Ethical Considerations for Schizophrenia Research

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SOWK 302

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April 6, 2019

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Working with vulnerable populations highlights the importance that ethics have in ensuring the public are not harmed social work interventions. On a larger scale, reviewing the ethics of our actions as practitioners in a research capacity highlights the responsibility of the social work profession to the community as a whole. This paper will explore the population of individuals who experience a diagnosis of schizophrenia, and briefly look at some of the research that has aimed to improve the quality of life of that population. With an understanding of the community, an examination of the considerations for ethical research will outline factors that are necessary for upholding our ethical duties and responsibilities as agents of social change.

Population Characteristics & Cultural Implications

To fully appreciate and honour the experiences of a population, one must consider the multiple dimensions that make up the experience of an individual living with schizophrenia. One of the ways characteristics relevant to research emerge is by examining the biopsychosocial elements in the academic literature that construct schizophrenia discourses. Biological perspectives, such as the dopamine hypothesis, propose that increased dopamine at certain synapses have an impact on the development of schizophrenia (Sarason & Sarason, 2005, p. 391). Being aware of biological research uncovers common characteristics that manifest through pharmacotherapy. Most Neuroleptics such as Pimozide and Haloperidol have common side effects of drowsiness and weight gain, while Chlorpromazine has the risk of movement disorders (tardive dyskinesia, tremors, parkinsonism) (Regehr & Glancy, 2014, pp. 167-168). Pharmacotherapy symptoms can co-cooccur with the negative symptoms (decreased motivation, lowered volition, and blunted affect) of schizophrenia (Sarason & Sarason, 2005, p. 400). Whether negative symptoms are experienced in isolation or along with medications, bio-psychological factors can impact social integration & socioeconomic status - leading to feelings of marginalization and isolation, as well as experiences of discrimination (Regehr & Glancy, 2014, p. 158).

Psychosocial characteristics are another relevant consideration of the population and extend beyond the societal implications of symptomology of the disorder and treatment regimes. Positive symptoms of schizophrenia include hallucinations, delusions, disorganized behaviour, and disorganized thinking (Regehr & Glancy, 2014, p. 157). The compelling reality of these perceptions can be distressing and distracting to the individuals who experience them (p. 157). This may thus have an impact on socialization with individuals unfamiliar with schizophrenia and lack an understanding of the effect positive symptoms have on an individual. Characteristics of negative symptoms can also have a variety of impacts on how the population becomes characterized by society. Sarason & Sarason (2005) outline negative symptom behaviours such as slowed movements & speech, reduced interest in social participation, reduced likelihood of responding in conversation, the restricted quantity of speech, restricted emotion, and avoidance of eye contact (p. 382). The language used within academic texts arguably casts many of these characteristics in a negative light, potentially furthering the alienation those living with schizophrenia may experience when the characteristics are present.

Benefits of Research Studies

Research on the efficacy of services has the potential to form a footing for social change. One example of this would be the progression of changes that have emerged in mental health care since the beginning of the deinstitutionalization movement of the 1950s (Dixon & Goldman, 2003, p. 668). Early criticisms of this transition from institutionalization to deinstitutionalization were the lack of supports that were needed to maintain wellbeing (p. 669). To fill the service gap, Community Support Team (CST) emerged as the predecessor to Assertive Community Treatment (ACT) and provided early "community support systems." The emergence of evidence-based practice allowed for CST to be refined by exploring service shortcomings and examine the impact community treatment had on reducing hospitalization time (pp. 670-671). Subsequent research provided insights on outcomes after services ended and informed changes to policies, such as the need to remove arbitrary limits on participation that created the revolving door phenomenon (p. 671). Newer research on adherence to the ACT can build an evidence-based case that paves the way for enhancements in service that maintain or improve client autonomy.

Risks of Conducting Studies

Part of the risk in conducting a study on individuals living with schizophrenia is the recreation of historical designs that depict individuals with schizophrenia from a medical model or deficit perspective (Baker, Bird, Lavin, & Thorpe, 1960). Careful consideration in the formulation of a study is that possible conclusions could cause harm by way of negatively shifting the social perception of the population within the society. This consideration would fit within Grinnell, William, and Unrau's (2019) concept of not increasing the knowledge base at the expense of human beings (p. 77), as well as section 6.2.2 of the Code of Ethics (CASW, 2005, p. 20). Considerations for research must seek to empower and improve service access/delivery for populations targeted by the research (Grinnell, Williams, & Unrau, 2019, p. 142). Persons who are (un)medicated, in varying in degree of medication compliance, or in remission could all have different experiences and experience varying degrees of harm. Designing experiments around evidence-based interventions versus best practice treatment as usual interventions (TAU) can provide a pathway to expand our evidence-base while not denying access to services (p. 152). Intervention vs. TAU designs can thereby maximize beneficence by not depriving participants of evidence-based services (pp. 152-153). Thus, designs of this nature seek to adhere to section 6.2.5 of the Code of Ethics and prevent participants from physical, mental, or emotional discomfort/distress/harm with supportive services and the right to withdraw without penalty (CASW, 2005, p. 20).

Who Benefits from Current and Future Research

Current research on psychosocial interventions for schizophrenia has a bi-directional benefit for workers and clients. As newer areas of focus such as modified ACT (MACT), where the ratio of client-to-worker is 1:30 instead of 1:15, can highlight how under-resourced programming can have a less substantial impact than traditional ACT (Razali & Hashim, 2015, pp. 172-173). In instances such as examining program efficacy, current research of program fidelity measures such as the Tools for Measurement of Assertive Community Treatment (TMACT) are a good path forward on enhancing community services (Monroe-DeVita, Teague, & Moser, 2011). One of the benefits of the approach is that fidelity measures acknowledge evidence-based practice and put a focus on service providers to maintain high standards of service. Thus, research does not place a further stigma on those already marginalized while improving opportunities to improve quality of life. When service providers become the target of research however, the balance becomes indicating and demonstrating social injustice and inequalities at a structural level, as part of section 6.5.3 while not blaming the service providers & users, or cause harm as per section 6.2 of the Code of Ethics (CASW, 2005, pp. 20-21).

Balancing Risks & Benefits: Acceptable Pathways Forward

One of the paths that can be taken in exploring the needs of vulnerable populations such as those living with schizophrenia is anti-oppressive research (Reisch & Garvin, 2016, p. 326). The approach aims to politicize the process of creating knowledge. Part of the method calls for an identification of who is "losing out" and how the population experiences losing out as opposed to placing blame on the individuals for their circumstances (p. 327). When looking at service(s) fidelity, research paves the way for the profession to actualize our ethical responsibilities to society (CASW, 2005, pp. 24-25).

Consent Considerations

One of the essential questions that comes up in the Standards of Practice is the communication and understanding of risks that are posed to participants (ACSW, 2019, p. 7). An important consideration is information processing and memory retention through the consent procedure (Regehr & Glancy, 2014, p. 154). Emerging research on best practices for consent have guided practitioners towards several ideas that can be implemented for ethical consent. Methods such as mixed-media & research associate facilitation through digitally-aided consent agreements offer the benefits of audiovisual learning that can enhance understanding of the research objectives, timeline, procedures, rights, risks, discomforts, contacts, and withdrawal for populations with schizophrenia (Harmell, Palmer, & Jeste, 2012). Being informed on alternative methods of improving understanding of consent would be consistent with responsible research practices under 6.1.1 of the Canadian Association of Social Workers (CASW) Code of Ethics (2005, p. 19).

While the use of technology can create barriers for participants and practitioners who feel uncomfortable with technology, a complementary approach in conventional consent procedures could include repetition of crucial information with follow-up check-ins and cues to enhance participant retention (Kaup, Dunn, Saks, Jeste, & Palmer, 2011, p. 6; Combs, Adams, Wood, Basso, & Gouvier, 2005). Training of research assistants would need to be mandatory so that these evidence-based consent strategies could be competently and consistently carried out. Doing so would adhere to the CASW Code of Ethics (2005) section 6.1.2, by ensuring that only qualified personnel are involved in carrying out research (p. 20).

Power differentials of participants and researchers must also be considered as a barrier to ethical consent. Coercion becomes a significant concern for all participants and would especially be the case with a group historically oppressed in research (Turek & Hanlon, 1977). While the literature on the topic suggests that perceptions of coercion are now uncommon within the population, there it is important to note that there are other ethical risks such as conflating researchers with clinicians (Kaup et al., 2011, p. 6). Clarifying the role of researchers, as well as the ability to withdraw without compromising professional services must be at the core of the process; complying with the ethical standards set out under sections 6.2.2, 6.2.4, and 6.3.1 of the CASW Code of Ethics (CASW, 2005, p. 20).

Methods to Ensure Confidentiality

There are multiple layers of protocols that can take place to ensure that confidentiality is assured. First is the coding of participants so that their name is not personally identifiable in documents or aggregated data (Grinnell, Williams, & Unrau, 2019, p. 140). Complimenting this with mandatory security protocols such as those outlined in FOIP (non-identifiable, only collecting need-to-know information, password/lock protection, etc) would fit within section 6.3.2 of the Code of Ethics (CASW, 2005, p. 21) Other means to ensure confidentiality stem from the way the data is collected itself. The CASW Code of Ethics outlines under section 1.5.6 the disclosure of confidential information should not take place in public or semi-public areas (p. 7). While this may not be applicable under quantitative research, qualitative researchers must have plans for private locations to gather data as part of their design process.

Ethics when Planning for Data Analysis

Data analysis would arguably include our ethical responsibility to understand how to analyze the data and make sense of its meaning (Grinnell, Williams, & Unrau, 2019, p. 140). The design itself needs to have a purposeful use data points collected and have a clear understanding of how it can be used for statistical/qualitative analysis that can add to the knowledge base. Furthermore, those doing data analysis (be it contracted-out or in-house) need to be legally bound to the same standards of confidentiality as that of social work researchers (be it the freedom of information and protection of privacy, the Code of Ethics, or both). In the case of program fidelity measures as the TMACT, what also becomes essential is an open and honest depiction - free of deception and omissions, while including methods of collecting and interpreting the data (pp. 158-159). Doing so would be in adherence to section 6.5 of the Code of Ethics (CASW, 2005, p. 21).

Decision on and Implications of Sharing Results of Research

Once data has been collected, aggregated and analyzed, there are ethical concerns around its dissemination to the involved parties. One of the reasons it may be unethical to release to participants directly is that it could compromise their privacy and implicate participants as research subjects and/or recipients of specialized services, and "out" personal details such as diagnosis (Grinnell, Williams, & Unrau, 2019, p. 160). On the service provider side, conclusions on services rendered can also run the risk of harming the perceptions or morale of the service provider(s). Thus, prioritizing the interests of research subjects (service users and providers) means that once data is collected and aggregated, those in the disadvantaged group need to be given remedial care to achieve the degree of benefits that were experienced by the advantaged group. To do this, participants, service providers, and communities need to have access to the research. Thus, part of the consent process must include options for if/how participants want to be informed of the findings as well as their rights to access remedial services if there was a degree of harm through lack of benefit.

Providing an option for access to results (to subjects and service providers) is crucial as it can be complemented with anti-oppressive research social justice movements that create a basis for social change. Considerations can include how and when data is presented to a service provider/subject, as certain windows of opportunity may create a convergence of interest to explore and enhance social programming & consequences of outcomes (McKenzie & Wharf, 2016, p. 99). Moments such as these may facilitate an environment that could mitigate negative impacts such as consequences in access to funding, or relationships between service providers and minimize conflicts of interests and renew interests in the constructive enhancement of services.

Potential for Misuse of Research Results with Population

As has been a theme discussed throughout this paper, the power research can have on shaping public perception is a significant issue worth addressing. This would fit with the communication laws of Osmo A. Wiio, in that "if a message can be interpreted in several ways, it will be interpreted in the way that does the most damage" (as cited in Kehoe, 2011, p. 4). To minimize the risks much consideration needs to be put into the wording of the report. Drawing from Grinnell, Williams, & Unrau (2019), reports must seek to be mindful of not confirming decisions already made - such as funding, caseload, services rendered (p. 163). Similarly, research should not be done for the benefit of avoiding the consequences of mishappenings, such as critical incidents in ACT programming. Lastly, the use of research to compete (such as to appraise staff performance of working with clients or pitting two community services against each other – H1 vs PSH) would be an unethical application of social work research (p. 163).

Conclusion

As outlined, the importance of context, methodology, purpose, framing, and degree of harm shape the ability to conduct ethical research. With the CASW Code of Ethics, and learnings from Grinnell, Williams, & Unrau, there is sufficient reason to believe that ethical considerations can be integrated into research on matters relevant to those living with schizophrenia. With ethical research comes an opportunity to facilitate empowerment through social change.

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