collaborative research relationships, but two or more agencies can unite to conduct outcome research that is beneficial to all participating facilities.

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Communication and accessibility of research findings is of paramount importance considering the pioneering status of outcome research on the deaf mentally ill. As the researcher provides research findings to professionals via conference presentations, publications, and private communication, others in the field will be prompted to instigate their own outcome studies in their respective agencies. In addition, professional feedback can be obtained, guiding the researcher in future outcome investigations.

Outcome research with deaf mentally ill populations should be of a utilitarian nature. Research hypotheses should be formulated so as to provide practical information to administrators and staff of residential facilities serving the deaf mentally ill. Direct applicability of research findings to program functioning will encourage administrators to pursue future collaborative research relationships, thus broadening the knowledge base of which client factors are predictive of program success.

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Notes

1. Sincere gratitude is extended to Carole Schauer, former Executive Director of Deaf-REACH for her expertise, participation, and contributions to the research investigations.
2. For further information on the results of this investigation please contact Cynthia Nickless, Gallaudet University, Department of Psychology, 800 Florida Avenue, NE, Washington, DC 20002.