

Preferences for Instructional or Proxy Advance Directives in Mental Health: An Exploratory Mixed Methods Study

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ABSTRACT

Psychiatric advance directives (PADs) are instructional documents that allow individuals to detail their treatment preferences in the event of future mental incapacity. Mandates in case of incapacity are proxy directives used in Québec whereby a mandator (maker) can appoint a mandatary (proxy) to make financial and/or personal care decisions. Little is known about the factors that lead individuals with particular forms of mental illness to choose instructional or proxy directives. A mixed methods study is used to examine predictive factors such as autonomy, empowerment, and recovery associated with choice of document among 65 individuals with schizophrenia-spectrum disorder, major depression, or bipolar disorder. The majority of participants chose a PAD (76%) rather than a mandate (24%). A logistic regression analysis reveals that being male, having a schizophrenia-spectrum disorder, and having greater awareness and insight into the need for treatment are associated with choice of mandates rather than PADs.

Key words: consent and capacity; ethics; psychiatry and law; psychosocial interventions; qualitative research

When individuals with mental illness experience a crisis, they may receive treatments that differ from their preferences had they been able to express them at the beginning of a crisis. Two types of legal documents have been proposed to allow individuals' preferences to be known in the event of mental incapacity. Psychiatric advance directives (PADs) are instructional directives used in some U.S. states that allow individuals to include detailed instructions regarding their treatment preferences (Srebnik et al., 2005). Mandates in case of incapacity are proxy directives used specifically in Québec that allow individuals to appoint a trusted third party, such as a family member, to make decisions in the event of mental incapacity (*Civil Code of Québec*, 1991). Some jurisdictions allow individuals to complete both types of documents. In this embedded mixed methods study, we examine the factors associated with individuals' choosing an instructional directive (PAD) or a proxy directive (mandate).

Information is empowering. Individuals with mental illness who are mentally capable to complete a PAD may feel more empowered and become more assertive in articulating their treatment preferences after the process (Wilder, Elbogen, Moser, Swanson, & Swartz, 2010). In Canada, mental health organizations and government agencies are becoming interested in the future of advance treatment planning (Mental Health Commission of Canada, 2009; Dunbrack, 2006; Kirby, 2004). While mental health legislation in all provinces

and territories, except Nunavut, enable individuals to complete proxy directives, only six jurisdictions have statutory provisions that enable the use of instructional directives (Dunbrack, 2006). In the province of Québec, for example, mandates in case of incapacity are proxy directives whereby a mandator (maker) can appoint a mandatary (proxy) to make decisions regarding the administration of property and/or personal care matters (*Civil Code of Québec*, 1991). We explore factors associated with treatment preferences of individuals with bipolar disorder, depression, or schizophrenia spectrum-disorder to complete an instructional directive (PAD) or a proxy directive (mandate).

Instructional Advance Directives (PADs)

There are three types of advance directives: instructional, proxy, and a hybrid that combines both (Appelbaum, 1991; Gallagher, 1998). Instructional directives allow individuals to include detailed preferences regarding their medical treatment in order to “memorialize the subjective intent” (Gallagher, 1998). Individuals who do not have others to rely on may be more likely to use instructional than proxy directives (Pellegrino, 1992). In the U.S., instructional directives also tend to receive greater constitutional protection than proxy directives (Winick, 1996). Although some suggest that instructional directives promote autonomy (Dunbrack, 2006) others argue that “instructional directive legislation gives a veneer of protecting patient autonomy” and does “nothing towards protecting patient autonomy” (Clough, 2006). These divergent views of whether instructional directives promote autonomy, in relation to proxy directives, warrant closer examination.

Individuals who have been coerced into medical treatment are more likely to report a desire for greater autonomy (La Fond & Srebnik, 2002). Decreasing coercion can lead to greater autonomy, which may be why some individuals with mental illness have a strong desire to complete PADs if they start with a belief that the document promotes autonomy (Swanson et al., 2008). As instructional directives, PADs provide individuals the opportunity to inform family, friends, and health care staff of their treatment preferences while retaining a measure of control in decision-making (Amering, Denk, Griengl, Sibitz, & Stastny, 1999; Scheyett, Kim, Swanson, & Swartz, 2007; Swanson, Swartz, Elbogen et al., 2006; Swartz & Swanson, 2007). When treatment preferences recorded in a PAD are subsequently honoured, it can increase individuals’ subjective perceptions of autonomy (Scheyett et al., 2007) and empowerment (Backlar, McFarland, Swanson, & Mahler, 2001). On the other hand, if individuals are not consulted regarding their treatment preferences before the onset of a crisis, there is a risk of making decisions against one’s true wishes (Goss et al., 2008; Szmukler & Dawson, 2006).

PADs can be considered a self-management strategy that helps individuals towards greater control, symptom recovery, and autonomy (Davidson et al., 2007). Of course, respect for autonomy to make independent choices has reasonable limits that require knowledge of one’s level of mental capacity, which can fluctuate with episodes or psychosis or mood, particularly among certain groups such as people with bipolar disorder (Backlar, 1998; Ritchie, Sklar, & Steiner, 1998). Contrary to common belief, individuals

who complete PADs rarely use the documents to refuse all medical treatment (Swanson, Swartz, Elbogen et al., 2006). Nonetheless, perhaps some physicians and lawyers are reluctant to promote PADs because they believe the documents will be used to refuse all treatment and that they do not build autonomy. In a survey conducted among legal and mental health professionals in Ontario and Québec, 90% of the sample reported that PADs have the potential to promote autonomous choice (Ambrosini, Crocker, Perreault, & Israël, 2008). Members of some professional groups, such as social workers, may face greater struggles than other groups in supporting the principle of autonomy through PADs as they weigh other considerations such as non-adherence to treatment (Scheyett, 2009; Scheyett et al., 2008). Although it is often said that PADs promote autonomy, there remains a dearth of empirical research on the relationship between PADs and autonomy, which may be due in part to the difficulty in operationalizing autonomy and thus the lack of instruments to measure it (Geller, 2000).

Proxy Directives (Mandates)

Proxy directives are, in the present context, documents that allow people with mental illness to appoint an agent to make decisions for them in the event of mental incapacity. Unlike instructional directives, proxy directives are less constrained by unforeseeable events although agents need to be informed of the values of the person they are representing ahead of time (Appelbaum, 1991; Pellegrino, 1992). In Québec, a civil law jurisdiction, such mandates are legal documents (Brown & Murphy, 2000; *Civil Code of Québec*, 1991). Neither Québec, New Brunswick, Ontario, British Columbia, nor the Yukon, in contrast, have legislation that enables the use of instructional directives (Dunbrack, 2006; Tapp, 2006). The relevance of mandates in Québec is particularly salient as the National Assembly of Québec (2010) recently completed a series of public consultations in the province to hear perceptions towards end-of-life, euthanasia, and palliative care issues for elderly individuals.

Some have challenged instructional directives because they do not always allow individuals such as family and friends to control treatment decisions towards the end of life (Ditto et al., 2001). Unfortunately, however, some individuals who complete proxy directives do not discuss their treatment preferences with their agents (Gillick, 2006), which can reduce the accuracy with which one’s treatment preferences are expressed and will be known in a crisis (Kirschner, 2005). One of the critiques of advance directives is that individuals’ preferences may change over time. Among a non-mentally ill aged population, research indicates that from the time an advance directive is completed to one and two years later preferences for life-sustaining medical treatment remain relatively stable (Ditto et al., 2003). Given the nature of mental disorders, the stability of preferences and values among individuals with mental illness may fluctuate more than among individuals in the end-of-life context.

Preferences for Instructional or Proxy Directives

A proxy directive combined with an advisory statement in the form of an instructional directive may have the greatest influence in guiding decisions that truly reflect an individual's wishes if they were mentally capable (Emanuel, 1993). Alternatively, people who are more autonomous from the outset may tend to choose instructional directives over proxy directives. A stronger evidence base is required to understand the factors associated with one's choice of instructional or proxy directives (Brown, 2003). Individuals with certain mental disorders may be more inclined to choose a certain type of document if they feel that it promotes greater autonomy, choice, and control (Campbell & Kisely, 2009; DeWolf Bosek, Ring, & Cady, 2008). For example, individuals may prefer PADs because they increase subjective perceptions of autonomy (Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008) or because they limit health care professionals' freedom (Atkinson, Garner, & Gilmour, 2004). The odds of wanting a PAD are significantly higher among individuals who feel pressured to take medication and lower among individuals who report a higher degree of personal autonomy (Swanson, Swartz, Ferron, Elbogen, & Van Dorn, 2006); however, it is unclear whether individuals prefer instructional to proxy directives because they want to refuse treatment (Fagerlin & Schneider, 2004).

Prior research examining the relationship between autonomy and choice for instructional or proxy directives has done so primarily through a philosophical or legal approach (Clough, 2006; Davis, 2008; Ritchie et al., 1998; van Willigenburg & Delaere, 2005; Winick, 1998). Autonomy can be distinguished from related ethical values such as empowerment and self-determination (Schurhofer & Peschl, 2005; Somerville, 1994). For example, self-determination has been referred to as the ability to express one's wishes, such as saying "yes" or "no" (Somerville, 1994), whereas empowerment is the process of gaining information that can lead to increased autonomy and control in one's life (Schurhofer & Peschl, 2005). Another approach to understanding autonomy has been to construct it as a normative and ethical *ideal* that one strives towards, rather than as a functional value (Stigglebout et al., 2004). Unlike empowerment that can involve a process of one person sharing information to empower someone else, autonomy can be understood as a self-referential and internally generated state or trait (Schurhofer & Peschl, 2005).

Some legal scholars have recommended standardizing instructional and proxy directive forms across Canada (Downie, 1992). Before taking such steps, it would be helpful to understand the reasons why individuals prefer certain types of documents. This study is important on several fronts. First, although the exact figures are unknown, among Canadians for whom advance directives are most relevant very few have completed one and those who have, have done so primarily in the end-of-life context (Bravo, Paquet, & Dubois, 2003; Molloy, Guyatt, Alemayehu, & McIlroy, 1991; Molloy, Harrison, Farrugia, & Cunje, 1993; Molloy et al., 2000; Patterson et al., 1997; Sam & Singer, 1993). Second, as mentioned above, currently six Canadian jurisdictions do not have enabling legislation for instructional directives (Dunbrack, 2006). If the demand for instructional directives is high among certain groups of individuals with mental illness, it may be desirable to pass legislation that would give greater legal force to such documents.

Third, as there is a strong impetus towards promoting a national mental health strategy across Canada, greater knowledge of preferences for advance treatment planning should precede legislative reform (Mental Health Commission of Canada, 2009; Kirby, 2004).

Goal of Present Study

The purpose of this study is to determine preferences for instructional or proxy directives among individuals with depression, bipolar disorder or schizophrenia, and to explore the factors associated with choice of document. An embedded mixed methods design using quantitative and qualitative components is used to examine the relationship between level of autonomy, empowerment, and recovery and choice of document.

Hypotheses

We developed four *a priori* hypotheses to be tested using quantitative or qualitative methods.

Quantitative

1. Individuals with higher levels of autonomy, empowerment, and recovery are more likely to choose instructional directives (PADs) over proxy directives (mandates). This hypothesis was based on previous literature that PADs represent the consumer choice model and promote autonomy more than other forms of advance treatment planning documents (Henderson, Swanson, Szmukler, Thornicroft & Zinkler, 2008).
2. Individuals with schizophrenia-spectrum disorder are more likely to choose instructional directives (PADs) than individuals with depression or bipolar disorder who would choose proxy directives (mandates). This hypothesis was based on the belief that individuals with schizophrenia-spectrum disorders may be more interested in medication refusal, which is addressed specifically in a PAD.
3. The degree of autonomy, empowerment, and recovery of individuals who completed a PAD will increase over a three-month period more than among individuals who completed a mandate. Although preferences for life-sustaining treatment are moderately stable over one and two years among older adults (Ditto et al., 2003), this third exploratory hypothesis was based on the possibility that autonomy, empowerment, and recovery may be more likely to fluctuate given the nature of choices made by individuals with mental disorder.

Qualitative

4. Individuals' values and experiences with mental illness, as communicated in an interview before (phase I) and after (phase III) completing a PAD, will be congruent with the instructions included in their PADs and the reasons for choosing an instructional directive.

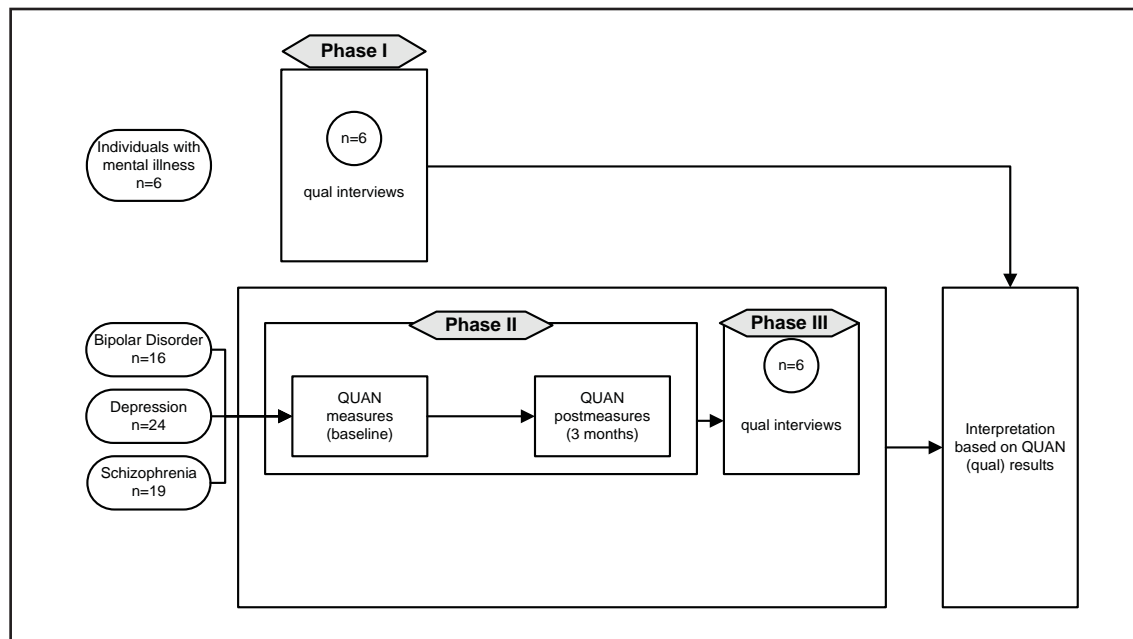


Figure 1. Flowchart of Embedded Mixed Methods Study Design

Methods

Participants

Participants were 65 individuals with serious mental illness living in Montréal, Québec. Participants were required to: 1) have a diagnosis of bipolar disorder, schizophrenia-spectrum disorder, or major recurrent depression (with or without psychosis); 2) be 18-65 years old; 3) be able to understand and speak English; 4) be capable of providing informed consent; 5) be followed by a psychiatrist. People who were incompetent to consent; under public curatorship; or had already completed an advance directive were excluded from participation in the study.

Recruitment

Participants were referred to the study from clinics associated with the Douglas Mental Health University Institute (DMHUI) in Montréal, a teaching hospital affiliated with McGill University, as well as from community mental health organizations in the Montréal area. Psychiatrists, case managers (or their delegates), and staff from the DMHUI and community mental health organizations asked eligible participants if a member of the research team could phone them to explain the research study. Recruitment took place from December 2009 to December 2010.

Study Design

Mixed Methods. An embedded mixed methods study design was used to synthesize quantitative and qualitative results to provide a robust understanding of reasons for participants' choices (Creswell & Plano-Clark, 2003). Mixed methods research has been used in mental health to examine delivery of services (Robins et al., 2008), management of anti-psychotic medication (Rogers, Day, Randall, & Bentall, 2003), acceptability of assertive community treatment

programs (Killaspy et al., 2008), and coping strategies (Kartalova-O'Doherty & Doherty, 2008). The flowchart in figure 1 depicts how qualitative phases of the study (I and III) were embedded into the primary quantitative phase (II).

Preference Trial. Although random allocation enables an internally valid comparison between the effects of two treatments, it does not take into account patients' preferences for treatment (Bowling & Rowe, 2005). Some have advocated for the greater use of preference trials to evaluate how choices affect treatment outcomes (Tilbrook, 2008), which can lead to a greater appreciation for how voluntariness affects outcomes in the delivery of mental health services (Howard & Thornicroft, 2006). This study addresses factors that motivate choice between PADs as instructional directives or mandates as proxy directives.

Interventions

Psychiatric advance directive (PAD). PADs are legal documents used in parts of the U.S. that allow individuals with mental illness to provide detailed instructions regarding their treatment preferences in the event of future mental incapacity (Swanson, Tepper, Backlar, & Swartz, 2000). A PAD contains provisions to appoint an agent/proxy (although in some jurisdictions this is optional), to include instructions regarding treatment, to share contact information, and to declare when it should be revoked. A copy of a PAD was obtained from the Bazelon Center for Mental Health Law (2010) in the U.S., which was adapted for use in this study under Canadian law. A Montreal lawyer who was independent from the research study verified that the PAD follows the general format required under Québec law that two witnesses are required to witness the signing of the document. Three additional pages were included in the PAD to allow participants to write detailed instructions regarding: physical symptoms, crisis situations, acceptable and unacceptable medications, allergies, hospitalization preferences

and objections, emergency contacts, stressors and triggers of crisis, wellness factors, helpful support, recovery, therapies, personal assistance, and instructions to hospital staff. In our version of the PAD, participants were able to appoint a proxy (but need not do so). Under Québec law, individuals have the right to choose a professional or institution from whom they wish to receive health or social services (*An Act Respecting Health and Social Services*, 2002). Individuals were able to use a PAD to record their preferred hospital where they wished to receive care, but were also informed that the availability of their choice would depend on available resources. PADs are not generally used to record detailed preferences regarding administration of property or finances.

Mandate in case of incapacity. Mandates are proxy directives used in the province of Québec and governed under articles 2130-2174 of the *Civil Code of Québec* (1991). A mandate enables individuals to appoint another trusted person to make decisions in anticipation of mental incapacity regarding administration of finances and property and personal care issues. A copy of the mandate was obtained from the website of the Office of the Public Curator who provides such a document to the public for free (Public Curator of Québec, 2009). A PAD also allows the designation of an agent/proxy; unlike PADs, however, mandates can be used to designate an individual with the right to administer finances and property and/or personal care (i.e. housing, consent to care, clinical trials, and last wishes) in the event of mental incapacity. Participants were informed that under Québec law mandates need to be homologated if a mandator becomes incapable (which often takes time), a process whereby a court confirms the individual's mental incapacity, verifies the mandate, and validates the presence of witnesses. Mandates do not generally focus on mental health issues in the same way as do PADs.

Measures

Mental competence. The MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) was used to measure competence to consent to clinical research (Appelbaum & Grisso, 2001; Candilis, Fletcher, Geppert, Lidz, & Appelbaum, 2008). The MacCAT-CR is a semi-structured interview to examine decision-making competence as it relates to four factors: understanding ability, appreciation ability, reasoning ability, and expressing a choice (Kovnick, Appelbaum, Hoge, & Leadbetter, 2003). The instrument has good inter-rater reliability with kappa coefficients previously calculated for measures of understanding (.69), reasoning (.53), and appreciation (.79) (Kovnick, Appelbaum, Hoge, & Leadbetter, 2003). The instrument included questions that were relevant to completing this study on advance directives. Each question is scored on a scale of 0 to 2 with the following ranges: understanding (0 to 26); reasoning (0 to 8); appreciation (0 to 6); expression of choice (0 to 2).

Autonomy. Autonomy was measured using two instruments. The first was the Ideal Patient Autonomy Scale (IPAS), a 14-item normative instrument on a 5-point Likert scale format (from 'disagree' to 'agree') that examines how ideals of autonomy in clinical practice align with alternative conceptions of autonomy found in the ethics literature (Stigglebout et al., 2004; Stigglebout et al., 2008). A higher score on the IPAS reflects greater agreement that patient autonomy is desirable. The IPAS was originally developed to guide doctor-patient relationships and to understand patients'

perceptions of the clinical decision-making process. The IPAS contains four subscales of autonomy: (i) doctor knows best (e.g. It is better that the doctor rather than the patient decides which is the best treatment); (ii) patient should decide (e.g. It goes too far when the doctor decides which treatment is best for the patient); (iii) right to non-participation (e.g. Patients should have the right not to be involved in the decision on the treatment); and (iv) obligatory risk information (e.g. The patient has to be informed on all the risks involved in an operation) (Stigglebout et al., 2004). Although the IPAS has not been validated for test-retest reliability in a psychiatric population, a review of 65 instruments measuring clinical judgment suggests it shows special promise as it is closely linked with ethical theory (Redman, 2006).

The Autonomy Preference Index (API) was used as an alternate measure of autonomy and incorporates two subscales: (i) six items on decision-making (e.g. You should go along with your doctor's advice even if you agree with it) and (ii) eight items measuring information-seeking preference (e.g. It is important for you to know all the side effects of your medication) (Ende, Kazis, Ash, & Moskowitz, 1989). Responses are recorded using a 5-point Likert-scale from 'strongly disagree' to 'strongly agree'. Test-retest reliability for the decision-making sub-scale is 0.84 and the information-seeking sub-scale is 0.83 (Ende et al., 1989). On the decision-making preference scale of 0 to 100, a 0 score indicates a very low and 100 indicates a very high preference for decision-making, whereas 50 is a neutral attitude. For the preference for information seeking scale ranging 0 to 100, a 0 refers to strong disagreement with statements favouring patient's being informed, 50 is neutral, and 100 is strong agreement.

Empowerment. The Making Decisions Empowerment Scale is a 28-item instrument on a 4-point Likert format (from 'strongly agree' to 'strongly disagree') designed to measure subjective feelings of personal empowerment among individuals with mental illness (Rogers, Chamberlin, Ellison, & Crean, 1997). The total score ranges from 28 to 112, with a higher score indicating higher empowerment. The Empowerment Scale contains five subscales: (i) self-esteem and self-efficacy (e.g. I have a positive attitude toward myself); (ii) power-powerlessness (e.g. Usually I feel alone); (iii) community activism and autonomy (e.g. People have a right to make their own decisions even if they are bad ones); (iv) optimism and control over the future (e.g. I can pretty much determine what happens in my life) and; (v) righteous anger (e.g. Getting angry about something never helps) (Rogers et al., 1997). The scale has good reliability in terms of internal consistency (Cronbach's $\alpha = 0.83$) (Hansson & Bjorkman, 2005; Rogers et al., 1997; Wowra & McCarter, 1999).

Recovery. The Recovery Assessment Scale (RAS) is a 41-item scale rated on a 5-point Likert format (from 'strongly disagree' to 'strongly agree') used to measure recovery (Corrigan, Salzer, Ralph, Sangster, & Keck, 2004). The RAS contains five factors: (i) personal confidence and hope (e.g. I am hopeful about my future); (ii) willingness to ask for help (e.g. I am willing to ask for help); (iii) goal and success orientation (e.g. I have my own plan for how to stay or become well); (iv) reliance on others (e.g. I have people I can count on) and; (v) symptom coping (e.g. Coping with my mental illness is no longer the main focus of my mental illness) (Corrigan et al., 2004). The RAS has good internal consistency (Cronbach's $\alpha = 0.93$) (Corrigan, Giffort, Rashid, Leary, & Okeke, 1999), and

each factor has satisfactory internal reliability (Cronbach's $\alpha = 0.73$ to 0.91) (McNaught, Caputi, Oades, & Deane, 2007).

Insight. The Insight and Treatment Attitudes Questionnaire (ITAQ) was used to measure participants' awareness of illness and insight into the need for treatment (McEvoy, Applebaum, Apperson, Geller, & Freter, 1989; McEvoy, Freter, Merritt, & Apperson, 1993). The ITAQ consists of 11 items phrased as open-ended responses scored as 0 (no insight), 1 (partial insight), or 2 (good insight). Total scores range from 0 to 22. Patients with a score of 15 or higher are defined as having good insight, 8-14 as fair insight, and 7 or lower as poor insight. Sample items include, Do the medications do you any good? Will you take the medication? The ITAQ has been shown to have good test-retest reliability at one year follow-up ($r = 0.70$) (McEvoy et al., 1993).

Coercion. Coercion was measured using the MacArthur Perceived Coercion Scale (MPCS), a scale that includes 5 true/false items to assess perceptions of freedom, influence, control, and treatment choices (Gardner et al., 1993). In its original form, participants were asked about coercion related to their medication and to clinical treatment in relation to their hospital admission (Rain, Steadman, Robbins, 2003). The five items include: I feel free to do what I want about getting treatment; I chose to get treatment; It was my idea to get treatment; I had a lot of control over whether I got treatment, and; I had more influence than anyone else on whether I got treatment. On the MPCS, each 'true' was scored 0 and each 'false' scored 1. Scores were dichotomized into low (0-2) or high coercion (3-5) for analyses.

Psychopathology. The expanded Brief Psychiatric Rating Scale (BPRS-E) is a 24-item scale measuring participants' severity of psychiatric symptoms over the past two weeks (Lukoff, Nuechterlein, & Ventura, 1986). Each item in the BPRS-E consists of a 7-point scale ranging from 'not present' to 'extremely severe.' The BPRS-E has been demonstrated to have good internal consistency among outpatients in three diagnostic groups (bipolar disorder, schizophrenia, and depression), and has a stable four-factor structure: (i) depression/anxiety; (ii) psychosis; (iii) negative symptoms (retardation); and (iv) activation (Velligan et al., 2005). Although an earlier version of the BPRS has been shown to have a four-factor model that includes thought disturbance, anergia, affect, and disorganization (Mueser, McHugo, Curran, 1997), the more recent version of the BPRS-E was used because it too has a stable four-factor structure making it useful as a clinical outcome measure (Velligan et al., 2005). The research assistant who administered the BPRS-E received specialized training over several weeks on how to administer the instrument from qualified clinicians.

Attitude toward medication. The Hogan Drug Attitude Inventory (DAI-30) was used to measure participants' subjective attitudes towards medication (Hogan, Awad, & Eastwood, 1983). The DAI-30 is a 30-item true/false instrument with seven factors: (i) subjective positive (e.g. For me, the good things about medication outweigh the bad); (ii) subjective negative (e.g. I feel weird, like a 'zombie' on medication); (iii) health/illness (e.g. It is unnatural for my mind and body to be controlled by medication); (iv) physician (e.g. It is up to the doctor when I go off medication); (v) control (e.g. I take medication of my own free choice); (vi) prevention (e.g. By staying on medication, I can prevent getting sick); (vii) harm

(e.g. Medication is a slow-acting poison). The DAI-30 consists of 15 items dealing with positive attitudes and 15 items addressing negative attitudes. Total scores were calculated by producing a score ranging from -30 to 30 where a positive total score indicated an overall positive subjective response, and a negative total score reflected an overall negative subjective response. The DAI-30 has good internal consistency (Cronbach's $\alpha = 0.84$) (Kuroda et al., 2008).

Preferences for advance directives. The Preference for Advance Directives Scale (PAD Scale) is 10-item scale measured on a 5-point Likert format (from 'strongly disagree' to 'strongly agree') developed by one of the authors (DA) to explore preferences for advance directives. The PAD scale was used in another study to examine preferences of PADs among social work students (Ambrosini, Lach, Charette, & Crocker, under review). A principal components exploratory factor analysis with Varimax rotation resulted in a four-factor model with good sample adequacy ($KMO = 0.65$). The four factors are: (i) choice (e.g. I want to write down detailed instructions about my treatment choices in an advance directive); (ii) interpersonal/individualism (e.g. I want my family to help me decide my treatment choices with my doctor before completing an advance directive); (iii) doctor involvement (e.g. I trust my doctor to help me decide which treatment choices to include in an advance directive); (iv) self-trust (e.g. I trust my own judgment regarding treatment choices to include in an advance directive). Data on the test-retest reliability of this scale are not available from this study.

Study Procedures

Phase I: Qualitative. Maximal variation sampling was used to recruit an equal representation of individuals who were purposefully selected across type of mental disorder and gender (Creswell, 2003; Whitley & Crawford, 2005). Sample size for the interviews was intentionally kept small to provide an in-depth understanding of participants' responses rather than obtain a breadth of information (Creswell, 2003). An experienced interviewer conducted and audio-recorded interviews in the homes of six participants ($n = 1$, bipolar; $n = 2$, depression, $n = 3$, schizophrenia). On average, these six interviews lasted 58 minutes. A second member of the research team, trained as a lawyer (DA), met with participants at the DMHUI approximately two days later to facilitate the completion of a PAD. The initial interviewer then returned to participants' homes one month later for a follow-up interview that averaged 30 minutes. Additional details of the study design and results are presented in chapter 4.

Phase II: Quantitative. An interviewer administered questionnaires, and laminated sheets showing participants the response options were used as supports during the interview. The time of baseline interviews was not measured but averaged between 75 to 90 minutes according to the interviewer. When participants returned to the DMHUI two to three days later, they met a member of the research team (DA) who gave them a choice between completing a PAD or mandate. Participants were provided two laminated sheets explaining in bullet format the differences between each document. In order to ensure that participants understood each document, they were asked to

TABLE 1. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF RESPONDENTS CHOOSING PSYCHIATRIC ADVANCE DIRECTIVE OR MANDATE IN CASE OF INCAPACITY (N=54)

	TOTAL	PAD		MANDATE		p-value ⁺
		N (%) of mean (SD)	N	% or mean (SD)	N	
Type of mental illness						p <0.007
Depression	24 (44.4)	18	75.0	6	25.0	
Bpolar	15 (27.8)	15	100.0	0	0	
Schizophrenia	15 (27.8)	8	53.3	7	46.7	
Age	45 (10.6)	41	45.5 (10.4)	13	46.6 (10.6)	0.746
Gender						0.526
Female	27 (50)	19	70.0	8	30.0	
Male	27 (50)	22	81.4	5	18.6	
Civil status						0.652
Married/remarried	8 (14.8)	7	87.5	1	12.5	
Never married	29 (53.7)	22	75.9	7	24.1	
Legally divorced	7 (13)	6	85.7	1	14.3	
Separated	3 (5.6)	2	66.6	1	33.3	
Living as married	7 (13)	4	57.1	3	42.9	
Children						1.000
Yes	19 (35.2)	14	73.7	5	26.3	
No	35 (64.8)	27	77.1	8	22.9	
Number of children	54	41	.61 (.919)	13	.92 (1.44)	0.609*
Prior psychiatric hospitalization						0.493
Yes	38 (70.4)	30	80.0	8	20.0	
No	16 (29.6)	11	68.8	5	31.2	
Number of hospitalizations	37	29	4.5 (7.4)	8	4.3 (3.1)	0.536
Involuntary hospitalization						1.000
Yes	16 (29.6)	12	75.0	4	25.0	
No	38 (70.4)	29	76.3	9	23.7	
Hospital restraints						0.076
Yes	18 (34)	15	83.3	3	16.7	
No	31 (58.5)	24	77.4	7	22.6	
No response	4 (7.5)	1	25.0	3	75.0	
Isolation or seclusion						0.063
Yes	17 (32.1)	13	76.5	4	23.5	
No	32 (60.4)	26	81.3	6	18.7	
Unsure	4 (7.5)	1	25.0	3	75.0	
Involuntary Treatment						0.740
Yes	8 (15.1)	7	87.5	1	12.5	
No	44 (83.0)	33	75.0	11	25.0	
Unsure	1 (1.9)	1	100.0	0	0	

+ Fisher Exact Test

* Mann-Whitney Test

recite similarities and differences before expressing a choice. All participants wrote their own instructions in the document. It took participants an average of 121 minutes ($SD = 30$) to complete the PAD, and 94 minutes ($SD = 18$) to complete the mandate. To create the document, it was formally witnessed by two independent persons from the hospital. The original document was given back to participants who were advised to keep it in a secure location. Participants who named a mandatary in their mandate were encouraged to inform the individual that they completed such a document. Participants who named an agent in their PAD were also advised to inform the agent of the document. A second copy of the document was provided to hospital clinics (depression, bipolar, schizophrenia) to include in patients' files; a third copy was retained for research purposes.

Approximately three months later, participants were telephoned by a member of the research team (DA) and asked to return to the DMHUI for a brief follow-up visit. Participants completed four questionnaires previously administered at baseline measuring their degree of autonomy (IPAS, API), empowerment (Empowerment Scale), and recovery (RAS). Participants discussed advantages and disadvantages of the document, and were asked whether they wanted to revoke or retain it. These sessions lasted an average of 30 minutes.

Phase III: Qualitative. Six participants from phase II who chose and completed a PAD were purposively selected, based on equal representation of sex and mental disorder ($n = 2$, bipolar; $n = 2$, depression; $n = 2$ schizophrenia), for a follow-up interview at the DMHUI. Purposive sampling involves having one or more predefined groups in mind and in this case involved an equal representation of sex and type of mental disorder (Creswell, 2003; Whitley & Crawford, 2005). These interviews were conducted and audio-recorded by an interviewer (DA) and averaged 48 minutes.

Mixed Methods Integration Procedure

Integration of data occurred in several ways during the collection, analyses, and interpretation of the study (Creswell & Plano Clark, 2007). Data was collected from participants using qualitative interviews before and after questionnaires were administered during the quantitative phase. Additionally, qualitative data was collected during the quantitative phase II as participants were asked to provide reasons for choosing a PAD or mandate. During the analyses, transformation methods were used to transform qualitative data into quantitative results that could be numerically coded and interpreted. A modified form of extreme case analysis was used in phase III to integrate participants' values, expressed during the qualitative interviews, with quantitative outlier scores to identify points of convergence or divergence (Caracelli & Greene, 1993). The six individuals for the modified form of extreme case analysis were already selected based on sex and type of mental disorder and not on their individual outlier scores.

Ethics Approval

The study was approved by the Research Ethics Board of the Douglas Mental Health University Institute (DMHUI), a teaching hospital affiliated with McGill University in Montréal, Québec. All participants provided written informed consent and were given the following compensation: Phase I (\$20); Phase II (\$20 for the first visit, \$20 for the second visit, and \$10 for the third visit); Phase III (\$10).

Results

The manner in which results are presented in a mixed methods study can vary (Creswell & Plano Clark, 2007). As this study was designed as an embedded mixed methods study prioritizing quantitative methods, the quantitative phase II results are presented first followed by qualitative results from phases I and III (Creswell & Plano Clark, 2007).

Sample Characteristics

Ninety-one individuals were referred to the study: 35% ($n = 32$) from community mental health organizations and 65% ($n = 59$) from clinics associated with the hospital. Among the 91, 4 individuals could not be reached by telephone, and 6 individuals were referred to participate in phase I. Among the remaining 81 individuals screened at phase II, 27% ($n = 22$) chose not to participate for reasons including: time constraints ($n = 11$), psychological barriers ($n = 5$), language issues ($n = 4$), and no reason provided ($n = 2$). Among the remaining 59 participants, 8% ($n = 5$) were mentally incapable to complete an advance directive, 4 of whom had a schizophrenia-spectrum disorder.

Participants' average age was 45 years ($SD = 10.6$) with a range between 27 and 64 years. Table 1 reveals the sample was 50% female, 54% ($n = 29$) had never been married, and 65% ($n = 35$) did not have children. Forty-four percent of participants had a diagnosis of major depression, 28% bipolar disorder, and 28% had a schizophrenia-spectrum mental disorder. Among the sample, 34% ($n = 20$) of participants lived alone in an apartment and 58% ($n = 34$) were not working. Regarding source of income, 31% ($n = 18$) received welfare, 22% ($n = 13$) received disability insurance, and 20% ($n = 12$) received payment for work. Fourteen percent had not completed high school.

The mean score on the BPRS was 41.8 ($SD = 9.7$) indicating moderate symptom severity. The mean score on the ITAQ was 13.7 ($SD = 2.3$) which, according to norms, reveals a fair level of awareness and insight and awareness into the need for treatment. The mean score on the MacArthur Perceived Coercion Scale (MPCS) was 3.5 ($SD = 1.4$) with the responses suggesting a high perception of coercion related to issues of medication and clinical treatment. Table 1 shows that 70% of participants reported at least one psychiatric hospitalization in their lifetime. However, 70% stated that they were not hospitalized against their wishes and 83% did not receive involuntary treatment. At the same time, among the sample, approximately one-third (34%) reported the use of hospital restraints, and another one-third (32%) stated that

isolation or seclusion had been used against them in the past. Interestingly, 83% provided written authorization for a research team member to verify their information with their medical file, although these were not verified.

Hypothesis 1: Autonomy, empowerment, and recovery as predictors of choice of document

Consistent with our first hypothesis, we found that 76% (n = 41) of individuals with mental illness chose an instructional directive (PAD) and 24% (n = 13) preferred a proxy directive (mandate). However, a simple univariate logistic regression was conducted and we did not find that individuals with higher levels of autonomy, empowerment, or recovery were more likely to choose instructional directives (PADs) over proxy directives (mandates). We did find that individuals who chose a PAD were significantly more likely than those who chose a mandate to have higher levels of subjective negative perceptions towards medications (OR = 1.3, 95% CI: 1.0-1.6). Although not directly related to our hypothesis, it should be noted that several participants reported to the interviewer that they would have preferred to complete both documents – the mandate for administration of finances and property and the PAD for mental health issues.

Results from phase II helped to explain reasons underlying participants' choice of document in line our goal of exploring reasons for choosing instructional directives. When participants reported why they chose a PAD (n = 41), their qualitative responses were coded into themes and transformed into frequencies. Among the coded responses, 51% (n = 21) reported that a PAD allowed them to provide detailed instructions, 39% (n = 16) believed it gave them greater control, and 39% (n = 16) stated it provided greater choice. When participants returned three months later and were asked about the advantages of PADs, the most frequent responses were that the document allows them to have greater trust in whom they choose as their substitute decision-maker (n = 10), provides security and peace of mind (n = 7), and allows them to control their own decisions (n = 7). Among the nineteen coded advantages reported by participants were that a PAD allows them to have a voice; feel empowered; be glad to have a written document; and that it provides greater choice. Among the twenty-five coded disadvantages of PADs, participants stated that it is difficult to choose an appropriate agent (n = 4); that it deals only with mental health issues (n = 4); and that the document may not be accessible during a crisis (n = 4).

Eighty-three percent of respondents who chose a PAD in phase II (n = 34) recorded that in a crisis they preferred to receive treatment at a specific hospital. Among this group, ten participants also objected to a specific hospital based on past mistreatment (n = 6); language barriers (n = 2); personal/family reasons (n = 1); and a lack of hospital funding (n = 1). PADs allow individuals to specify their preferred intervention to be used in the event of an emergency. Among those who completed this provision of the PAD (n = 39), 62% reported their first choice of emergency intervention was medication in pill form, 15% wanted medication by injection, and 15% requested seclusion. The reason participants chose an emergency intervention was then coded into one of three factors:

(i) medication is effective; (ii) trying to avoid coercion from the social involvement of others; or (iii) unclear response. We found that 45% reported that the reason for their choice of emergency intervention was based on effectiveness of medication, 35% related their choice to some form of social coercion involving others, and 20% of responses were unclear.

'This choice is based on past experiences that proper medication has been most effective for me.' (Effectiveness)

'Because medication has always worked for me in past.' (Effectiveness)

'Fearful memories of seclusion and restraints in the past.' (Social coercion)

'I prefer medication first because if I'm being aggressive or fighting I don't need seclusion or physical restraints.' (Social coercion)

In addition, 56% (n = 23) of respondents who included a refusal of at least one medication in their PAD. The medications most commonly refused were Seroquel (n = 7), Lithium (n = 7), and Haldol (n = 5). When individuals were asked in an open-ended question to provide a reason for refusing medications, responses were coded as quantitative data as the ability to provide a specific reason related to medical symptoms (83%) or to a general reason (17%).

'Lithium: I have taken this drug with very difficult side effects: somnolence, tremors, impotence, excessive sleeping, increased appetite, profound dimness of mind.' (Specific reason)

'Lithium: Bad side effects. Never felt like myself while on it.' (General)

Among the seventeen participants who refused to consent to medications that gave them unwanted side effects, the most frequently cited were tremors (n = 9), weight gain (n = 7), and motor restlessness (n = 5).

Among participants who included wellness factors in their PAD (n = 37), after coding responses into themes, we found that 38% reported that they wanted to be outdoors, 32% stated they wanted to be active, and 30% stated that music helps. Other wellness factors include having a social life, reading books, animal therapy, hobbies, watching television, closeness to family, and religious activities.

At three months, participants were asked what they thought about the PAD. Responses reflected a strong appreciation for the PAD with only one participant who chose to revoke the document.

'Kind and imperative tool to help ill person get better using active support of family and friends and medical practitioners. Most important strength is that it creates hope of a healthy recovery without fear of being abused. Have someone to help me without fear of someone abusing me.' (Individual with bipolar disorder)

'Makes more sense than delegating power to someone else. Gives more power as to what can happen in the future. More comfortable that things will be taken care of according to principles in life.' (Individual with depression)

'Never heard of it before. Good to know something can be planned for future and that things will be looked after. Provides reassurance. Was not difficult to understand and gave a lot of options so could be able to include more detail if wanted. Have power to help yourself in the future.' (Individual with depression)

'I feel a bit safer about my future in case something happens. Had friend at work who could not function. Someone had to take care of it.' (Individual with schizophrenia)

Among participants in phase II who completed a mandate (n = 13), 46% (n = 6) stated that they chose the document because they trusted others, 39% (n = 5) reported that it deals with both mental and physical/financial matters, and 31% (n = 4) stated that mandates were recognized as legal documents in Québec. When asked about the advantages of mandates, participants reported that they offer greater control over one's decisions (n = 3), provide peace of mind (n = 2), and allow for greater trust with their mandatary (n = 3). The disadvantages of mandates were that their mandatary could die (n = 3), they are giving a measure of control away to someone else (n = 2), and they need to have complete trust in their mandatary (n = 2). When participants were asked at three months what they thought about mandates, responses were consistent with earlier reasons.

'Document is good in that it handles bodily illness but also material/financial issues. Being able to say which percentage goes to whom. When someone has faculties, have say. Someone will know that when sick I have appointed someone. Brought the mandate to job and intentionally left the document on desk and boss thought it was stupid. Ask questions when sick.' (Individual with depression)

'Good thing to sign up for the document because if an emergency occurred someone could take over my finances and personal health issues. Did have some wealth that would want to be taken care of.' (Individual with schizophrenia)

Hypothesis 2: Type of mental disorder and choice of document

There was a significant association between choice of document (PAD or mandate) and type of mental illness (bipolar disorder, depression, schizophrenia) (Fisher's exact test, two sided, $p < 0.01$) (Table 1). However, we did not find support for our second hypothesis that individuals with schizophrenia spectrum disorders would be more likely to choose instructional directives (PADs) than proxy directives (mandates). Instead, all individuals with bipolar disorder, three-quarters of individuals with depression, and approximately half of individuals with schizophrenia chose a PAD (Table 1). Table 2 depicts the development of a multivariate logistic regression model. To identify variables that could be entered into the multivariate logistic regression analyses, bivariate correlation analyses using SPSS 17.0 (2008) was performed to assess which variables were significantly correlated at a $p < 0.25$ level and could be included as candidate variables into the multivariable model (Hosmer & Lemeshow, 2000). The predictor variables were age, sex, insight and awareness into the need for treatment, not currently working, and type of mental illness. Due to the small sample size, we were limited to five variables to include in the model and we chose to compare schizophrenia-spectrum disorders as a psychotic disorder to bipolar disorder and depression as mood disorders. Table 2 shows the logistic regression coefficient, Wald test, and odds ratio for each of the predictors. Employing a .05 criterion of statistical significance, sex (male) (6.9 [1.07-44.99]), insight and awareness into the need for treatment (0.57 [0.33-0.97]), and schizophrenia-spectrum psychotic disorder (0.02 [0.002-0.25]), had significant partial effects. In order to provide a context for interpreting the meaning of non-significant coefficients, a post-hoc power calculation was conducted using SAS software (PROC power) based on the sample size used in this study, and to achieve 80% power the sample size required is a minimum of 75 participants.

Hypothesis 3: Results of exploratory analysis on stability of preferences over time

In line with our third exploratory hypothesis, we examined the stability of participants' preferences over three months to

TABLE 2. LOGISTIC REGRESSION MODEL OF FACTORS ASSOCIATED WITH CHOOSING A PSYCHIATRIC ADVANCE DIRECTIVE OVER A MANDATE IN CASE OF INCAPACITY (N = 54)

Variable	Coefficient (β)	Wald χ^2	p value	Odds Ratio (95% CI)
Age	-.038	.979	.375	0.96 (.89, 1.05)
Sex (Male)	1.934	4.12	.042	6.93 (1.07, 44.99)
Schizophrenia-spectrum psychotic disorder	-3.92	9.14	.002	0.02 (0.002, 0.25)
Not currently working	-1.12	1.71	.191	0.963 (0.89, 1.05)
Insight and awareness into need for treatment (ITAQ scale)	-.57	4.22	.040	0.57 (0.33, 0.97)
Intercept	12.30	6.36	.012	

*Cox and Snell $R^2 = 0.30$.

determine to what extent individuals with mental illness fluctuate in their perceptions and decision-making. Figure 2 reveals that participants' responses remained relatively stable over time from baseline to three months on measures of autonomy (IPAS), empowerment (Empowerment scale), autonomy (API), and recovery (RAS). Additionally, we performed a paired t-test among the full sample (PAD and mandate combined) to examine any significant differences over time for the mean score. No such difference was found for the IPAS ($t = -.432$ (48), $p = n.s.$), Empowerment scale ($t = -.176$ (48), $p = n.s.$), API ($t = -1.509$ (48), $p = n.s.$), and the RAS ($t = -.918$ (48), $p = n.s.$). However, when the sample was separated by the group who chose PADs from the group who chose mandates, there was a significant difference (small increase) over time on the API for participants from the PADs group ($t = -2.7$ (36), $p = .01$). Among participants in phase II who returned at three months, only two individuals ($N = 59$) asked to change a specific provision within their PAD and in both cases it involved replacing the agent. The reasons were that the agent was no longer well enough to act or that they no longer trusted whom they initially chose.

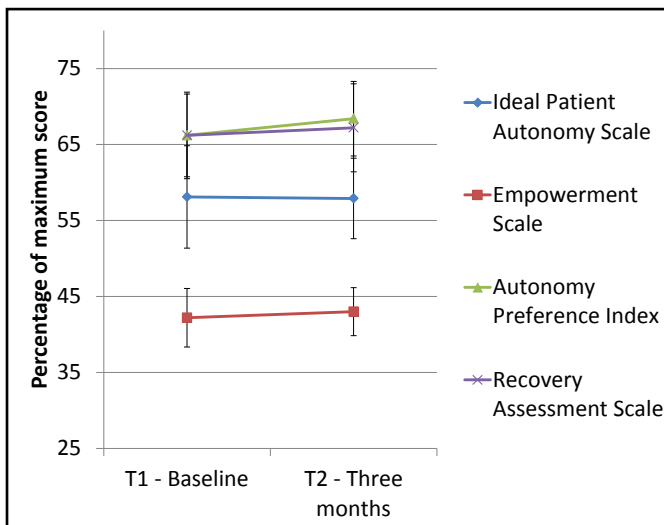


Figure 2. Stability of Responses to Questionnaires over Time among Participants Choosing PADs and Mandates ($N=59$)

Hypothesis 4: Phase I – Attitudes and experiences with mental illness before completing PADs

In phase I, we explored participants' attitudes and experiences with mental illness before they completed a PAD, and then examined these in relation to instructions included in the document to identify points of convergence or divergence. Four out of six participants initially interviewed agreed to complete a PAD. One female with depression during the initial interview reported feelings of anxiety, isolation, and tension with her spouse.

Well, when I went in [hospital], it was more or less away from anybody. I was at the very end of the hall in the very end room, so I had privacy. And the whole time, the two months, the last day I shared a room with two people, with three people. I was very afraid, I kept a chair by the door...I think I would like to negotiate but sometimes a person's looks

don't correspond with their mental capacity...I would like to get along better with my husband. Sometimes he makes me nervous. He has no patience. So when he has no patience that's when I feel anxiety. We used to be close and we are not very close these days. (Individual with depression)

This participant did not appoint her husband to be the primary agent in her PAD but rather another family member, and included in the document that one of her stressors or triggers of crisis was her husband. After the first interview this participant was re-hospitalized but then stated during the second interview regarding her husband, "He came almost every night to the [hospital] and sat with me for a while and we talked...he was a big support." On the second interview she had a difficult time locating her PAD among all her papers.

A male with depression emphasized during the first interview how he trusted implicitly his spouse, whom he chose as agent, and that he and his doctor were working to discover the cause or causes of his depressive symptoms. He stated, "I'm an open book...I don't have mistrust in the medical system." He appointed his wife as agent in the PAD, but included virtually no written instructions other than that music was an important wellness factor for him. During the second interview, he stated,

I read it over and sat down with my wife. We looked at it, and I don't think there's anything in there that was written that I would change...I found it to be a very good thing because especially in this sector of medicine it's important to have some kind of appropriate documentation in case something happens, and you would like to have someone have access to this to follow what was decided...I think we pretty well know each other inside out, we don't withhold or hide any information about each other...she was like reading it and going like "Yeah this is what I thought you would say"...she made the same observation "I would have never thought of documenting this question"...so we had a good conversation and we know this document is put away for good safe-keeping and we made a scan of it to keep in our computers; you know it's easy to lose a piece of paper. (Individual with depression)

Another male with bipolar disorder discussed, during the first interview, the genetic contribution he believed his family members could have had in his mental disorder, and discussed several coping strategies he used to circumvent the onset of a crisis, including the use of music. Then he chose to document in his PAD a limited refusal of lithium (unless necessary), and included wellness factors others should know about if mentally incapable (i.e. music, animals, parks). He suffered a minor heart attack before returning for the second interview, and stated how glad he was that his partner was named as an alternate agent because she handled his physical health crisis so well.

A male with schizophrenia described his experiences with hallucinations and delusions, being isolated, the hospitalization of his father, and spirituality as a coping strategy. He also detailed the negative experiences of being physically restrained by four hospital staff against his wishes. In his PAD, he recorded that his mother, whom he lived with, should act as an agent; refusal of certain medications that caused him to lose his thinking ability; and to be in a hospital room alone rather than to be physically restrained.

TABLE 3. JOINT DISPLAY ANALYSIS OF INTEGRATION OF QUANTITATIVE/QUALITATIVE DATA WITH EXTREME CASE ANALYSIS IN PHASE III PARTICIPANTS (N = 6)

Mental Disorder (Gender)	Extreme Outlier Baseline	Reasons for Choice of PAD		PAD Instructions	Extreme Outlier 3 Months	Qualitative Interviews ≈ 1 Month Later
		Advantages	Disadvantages			
Depression (male)	↑Depression/anxiety (BPRS)● ↓Reliance on others (RAS)● ↓Doctor involvement (PAD scale)*	Broader scope than mandate Deals with daily situations Lots of options	Mandate involves court process and PAD does not	Agent: Brother Refuse Seroquel because side effect of acute confusion Refuse ECT	↓Goal and success orientation (RAS)● ↓Reliance on others (RAS)●	“I get the right to live my life...to be forced into a hospital, that’s not autonomy to me. That’s not being able to live your life the way you choose... At some point you have to make your own decisions...I know enough about drugs that that they’re not the answer to everybody.”
Depression (female)	↑Depression/anxiety (BPRS)●	Deals with mental health issues	No alternative to include instructions in mandate	Agent: Son Side effects of medication Refuse ECT	**CHOSE TO REVOKE PAD	“It might very well be that there is a stigma still even with the people that are closest to you with regards to mental illness, or maybe you have lost it, maybe they’re reacting to a change, so you’re maybe giving up autonomy...I’m more convinced than ever that the mandate has to involve both medical and mental.”
Bipolar disorder (male)	↑Autonomy (IPAS)●	Can control decision-making and be involved	Afraid of mandate because mother had him involuntarily hospitalized	Agent: Sister Side effect from medication (weight gain) Refuse ECT	↑Autonomy (IPAS)●	“I had told my doctor that there’s diabetes in my family and I find that Zyprexa I’m taking it made me gain some weight. Since I took Zyprexa I’ve gained maybe 60 pounds... [autonomy means] my well-being...I’ve been doing that since I ran away from my mom. I was 13... I always managed to find a job and have a place to live. I was never on the street... I always had a job and a place to live.”
Bipolar disorder (female)	↑Activation (BPRS)● ↑Willingness to ask for help (RAS) ● ↑Doctor involvement (PAD scale)● ↓Self-trust (PAD scale)*	More things can choose herself Very important to choose as hospitalized many times	Mandate is more general and simple Does not give choice of hospitals	Agent: Father Refusal of medications: Seroquel, Zyprexa, Lithium, Zeldox, Clozapine No ECT	↑Optimism and control over future (Empowerment Scale)●	“Autonomy is when you can, be on your own, have access to your own money, have access to a car if you can afford it... I believe [a PAD] gives my family the right to be part of my life... I could actually choose as well as my parents if I should be in a hospital and for how long I should be able to stay.”
Schizophrenia (male)		When first admitted at 18 didn’t have a choice Gives more freedom and choice		Agent: Friend Refusal of medications: Largactil, Paxil, Prozac (“These drugs make me feel suicidal thoughts”) No ECT	↑Optimism and control over future (Empowerment Scale)●	“At least I know there is going to be somebody looking after me...I was given a voice of what I need, not what the hospital, the doctors wanted to do with me...it’s like not signing your life away but you know there’s somebody who’ll look after you no matter what happens... there’s some value in being able to tell your story to others.”
Schizophrenia (female)	↓Reasoning ability (MacCAT-CR)● ↑Psychosis (BPRS)* ↑Negative symptoms (BPRS)● ↓Information-seeking preference (API)● ↓Autonomy (API)●	-Understands it better		-Agent: Father -Refusal of medications: Seroquel, Risperdal, Celexa (“Didn’t relieve my symptoms”) -Yes ECT	↓Obligatory risk information (IPAS)*	“Sometimes I think my life is planned already. I think he’s like someone I’m going to be with later and in a way don’t feel like I like I chose it.”

● = Outlier from 1.5 to 3.0 * = Outlier above > 3.0

When asked what comes to mind the most about the PAD during the second interview he stated, “The thing I remember is that they could avoid the medication.” Two females with schizophrenia living independently in the community described at length how they perceived the doctor-patient relationship. One of the female participants trusted her treatment team implicitly describing them as closer than family; the other distrusted the medical profession. Both chose not to complete a PAD.

These interviews can be integrated into a few general results. First, although participants often discuss their experiences with mental illness in relation to their family members, not all participants are necessarily comfortable in letting their family members know they have completed a PAD. This may vary depending on the level of trust in family. Second, after completing the PAD and a crisis event occurred, some participants found that their choice of agent was reinforced because that person supported them through the crisis. Third, some individuals with schizophrenia may be less likely to recall the detailed instructions in their PAD, which may be due to the nature of the mental disorder.

Phase III– Modified extreme case analysis

In phase III, we explored six individuals’ reasons for choosing PADs (advantages/ disadvantages) using a variant of extreme case analysis to identify convergent (congruent) and divergent (discrepant) findings. Table 3 depicts a joint display analysis of the integration of questionnaire data (Time 1), PAD instructions, reasons for choice, questionnaire data (Time 2), and interviews. A joint display is a table that allows both quantitative and qualitative data to be directly compared. Along the vertical dimension of Table 3 are the six participants (by mental disorder), and the horizontal dimension shows the quantitative/qualitative results in the sequential order they were obtained. Extreme outlier categories were generated using box plots to examine cases at baseline and 3 months where the six participants were outliers (compared to all phase II participants) on quantitative measures. The six participants were recorded as outliers after the fact because the goal was to explore how later qualitative interviews converged or diverged with earlier recorded extreme outlier scores. Participants were recorded as high or low if they fell in the lower or upper quartiles of 1.5 - 3.0 or > 3.0, respectively.

Participants’ outlier scores generally converged with qualitative expressions during the interviews and reasons for choosing a PAD. A male participant with depression scored in the lower quartile on his level of involvement he wanted from his doctor regarding advance directives and the degree of reliance on others towards recovery. During the qualitative interview, he described in depth an extremely negative experience with a clinician from a psychiatric hospital, how he felt alone since his parents died, without any support other than his brother, and his fear of hospitalization. A female participant with depression initially chose a PAD, but explained during the qualitative interview that she was currently experiencing medical issues that made it difficult for her to choose between the mandate and PAD. She was the only participant who revoked her PAD.

A male participant with bipolar disorder was in the upper quartile

on his degree of autonomy and stated that he chose the PAD because he can control his decision-making. During the qualitative interview, he described how he left home from a young age, and experienced problems with his mother who had him involuntarily hospitalized. As a result, he chose his sister to act as agent rather than his mother. A female participant with bipolar disorder was in the upper quartile on the level of doctor involvement she preferred regarding advance directives and willingness to ask for help towards recovery. She had experienced numerous hospitalizations from an early age, which was an overriding reason for her choice of PAD over mandate. Both the female and male individual with bipolar disorder discussed the value of finances and living independently as indicators of their degree of autonomy.

A male participant with schizophrenia stated that he chose a PAD because when he was first admitted to a hospital involuntarily by his mother several years earlier he disagreed with the decision. Although he had several siblings, he chose a friend to act as his agent because he felt alienated from his family due to his mental illness. His score in the upper quartile score of optimism and control over the future, as a sub-factor of empowerment, could be explained by his extensive involvement in mental health advocacy and strong belief in the defence of legal rights. This participant also stated that his reason for choosing a PAD over a mandate was that it provides greater freedom and choice. A female with schizophrenia who scored in the upper quartile on the measure of psychopathology (psychosis and negative symptoms), was at the same time in the lower quartile on the degree of information she sought from her doctors regarding advance directives. She stated that she chose a PAD because she understood it better than the mandate. She was one of the few individuals who agreed to the administration of electroconvulsive therapy in her PAD because it helped her in the past. During the qualitative interviews she expressed not having control of her life; which was generally planned for her but that she had strong family support.

Discussion

There has been uncertainty and some debate as to whether instructional or proxy directives should be promoted (Emanuel, 1993; Fagerlin & Schneider, 2004). The findings in this study suggest, according to individuals’ preferences, that both instructional and proxy directives have an important role for mental health. The demand for instructional directives among individuals with mental illness is not being fully met as evidenced by provinces such as Québec where proxy directives are promoted almost exclusively. Many individuals with mental illness have not been offered the opportunity to complete advance directives specifically related to mental health. Provincial and territorial mental health legislation deals with instructional and proxy directives in a patchwork manner (Dunbrack, 2006). In the end-of-life context, national frameworks are being established to promote advance treatment planning (Canadian Hospice Palliative Care Association, 2010). To our knowledge, this is the first study to examine preferences among individuals with mental illness for instructional or proxy directives.

Preferences for Instructional or Proxy Directives

The finding that three-quarters (76%) of individuals with mental illness in this study prefer instructional directives (PADs) over proxy directives (mandates) suggests there is a need to examine more closely the value of making independent decisions regarding treatment and appointing a proxy agent. Preferences of individuals towards end-of-life are of a different nature than those of individuals with mental illness who may regain their mental capacity (Appelbaum, 2005; Foti, Bartels, Van Citters, Merriman, & Fletcher, 2005). In Québec, mandates in case of incapacity are proxy directives with a strong emphasis on appointing a mandatary to administer one's finances and property (*Civil Code of Québec*, 1991). The reality is that individuals with mental illness often have low income and limited assets, and instead depend on disability benefits or their families to care for them financially. Indeed, this may be one of the reasons that having a schizophrenia-spectrum psychotic disorder predicts choice of mandates if such individuals are more likely to rely upon others for social support. It is not surprising that, overall, individuals with mental illness preferred PADs to mandates as they allow individuals to voice their clinically relevant treatment preferences. Although the results from this study were obtained from Québec, several other Canadian jurisdictions have only proxy directive legislation.

The qualitative in-depth interviews helped to explain why individuals made certain choices. For example, we found that individuals who chose PADs often had greater knowledge of their mental illness and wanted to include details that gave them control over their illness. Conversely, individuals who chose a mandate often stated that they trusted others, preferred the simplicity of the document, and had a lack of knowledge about their mental illness. These results fit with findings from the logistic regression that individuals with higher levels of insight and awareness into the need for treatment, as measured using the ITAQ, predict choosing a mandate. Individuals who chose instructional directives often had good knowledge of symptoms around their mental illness, which does not align completely with the notion that patients lack knowledge to make good treatment decisions (Clough, 2006). The reason individuals choose not to complete instructional directives such as PADs does not appear to be related to disinterest (Clough, 2006). Instead, it may be that they have not been given the opportunity to choose a relevant document. Consequently, several participants mentioned they would have preferred to complete both documents.

Stability of Preferences over Time

One of the challenges that can arise with advance directives is to ensure individuals' preferences remain stable over time (Foti et al., 2005). Some question the value of instructional directives on the basis that they may not reflect one's current wishes (Clough, 2006). Undoubtedly, preferences regarding medications and treatment may, and should, change over time. Whereas identities may be more constant, preferences are dynamic in nature. Even if individuals change their preferences over time, this alone is not a compelling argument to negate one's right to use

instructional directives in the event of mental incapacity. Prior research has suggested that treatment choices included in advance directives remains moderately stable over time in non-mentally ill populations (Emanuel, Emanuel, Stoockle, Hummel, & Barry, 1994). It is important to recognize that proxy studies differ from stability studies, in that they compare either agreement between people or agreement over time, respectively (Emanuel, Emanuel, Stoockle, Hummel, & Barry, 1994). This study takes a preliminary step to extend previous findings for mentally ill individuals in two ways. First, as shown in Figure 2, results indicate that level of autonomy, empowerment, and recovery remained stable over three months on responses to the four questionnaires, for which we hypothesized there would be changes. We also found that among all participants who completed a PAD, only one requested to change a single provision of their document three months later, suggesting that treatment preferences may be relatively stable over the short-term. Furthermore, the change that was made by this single participant was specifically related to who should be appointed as agent, and not the content of instructions. Over three months, participants informed an average of 2.7 persons that they had a document that included friends, family members, work colleagues, or a member of their treatment team. Several participants stated "just knowing the document was there" provided peace of mind. We were unable to determine to what extent family members reinforced or discouraged participants' choice of document, other than through comments expressed by participants.

Autonomy, Empowerment, and the Doctor-Patient Relationship

It has often been stated that PADs may promote autonomy (DeWolf Bosek et al., 2008; Emanuel, 1993; Scheyett, 2009). It is possible that individuals feel empowered after completing instructional directives such as PADs (Wilder et al., 2010) and three months is insufficient time to assess such changes. We also did not find support for the hypothesis that individuals with depression would be more likely to choose mandates than would individuals with bipolar disorder or schizophrenia. However, a significant finding was that type of mental illness is associated with choice of document. The preference individuals with schizophrenia have for mandates may be related primarily to whether there is a trust relationship with one's doctor and agent rather than level of autonomy (Laugharne & Priebe, 2006). The fact that half of individuals who chose a mandate had a schizophrenia-spectrum psychotic disorder suggests there is need to examine closely the social support individuals have when choosing a document.

Although individuals with mental illness may not use the term autonomy, as few people do, many described PADs as giving them greater control and choice. Individuals with higher levels of empowerment were significantly less desirous of having their doctor involved in discussing choices related their advance directive, and they had higher scores of reasoning ability. This raises concerns about the changing face of the doctor-patient relationship in psychiatry and, more specifically, the level of trust and autonomy participants have with their physicians (Dworkin, 2003; Tauber, 2003; Drake, Deegan, & Rapp, 2010). It is possible that the more mentally capable individuals are, the greater the empowerment they will experience, and greater likelihood of wanting to make

independent choices regarding treatment. Teaching individuals how to negotiate their treatment preferences and choices with physicians may be an important element to promote autonomy and empowerment (Botelho, 1992).

Mental Illness, Capacity, and Insight

Level of insight into one's mental illness and need for treatment is related to completion of a PAD (Swanson, Swartz, Ferron et al., 2006). Type of mental illness is a relevant factor in the choice between instructional or proxy directives (Khazaal et al., 2008). Our finding that every participant with bipolar disorder, two-thirds of people with depression, and just over half of individuals with schizophrenia chose a PAD suggests that type of mental disorder is important. One possible explanation is that individuals with schizophrenia, who often have increased symptoms of psychopathology influencing their mental capacity and insight, prefer mandates because they are more likely to rely on a proxy agent to help them make decisions; it is possible that they have been socialized into a role of dependency. Certain sub-groups of individuals with mental illness may perceive certain types of advance directives as more effective in opening the lines of communication with their doctors (Ditto et al., 2001). Future research should explore to what extent individuals with depression, bipolar disorder, and schizophrenia perceive only social and family support as helpful towards completing advance directives. The relationship individuals with schizophrenia have with their doctors may be markedly different from those with mood disorders, which may also influence how advance treatment planning will be perceived by physicians.

Medication, Hospitalization, and Coercion

Some individuals complete PADs in order to limit doctors' freedom to make decisions (Atkinson et al., 2004). Some individuals in this study may have chosen a particular document because they were not given enough time to consult their doctor or family member prior to completing the document. The degree to which participants want their doctor involved will depend partly on the level of trust and power dynamics of earlier experiences (Laugharne & Priebe, 2006). The qualitative responses reveal that several participants may have also chosen PADs because they were afraid of being coerced into involuntary hospitalization.

In the simple univariate logistic regression analysis we found that individuals who had a subjective negative attitude towards medications predicted choice of mandate. One of the items on the subjective negative sub-scale of the Hogan Drug Attitude Inventory was 'I feel weird, like a zombie on medication.' During in-depth interviews, five participants mentioned that medications made them feel like a zombie, and some participants included the term in their PAD. We found that the medications individuals were most likely to refuse included Seroquel, Haldol, and Lithium, which is similar to results reported elsewhere (Wilder et al., 2010). Participants' strong reactions to side-effects of medication raises questions about the extent to which our mental health system

over-relies on medications (Whitaker, 2010), and may spend too much on them relative to other psychosocial interventions. Despite strong reactions from participants towards negative side effects of medications during the interviews, individuals who completed PADs did not use the documents to refuse all treatment as was found in the Swanson et al., study (2006). Instead, individuals with mental illness are often well informed of which medications are effective for them. Consequently, 86% of respondents agreed that the medications they were currently taking were good for them, and they often showed judiciousness, reasonableness, and restraint in what to include in their document. Perceived coercion is positively correlated with participants' self-reports of whether they will adhere to injected medications (Rain, Steadman, & Robbins, 2003). Our finding that perceived coercion was significantly associated with negative perceptions of medication, and that participants want to retain control in managing their medications, helps explain individuals' concerns with side effects from medication.

Limitations

This study presents several limitations. First, the sample size limits the reliability of the findings. Second, there may have been a selection bias among participants who refused to participate in this study due its legal component. Third, the instructional directive (PAD) was of a hybrid nature in that participants could also appoint an agent while including detailed instructions in the document. Therefore, it is difficult to know to what extent individuals made their choices based on being able to include either an agent or mandatory in their directives. Fourth, the results need to be interpreted in light of the fact that the facilitator who assisted participants to complete the advance directives was trained as a lawyer, which can lead to a strong experimenter's bias affecting individuals' responses, choices, and instructions.

Future Directions

Based on our sample, there is a strong response from individuals with mental illness to complete instructional directives in conjunction with proxy directives. Yet, more research is needed to determine how these findings would apply if other types of proxy directives are used. Currently, not all provinces and territories have legislation that specifically enables the use of instructional directives (Dunbrack, 2006). It has been suggested that, in Québec, living wills could be used in the form of instructional directives under article 12 of the *Civil Code of Québec* (CCQ, 1991; National Assembly of Québec, 2010). In practice, unless alternatives are offered, it is likely that most individuals will simply rely on template legal documents provided by governments in their jurisdiction (Public Curator of Québec, 2009); others may seek the assistance of a lawyer to help them draft a specific document if they have the financial means. The origin of mandates derived from a curatorship system primarily focused on protecting individuals' finances and property; PADs represent a new approach that allow individuals with mental illness to make independent choices regarding treatment preferences. Individuals with mental illness do not have the concerns as individuals towards the end-of-life who frequently

experience diminishing or deteriorative mental capacity.

Another policy issue that will need to be addressed in future research is how to make advance treatment plans accessible during a time of crisis (Srebnik & Russo, 2008). Several participants acknowledged that accessibility to such documents in a time of crisis is important otherwise they may be pointless documents. The development of electronic health records provides an opportunity to ensure that PADs will be visible whenever a provider consults a service user's records. As provincial and federal agencies begin to contemplate the value of advance treatment planning on a national scale, it would be useful for provinces and territories to examine to what extent their mental health legislation promotes autonomy, empowerment, and self-determination.

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