



Are individuals living with mental illness and their preferred alternative decision-makers attuned and aligned in their attitudes regarding treatment decisions?



Laura Weiss Roberts^{*}, Jane Paik Kim

Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, United States

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ABSTRACT

Background: Mental disorders account for considerable suffering and societal burden. Prospective alternative decision-makers may be engaged in helping make treatment decisions for those who live with serious mental disorders. Little is known about the ways in which alternative decision makers arrive at treatment recommendations and whether the perspectives of alternative decision makers and ill individuals are aligned.

Methods: The authors queried community-dwelling individuals diagnosed with schizophrenia, anxiety, or mood disorders and their preferred alternative decision-makers on issues regarding treatment decisions and underlying ethically-salient perspectives using a written survey instrument. Complete data were obtained on 26 pairs ($n = 52$, total). Outcomes included perspectives on clinical decision-making and underlying values that may shape their life choices. Two-sided paired t-tests and graphical representations were used.

Results: We found that preferred alternative decision-makers overall accurately predicted the views of ill individuals with respect to the role of the individual and of family in treatment decision making. Preferred alternative decision-makers slightly overestimated autonomy-related perspectives. The personal views of ill individuals and preferred alternative decision-makers were aligned with respect to different physical and mental disorders, except in relation to alcohol and substance use where alternative decision-makers placed greater emphasis on autonomy. Alignment was also discovered on underlying life values, except the role of spirituality which was greater among alternative decision-makers.

Conclusion: Preferred alternative decision-makers are an ethical safeguard to ensure the wellbeing and rights of seriously ill individuals. In this pilot study, preferred alternative decision makers were aligned with their ill family members concerning treatment-related decisions and underlying life values. Future research should continue to explore and clarify the views of ill individuals and alternative decision makers to determine the quality of this safeguard used in clinical settings.

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Mental disorders cause great suffering and represent the second-leading cause of years of life lost to disability and premature mortality throughout the world – first leading among economically WHO established countries (WHO, 2011). The need to discover the causes and most effective treatments of mental disorders is a global health imperative and it is increasingly recognized. Schizophrenia is among the most devastating of all mental and physical health conditions, and the 1% of the world's population who live with this condition may experience periods of

diminished or compromised decisional capacity (American Psychiatric Association, 2013). Anxiety and mood disorders, similarly, account for 10% of the total burden of all mental, neurological, and substance use disorders as measured by disability-adjusted life years, and may be characterized by periods of uncertainty, emotional lability, and cognitive distortions, which can compromise the ability to provide authentic informed consent for treatment decisions (Cassem et al., 1998; Carpenter et al., 2000; Dunn et al., 2006; President's National Bioethics Advisory Commission Report, 1998).

Clinicians routinely engage family members and others involved in the lives of people with mental disorders regarding their health

^{*} Corresponding author.

E-mail address: lwroberts.author@gmail.com (L.W. Roberts).

care decisions (Dunn et al., 2011, 2013; Overton et al., 2013). These individuals may become alternative decision-makers in clinical situations, a safeguard relied upon clinically and legally to protect the wellbeing and rights of the seriously ill (Roberts and Dyer, 2004). In an ethical framework, alternative decision-makers may follow two different approaches or legal standards. One approach is to try to identify what the patient himself or herself would choose (“substituted judgment”), and the other approach seeks to protect and advance the objective interests of the patient (“best interests”). The substituted judgment approach emphasizes individual autonomy whereas the best interests approach emphasizes anticipated benefit and minimization of risk. Little is known about the attitudes of individuals who may undertake the role of alternative decision-maker and how well aligned their views are with ill individuals. Moreover, little guidance exists to help alternative decision-makers as they shoulder this important responsibility.

To better understand the views of community-residing individuals diagnosed with psychotic, mood, and anxiety disorders, we conducted a novel pilot study to evaluate if their personal perspectives were similar to (“alignment”) and well understood by (“attunement”) the individuals whom they preferred to serve as their alternative decision-makers. We queried ill individuals regarding several attitudes and issues that are salient to the process of alternative decision making, such as the role of the ill individual and of family in arriving at treatment decisions. In addition, we asked specifically about the importance of autonomy and the role of family members and other stakeholders across several mental health conditions. We also asked about ethically important values shaping aspects of one's personal life that may have salience for treatment decisions.

To test attunement, we asked the preferred alternative decision-makers to predict the beliefs of the ill individual for whom he or she might be entrusted with decision making. To test alignment, we compared the views of the ill individuals and their linked preferred alternative decision-maker for similarities and differences. In this report, we present a descriptive and unique graphical summary of our findings.

1. Methods

The National Alliance for Research on Schizophrenia and Depression and the National Institute of Mental Health (K02 MH001918) funded this IRB-approved project. Informed consent was carefully obtained through verbal and written procedures.

1.1. Survey instrument

A new written survey instrument was developed for this project, as described in further detail in Roberts and Kim (2015), and was informed by community-based participatory research methods (Roberts et al., 2013). The written survey was based on prior work in the area of informed consent and alternative decision-making (Roberts et al., 2000, 2004; Roberts, 2002; Roberts et al., 2004).

The survey consisted of 63 items overall, with 8 items on the characteristics of the dyad relationship, 13 items of demographic and background information, 20 items on decisions related to treatment, and 22 items on decisions related to research. One survey form was administered to ill individuals, and a parallel version of the survey was administered to alternative decision-makers. Items were rated on a 9-point scale ranging from not at all important (1) to very important (9). Data presented here are based on responses to Likert-scaled attitude items and participant background information.

1.2. Study population

Eligible adults included those who were invited via printed ads that were circulated through the local chapter at the National Alliance of Mental Illness in Albuquerque, NM, and posted at the University of New Mexico Mental Health Center, the Albuquerque Veterans Administration (VA) Medical Center, and/or community mental health organizations. We conducted the written survey at a routine evening meeting at the invitation of a local chapter of the National Alliance for the Mentally Ill in the community of Albuquerque, New Mexico, and in convenient locations nearby.

Of the 39 complete pairs who expressed interest in participating, 27 pairs fully consented to participate in this study. For analysis, 1 record was excluded from the final analytic cohort.

1.3. Outcome measures

Ill individuals and linked preferred alternative decision-makers were queried on their perspectives pertaining to three domains.

1.3.1. Domain 1

Ill individuals were asked to rate the importance of several issues in relation to treatment decisions. These issues fell into two categories: issues related to the role of the individual, and issues related to the role of the family. The former category included the questions on the importance of: “including the ill individual in treatment decisions”, “ill individual is free to do what he wants”, and “ill individual is able to decide to continue or stop treatment”. The second category included questions on the importance of: “including family members in decisions”, “family's understanding of how the treatment will affect patient”, “family having to take care of ill individual during the treatment”, “what family recommends”, and “family able to decide to continue or stop treatment”. Preferred alternative decision-makers were then asked to predict the perspectives of the ill person to whom they were linked, thus allowing us to compare the predictions of the alternative decision-makers to the actual perspectives of the ill individuals (“attunement”).

1.3.2. Domain 2

Ill individuals and preferred alternative decision-makers were asked about the importance of family members and other stakeholders in clinical decisions related to different health conditions. They were asked: “How important is it for the following people to be involved in making treatment decisions?” in the following health conditions: serious physical illness, serious mental illness, serious alcohol abuse, serious drug abuse, Alzheimer's disease, and developmental disability. Responses related to personal views, thus allowing the comparison of personal perspectives (“alignment”).

1.3.3. Domain 3

Ill individuals and preferred alternative decision-makers were asked to rate the importance of several ethically-important issues and values shaping every day life. These issues were organized into 5 main themes: trust and respect, autonomy, comfort and compassion, issues related to responsibility to others, and religious or spirituality related issues. Responses related to personal perspectives, thus allowing the comparison of personal perspectives (“alignment”).

All responses were measured on a 9-point Likert scale.

1.4. Statistical analysis

Statistical aims. Our aims were to assess attunement in domain 1, and alignment in domains 2 and 3.

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