

Narratives of Individuals Concerning Psychiatric Advance Directives: Qualitative Study

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ABSTRACT

Little is known about the values individuals living with specific mental disorders that complete psychiatric advance directives (PADs) hold. The aim of this study is to explore how individuals narrate their experiences with mental illness and PADs in relation to autonomy, mental capacity, medications, involuntary treatment, the doctor-patient relationship, substitute decision-makers, and recovery. Semi-structured interviews were conducted with individuals living in the community with schizophrenia, depression, or bipolar disorder (N=12). Transformation methods were used to yield new and emergent themes. The quality and quantity of trust one has in family members and friends are two important factors to explain why some individuals choose a particular substitute decision-maker when mentally incapable. Individuals perceive PADs as useful for themselves to improve communication with doctors, avoid side effects, and prevent involuntary treatment. PADs could be offered as documents that promote trust in the doctor-patient relationship.

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

Psychiatric advance directives (PADs) are legal documents in which individuals can provide detailed instructions regarding treatment preferences in the event of mental incapacity (Appelbaum, 2004; Swanson, Tepper, Backlar, et al., 2000). Although Canadian research on advance directives has tended to focus on the end-of-life context (Bravo, Dubois, & Wagneur, 2008) PADs could be implemented in Canada for individuals with mental illness (Ambrosini & Crocker, 2007; Ambrosini & Crocker, 2009). As little is known about whether individuals' values correspond with instructions included in PADs, understanding the narratives can provide valuable insight into the illness experience and socially embedded meanings (Kielstein & Sass, 1993). PADs are based fundamentally on the value of autonomy because they allow individuals to make independent choices and express treatment preferences (Amering, Stastney, & Hopper, 2005). Autonomy is closely related to how individuals perceive their mental capacity (Silberfeld, Nash, & Singer, 1993), involuntary treatment (Kim et al., 2007), and who will act as substitute decision-makers (High, 1994). Instructions included in PADs may be related to self-perceptions of the recovery process

(Davidson, Ridgway, Kidd, Topor, & Borg, 2008) and one's relationship with their doctor (Kim et al., 2007; Goss, Moretti, Mazzi, Del Piccolo, Rimondini, & Zimmerman, 2008). Therefore, the aim of this qualitative study is to explore how individuals with severe mental disorders (schizophrenia, bipolar disorder and major depressive disorder) narrate their illness experiences and perceptions of PADs. Understanding how individuals talk about their mental illness in relation to PADs, along with the reasons for choosing to include certain instructions in their document, may reveal that individuals with severe mental disorders are often able to make thoughtful decisions about their treatment.

Method

Study design and recruitment

Qualitative interviews were conducted among individuals with mental illness affiliated with the Douglas Mental Health University Institute (DMHUI) in Montréal between December 2009 and December 2010. A semi-structured interview guide was developed a priori to explore eight themes: autonomy, advance directives, mental capacity, medications, doctor-patient relationship, involuntary treatment, substitute decision-makers, and recovery (Figure 1). The reason for choosing these specific themes was based on a review of the literature that these themes are often

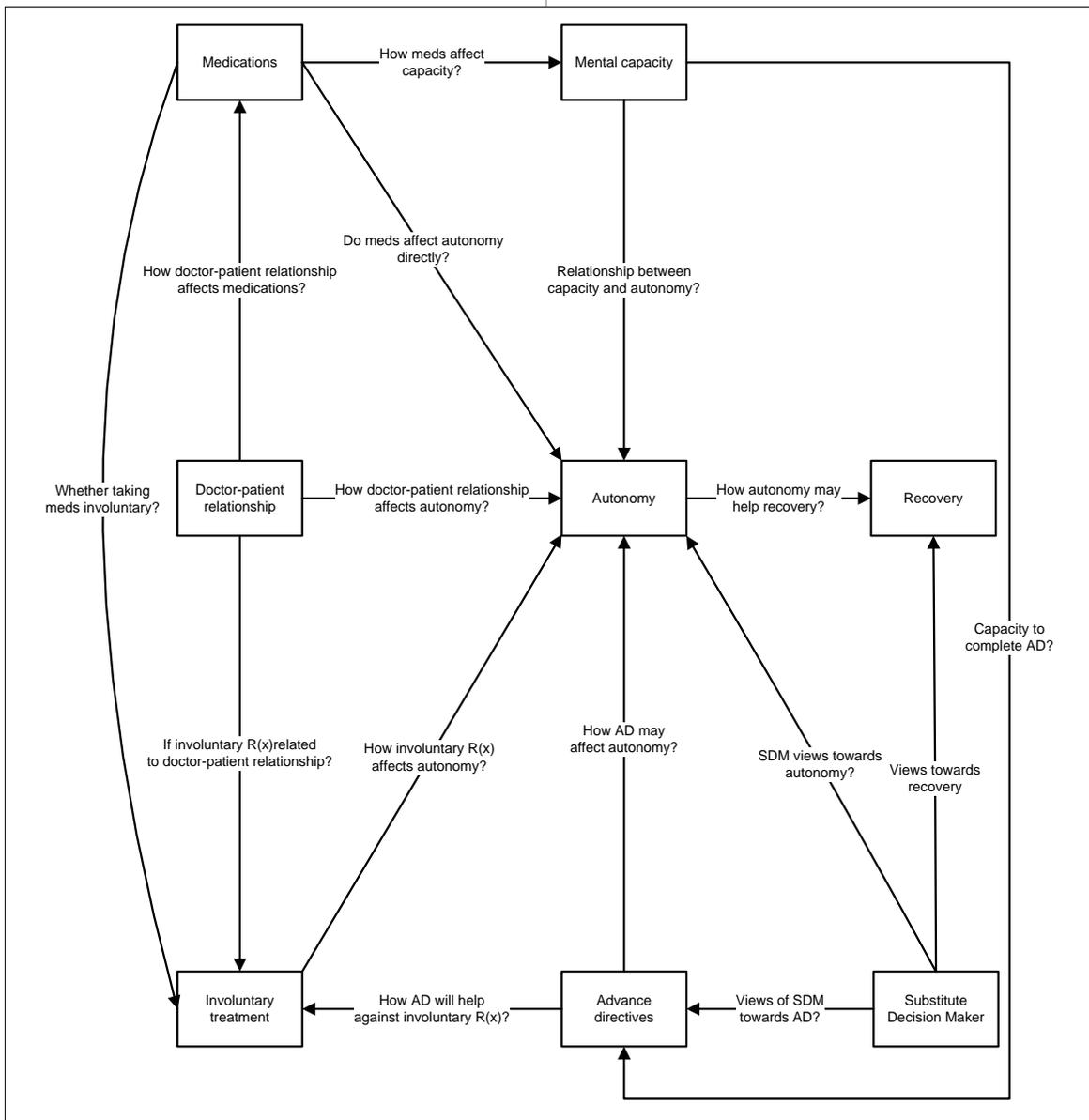


Figure 1. Quality Interview Guide

The above Guide was used by interviewers to inform the types of questions asked during interviews. The themes (medication, mental capacity, doctor-patient relationship, recovery, involuntary treatment, advance directives, and substitute decision-makers) were centralized around the core theme of autonomy.

central to how PADs may be perceived. In phase I, an interviewer (DB) conducted and audio-recorded interviews in the homes of six individuals with mental illness (n = 1 bipolar disorder; n = 2 depression; n = 3 schizophrenia) and gender (female = 3; male = 3). The six interviews averaged 58 minutes during this first visit. A lawyer (DA) then met with participants at the DMHUI two days later to facilitate completion of PADs. Only four of the six participants agreed to complete a PAD. The two participants who declined were both females with a schizophrenia-spectrum disorder. An interviewer (DB) then conducted a third interview with participants in their home approximately one month later to explore perceptions of PADs. The completed four interviews averaged 30 minutes.

Phase II was part of a larger study that involved recruiting 59 participants to complete questionnaires and examine whether level of autonomy, empowerment, and recovery predict choice between an instructional directive (PAD) and proxy directive (mandate). In phase III, an interviewer (DA) purposefully selected and interviewed six participants from phase II who completed a PAD and were representative across mental illness diagnoses (n = 2 bipolar; n = 2 depression; n = 2 schizophrenia) and sex (female = 3; male = 3). These interviews were conducted at the DMHUI averaging 48 minutes. All participants were referred to the study by DMHUI clinics and community mental health organizations in Montréal. Purposeful sampling was used to represent the twelve individuals across diagnoses (n = 3 bipolar; n = 4 depression; n = 5 schizophrenia) and sex (n = 6 male; n = 6 female) (Creswell & Plano-Clark, 2003).

Data collection and analysis

Data from the interviews were audio-recorded and transcribed into textual format by a trained research assistant. Two individuals (one was an interviewer) used the software program ATLAS.ti (2010) to code themes inductively and deductively (Gribich, 2007). The content and meaning of individuals' narratives were analyzed in relation to their experiences with mental illness and instructions included in PADs (Peters & Chiverton, 2003). Enumerative approaches and transformation methods were used to convert qualitative responses into quantitative numeric counts.

Ethical considerations

This study was approved by the DMHUI Research Ethics Board. Informed consent was obtained from participants prior to enrolment and \$20 compensation was provided for each interview. All key identifying variables have been omitted in the results to ensure participant anonymity.

Results

Results have been grouped and presented by interview themes. Two female individuals with schizophrenia who were enrolled in phase I initially chose not to complete a PAD after being interviewed.

Psychiatric advance directives

Participants described PADs as useful if they were mentally incapable by comparing the document to another person speaking for them if they could not do so themselves.

'What if both of us couldn't make the decision...There's no one left. This document would be almost invaluable in that respect. It's like having an extra person there in case.' (Male: depression)

'At least I know there's going to be somebody...I won't be just left alone.' (Male: schizophrenia)

When participants were asked about advantages of PADs one of the emerging themes was "peace of mind." They also stated that PADs are helpful to avoid certain medications, to communicate with others when incapable, and to make independent treatment decisions.

'It will give me peace of mind that I know if I get to the point that I can't say anything, there's something in place that can represent myself.' (Male: bipolar disorder)

'I was given a voice of what I need, not what they, the hospital, the doctors wanted to do with me. It was a little bit of freedom...I thought it would give me more independence.' (Male: schizophrenia)

'I believe [a PAD] gives my family the right to be part of my life, even though they are part of my life...in a deeper way... if something does happen they won't be afraid that I will make the wrong choices.' (Female: bipolar disorder)

Individuals who had not been hospitalized emphasized the usefulness of PADs to avoid future hospitalization, whereas those who were previously hospitalized saw the documents as helpful to avoid unwanted medications. Perceptions of PADs appear to be grounded in specific individual experiences with their illness.

Autonomy

We explored how participants understand the meaning of autonomy and its relationship to PADs. To account for individual ways of discussing personal values, interviewers adapted their wording and questions to participants' manner of expressing themselves. Instead of using abstract terms such as "autonomy," participants often framed it as "being able to make one's own decisions." Perceptions of autonomy frequently emerged from concrete personal experiences. For example, several participants associated the desire for greater independence with the ability to control their personal finances.

'That's one of my struggles at the moment. I've always been very autonomous, always taken care of things in spite of my, my alcoholism...So my autonomy is, I wouldn't say it's gone, but it's not that I don't feel the autonomy, it's just I have problems dealing with day to day responsibility at the moment...autonomy is good, it's always been good, at the moment it's not as good as it was and I'm sure it'll come back.' (Male: depression)

'I think when the medical and mental become very intertwined, then I think you have to give up autonomy. So I can see myself giving up autonomy when I can't move anymore...if I'm incapable of making my own decision because that's what it implies, I think it takes away from the image we have of ourselves to be self-sufficient...the thing that makes you feel most autonomous is to have enough financial resources.' (Female: depression)

'Autonomy is when you can be on your own, have access to your own money, and have access to a car.' (Female: bipolar disorder)

Overall, we found that when participants narrated the meaning of autonomy, or associated terms, they referred to it as a dynamic rather than static value that can be increased or decreased, lost or regained.

Medications and treatment

Most participants expressed mixed feelings about their medications. Although participants believed medications were necessary for their well-being, many were deeply concerned with the effects of medication changes, not receiving adequate information about their treatment options, and harmful side effects.

'Hopefully they would have the best interest for me and not just sell medication like a lot of doctors do, unfortunately.' (Male: bipolar disorder)

'They give medication. They don't give advice...He'll say, "We help some people by giving this kind of medication so we have no choice. Only thing we can do is suggest you take medication and it's going to calm you down...they try too many medications."' (Male: schizophrenia)

'The doctor told me, "I'm giving you this medication. If you're going to get ill effects, give me a call. Stop the medication. I'll see you again. We'll try something else"...I mean, after three or four months of taking medications, if there's no improvement I don't think there will be.' (Male: depression)

'Unfortunately, in order to be healthy I have to take this medication...medications are very helpful when you need them. I unfortunately need to take 22 pills a day, 7 different pills, 9 different medications, but in total 22 a day, and that includes 11 sleeping pills...sometimes they make you feel like a zombie...I don't have very much choice.' (Female: bipolar disorder)

Participants reported that it was their family members who frequently encouraged them to increase or decrease their use of medications based on observable symptoms.

Doctor-patient relationship

Although several participants expressed a desire to make independent choices, others held the view that 'doctors know best' about which medications they should take. Trusting one's

doctor and having sufficient time to discuss medications were both prevailing themes.

'I don't control my medication. I give that to my doctors to do, my psychiatrist, because he is the one who knows best. I don't know what to take.' (Male: depression)

'I'm giving all my trust in the doctor completely because he knows what he's doing...they're the experts...I'm a patient whereas the person on the other side has a lot more information.' (Male: depression)

'I do trust them...there are some doctors who put you on medication without even consulting with you...he's very thorough and very informative when it comes to changing drugs.' (Male: bipolar disorder)

'My trust is complete...all my trust is there...I don't have mistrust in the medical system.' (Male: depression)

'Even though you trust your doctors, I don't think it's safe to just give it up to a doctor. It would have to be somebody who cares for you as a person.' (Female: depression)

'They are the best doctors...I trust them with my life.' (Female: bipolar disorder)

'Because when you go in there they give you a doctor and then you are stuck with that doctor. So you can have Doctor A, B, C, or D, so you have to be lucky to have the doctor that you find that you like.' (Female: depression)

Two female individuals with schizophrenia both chose not to complete a PAD. One decided she trusted her doctor and treatment team implicitly and does not need a PAD; the other chose not to complete a PAD because she perceived it as part of the medical system that she did not trust.

Involuntary treatment and medication refusal

Seven out of ten participants who completed a PAD included in their document the name of a specific medication that they would refuse if mentally incapable (Table 1). Further, seven out of these same ten individuals did not consent to electroconvulsive therapy (ECT) in their PAD. One participant who refused medications described how his treatment team coerced him into taking a particular medication stating that he was not permitted to leave the hospital until he followed their instructions. Others expressed concern with treatment practices that they perceived as coercive:

'I don't want the electroshock treatment because I've seen how it works. My sister had it. It did marginal good for a short term and then it regressed.' (Male: bipolar disorder)

'The doctor was saying that he could force me into hospital. He had mentioned ECT or something. It's like a two-headed monster, you don't want to know nothing about it...I'm terrified of ECT.' (Male: depression)

'They shot me with an injection...for no reason against

TABLE 1. PARTICIPANTS' INSTRUCTIONS IN PADs DURING PHASES I AND III (N=12)

Participants	Primary Agent (Family/Friend)	Alternate Agent (Y/N)	Medical Refusal	Number of Instructions (/18)	Consent to ECT (Y/N)	Number of Contacts	Self-Binding Revocation
PHASE I Interviews							
Male, Bipolar disorder	Family	Yes	Yes	6/18	No	2	Yes
	I prefer not to take lithium; only as last resort (medication preferences); Making sure I'm eating well; positive reinforcement (helpful support).						
Female, Depression	Family	Yes	Yes	11/18	Yes	2	No
	Would like affection and compassion shown in time spent together (wellness factors); I would like a private room because I feel I don't have anything in common with other people (instructions to hospital staff).						
Male, Depression	Family	No	No	2/18	No	1	Yes
Music (wellness factor).							
Male, Schizophrenia	Family	No	Yes	3/18	No	1	Yes
	Loxapac: I'm shaking, spitting, uncomfortable all the time. Have to move frequently (medication refusal); When I do sports I feel more awake and able to think clearly. Listening to music could be a good therapy (wellness factors); Prefer to be in a room alone if possible (instructions to hospital staff).						
Female Schizophrenia							
Female Schizophrenia							
PHASE III Interviews							
Male, Bipolar disorder	Family	Yes	No	4/18	No	2	Yes
	Before a psychiatric episode I often repeat my words not knowing I had just said them already (crisis symptoms); If hospitalized I would want visits from my clergy (wellness factor).						
Female, Bipolar Disorder	Family	Yes	Yes	6/18	No	3	Yes
	Music, reading, visitors, going outdoors (wellness factors); Medication (recovery of control); Need my agent to pay my monthly expenses from my disability pay cheque (personal assistance).						
Male, Depression	Family	No	Yes	4/18	Yes	1	No
	I am more comfortable and feel safer when alone (emergency intervention); I have an extreme sensitivity to any form of criticism which triggers a crisis (stressor/trigger of crisis); I would like the ability of going out for a walk for a breath of fresh air (wellness factors).						
Female, Depression	Family	Yes	No	3/18	No	3	Yes
	Group therapy, contact with others with same symptoms (helpful support).						
Male, Schizophrenia	Friend	No	Yes	11/18	No	2	Yes
	Do not overmedicate me to the point of loss of touch with reality (medication preferences); Prefer to have my own room if possible because fearful of others (hospitalization preferences); Please do not use restraints. Have had negative experiences with this (hospitalization objections).						
Female, Schizophrenia	Family	Yes	Yes	6/18	Yes	4	Yes
	Seroquel: I tried it and it didn't relieve my symptoms (reason for refusal); Listening to music makes me happy (wellness factors).						

my will. They turned me on the bed and it wasn't really enjoyable...I could be really mad...but I forgive.' (Male: schizophrenia)

'I took the medication every time I was supposed to. I wanted to get out of there.' (Female: depression)

'When you refuse they find a way for you to accept it and say that, "You won't get out of here unless you take your medication." So everybody finally ends up taking the medication.' (Male: schizophrenia)

All participants were concerned with side effects from medications, with the most commonly cited being weight gain and the inability to think clearly. One male individual with schizophrenia described how he was certain that the side effects of medications he was taking caused him to attempt suicide.

'During 1998, when I had this episode I was on Paxil or Prozac. I don't remember but it was on one or the other and the suicide attempt was way over the top for me...took

the knife and I injured myself and I cut my intestines right in half...no drinking, no alcohol, nothing...I was asking to get off that stuff.' (Male: schizophrenia)

'I was shaking, spitting, and I wasn't able to stay 15 minutes in the same place. I had to move all the time. It was torture to get that medication.' (Male: schizophrenia)

'I waited ten years to get medication because I was afraid of the side effects.' (Female: depression)

'It's very hard to lose the weight with those medications... these medications all put weight on you.' (Female: depression)

'This new medication...I was walking into walls. I couldn't even go out to run an errand...before I take the medication, first of all, I always read the profile of the medication to know what the possible side effects are...I mean, I can take medications that have certain side effects but I also have to be able to function to a certain extent. If I can't even talk on

the phone, that's pretty bad.' (Male: depression)

'I've gained about 100 pounds which is very depressing, very sad to me...But that's caused by the medication...The first question that pops out of my mouth when he gives me a medication or a new medication is, "Is this going to cause weight gain?"' (Female: bipolar disorder)

'Since I took Zyprexa I've gained maybe 60 pounds...I say, "Isn't there another drug I could take that doesn't have side effects such as weight gain"...I said, "I'm not going to take these pills anymore," so I stopped taking them. And I lost another 10 pounds, but not taking these pills was making me more crazy.' (Male: bipolar disorder)

Participants did not, despite such views, try to include instructions in their PADs to categorically refusal all medications, and instead they selectively chose only those medications perceived to have harmful side effects.

Mental capacity

Eight out of ten participants who completed a PAD agreed to a self-binding clause in their document that if they became mentally incapable their substitute decision-maker should follow their instructions rather than changed wishes in the future (Table 1). Participants often attributed previous episodes of mental incapacity to their illness, side effects of medication, or both.

'I'm not sure all the time as to whether the decisions I'm making are due to drug symptoms or whether after all this time my mind has evolved, and it certainly has dulled part of my brain cells on the way.' (Female: depression)

'Now they put me on Seroquel once, forget it. I can't take this drug. This is like out of this world crazy...I would wake up confused and I didn't know where I was...it took me like two minutes to become aware of where I am...it was just a side effect of that drug.' (Male: depression)

Five participants used the expression 'zombie' in relation to episodes of mental incapacity, which was often related to the use of medications or they were referred to as such by family members.

'Sometimes they [hospitalized patients] can be very sedative or make you feel like a zombie...Maybe they need a higher dose to be stabilized, but if it's going to cause them to walk around like a zombie and not have a life in a hospital.' (Female: bipolar disorder)

'Like they'd say, "Oh, pill popper," "zombie," "you're addicted"...any anti-depressant...I just felt they made me zombie-like...I didn't want to be a zombie...my father would say..."you're walking around like a zombie." (Male: schizophrenia)

'My mom would be like, "You're a zombie." She didn't like what the medication was doing to me.' (Female: schizophrenia)

'I tried a lot of medication for depression and...the

medication puts me in such a state of zombieness that I can't keep taking it.' (Male: depression)

'Some of them [hospitalized patients] walked around like zombies.' (Female: depression)

Substitute decision-makers

Participants who lived at home tended to choose one of their parents to be a substitute decision-maker (SDM). Table 1 reveals that nine out of ten participants included a family member as their primary SDM, and six out of ten individuals selected an alternate SDM. Choice of SDM was related to both the quantity and quality of social contacts. Participants (N = 46) from phase II informed, overall, an average of 2.7 persons that they completed a PAD and individuals discussed it with friends/others more than with family/partner. Approximately 63% of persons whom participants told about their PAD had positive reactions, 25% were neutral, and 12% were less than positive.

'Well they knew about it and my father was like, "Wow, you did that?" I said, "Yes, dad"...I'm not going to ask my grandmother, she's 75 or 80 years old. So my dad's very happy that I did that because at least now he has security... he has the right to say no.' (Female: bipolar disorder)

Recovery

We explored how individuals described the meaning of recovery within the context of PADs and mental illness and found that recovery holds different meanings for different persons.

'Recovery means I'd be able to function properly in a social and personal environment. By function, I mean to achieve and contribute to a situation and an environment in some way. It means being productive...vegetating the way I am is not recovery.' (Female: depression)

'No such thing...there is no recovery for bipolar disorder...there's only maintenance...it takes time. It's a process...I define recovery as maintenance.' (Female: bipolar disorder)

'To be functional...to be emotionally stable and to come to terms with what happened with my parents...to regain my friends.' (Male: depression)

'It means being part of the community and a productive citizen.' (Female: schizophrenia)

When participants were asked what could assist them to recover from their illness, responses ranged from listening to music, learning about their illness, engaging in productive work, and the stable, regular use of medications. We found considerable overlap between interviewees' responses with results from phase II where participants reported specific wellness factors in their PAD (Figure 1).

'With my manic stages I need to come down so I get a little bit depressed with music...I put on a piece of music... sometimes quiet is a way of coping with a certain type of

mood...sometimes I can steer myself out of it before it gets too serious.' (Male: bipolar disorder)

'Keep busy, keep active, and get involved with research. Try to understand mental health more. That's what I've been trying to do. Understanding all aspects, not just mine...Recovery? Live happy without hurting yourself and inflicting pain on yourself and not always feeling blue... it's getting the message across that we're not alone.' (Male: schizophrenia)

Among participants in this study, recovery appears to be closely related to the ability to obtain information allowing them to learn about their mental illness.

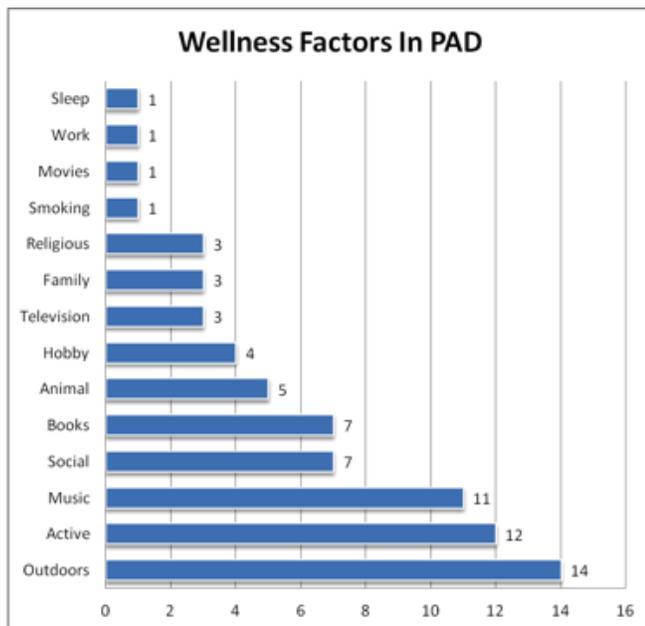


Figure 1. Wellness Factors Included in PADs by Phase II Participants (N=37)

Discussion

Although individuals with mental illness, similar to others, may not use the language of autonomy, they are familiar with associated terms such as choice, independence, and control. Most participants did not want others to assume complete control over their choice of treatment if they became mentally incapable. The level of trust that individuals have with their doctor, along with the quantity and quality of social contacts, are likely to affect whether a PAD is completed and who is appointed as SDM. Figure 2 shows an inverted U-relationship of how these factors may interact. Individuals with low social network (a reduced number of connections to others) and a moderate level of trust may be the most likely to complete PADs. Individuals with high social support (either through a few individuals, such as family and friends, who provide increased support or through many people who provide diffuse support) and a high level of trust in their physicians may be less likely to complete PADs if they can rely on others to make decisions for them if they become mentally

incapable. Alternatively, individuals with high social support and low trust may be less likely to complete PADs because they distrust the mental health system. Of course, further research is needed to test this hypothetical model that arises out of an exploratory analysis of data from a small sample of individuals.

Ideally, PADs could be considered more than simply legal documents completed at a single point in time as they involve a process that allows individuals to understand their personal values over time (Stigglebout, Molewijk, Otten, Timmermans, Van Bockel, & Kievit, 2004). Autonomy can be a value, right, or ideal in the context of the doctor-patient relationship (Amering, Stastny, & Hopper, 2005; Kim et al., 2007; Stigglebout, Molewijk, Otten, Timmermans, Van Bockel, & Kievit, 2004). When individuals with mental illness use expressions such as independence, choice, control, or freedom, they may be referring to autonomy as a state that can change over time. The empowerment process has been described as "the cognitive change of being powerless to the point where expectation of controllability arises" (Kane, 2002). Individuals with mental illness are empowered when they are given sufficient information to make independent decisions (Linhorst, Hamilton, Young, & Eckert, 2002). For individuals in this study, autonomy was associated with practical concerns including control of finances, meaningful work, and the knowledge one will not be alone during a crisis.

Individuals must be mentally capable before completing a PAD (Silberfeld, Nash, & Singer, 1993). We found divergent responses in how individuals with schizophrenia, bipolar disorder, and depression monitor their mental illness and their level of mental capacity. Whereas individuals with schizophrenia appear to be high self-monitors in evaluating their mental capacity around others, individuals with depression and bipolar disorder were more concerned with identifying the triggers of incapacity.

Prior research shows that individuals with mental illness perceive PADs as a tool to communicate medication preferences (Wilder, Elbogen, Moser, Swanson, & Swartz, 2010) and as a self-management tool (Bilsker, Goldner, & Jones, 2007). Participants did not perceive PADs as documents to refuse all medications, yet expressed concern that psychiatrists do not provide adequate follow-up information regarding medication. Irregular patterns of use and non-compliance with medication may be due to lack of knowledge of one's illness in an effort to prevent negative side effects. Individuals may perceive value in PADs because they offer primarily some level of protection from unwanted side effects.

Trust and some degree of empowerment through a physician are important in that they allow individuals to discuss treatment preferences openly (Laugharne & Priebe, 2006). PADs provide individuals with mental illness an opportunity to reflect on the level of trust they have with their doctors and mental health institutions (Laugharne & Priebe, 2006). Additionally, PADs can be seen as a type of collaborative contract to protect oneself from unwanted treatment (Amering, Stastny, & Hopper, 2005). An open line of communication between doctors and patients can assist clinicians to learn about PADs (Kim et al., 2007). In listening to participants, we found that positive perceptions of one's doctor are independent of their views towards hospitals. Future research should explore whether prohibitive instructions included in PADs are primarily related to a doctor-patient or hospital-patient relationship.

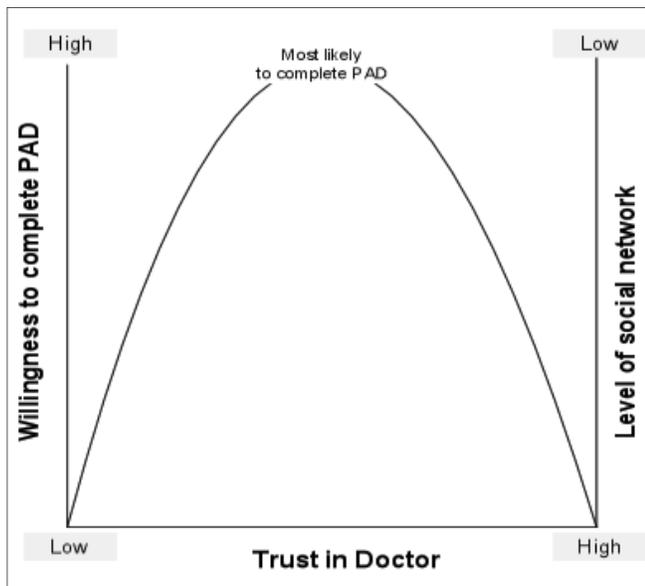


Figure 2. Hypothesized Model of Willingness to Complete PADs Based on Trust and Social Network

Some individuals see PADs as a tool to refuse involuntary treatment (Kim et al., 2007) such as side effects of medication (Greenberg, Moore-Duncan, Herron, 1996). Participants' perceptions in this study suggest that the primary reason for refusing treatment may not be to increase autonomy generally, but rather to avoid specific medications. Individuals with mental illness rarely use PADs to refuse all medications (Amering, Stastny, & Hopper, 2005), and tend to describe their medication-taking behaviour in terms of personal ownership and self-confidence (Rogers, Day, Randall, & Bentall, 2003). The 70% of participants who refused ECT is similar to figures reported elsewhere where refusal hovered around 60% (Van Citters, Naidoo, & Foti, 2007), and for the most part individuals in this study were able to provide rational reasons for the refusal. Some argue that patients' choice to refuse psychotropic medications upon discharge from hospitals is primarily a manifestation of their mental illness and does not reflect autonomous functioning (Schwartz, Vingiano, & Perez, 1988). These results suggest that a major reason for medication refusal may be fear of side effects (Schwartz, Vingiano, & Perez, 1988).

Although individuals want to rely on family members to act as SDMs (High, 1994; Ho, 2008), not everyone can do so if it is impractical or strained family relationships exist. Some participants did not want to burden their family or friends with such a responsibility. Others attributed the cause of their mental illness to one or both parents, which is likely a factor in who is chosen as the SDM. PADs could have a unifying effect in building relationships between family members during a crisis (Ambrosini, Crocker, Perreault, & Israel, 2008), as expressed by one participant who stated, "I believe [the PAD] gives my family the right to be part of my life."

Recovery from mental illness can mean, among other things, being free to make choices, working closely with health care providers, or being able to return to work (Davidson, Ridgway, Kidd, Topor, & Borg, 2008). PADs can also help individuals to achieve their recovery goals (Swartz & Swanson, 2007) by developing insight, gaining information about their illness, and becoming empowered

throughout the process (Bisson, Hampton, Rosser, & Holm, 2009). Prior research shows that an important part of the recovery process involves engaging in meaningful work (Davidson, Ridgway, Kidd, Topor, & Borg, 2008); still, some participants had a palpable fear that returning to work may trigger a relapse in their illness. Based on participants' narratives, stresses in the workplace may be valuable to include in PADs to inform others of possible triggers of relapse. Future research should examine whether individuals completing PADs are more likely to achieve their recovery goals than those who do not complete such documents.

Limitations

A limitation of this study is that data was collected and interpreted from only twelve individuals. Nevertheless, qualitative research allows for in-depth analysis and understanding of autonomy and the meaning of PADs, rather than applying broad generalizations. A second limitation is that interviews were conducted by two different individuals at different points in time, one of whom was trained as a lawyer that may elicit different responses from interviewees between the two sets of interviews.

Implications

Listening to the narratives of individuals with mental illness can help to explain why some prefer to include particular preferences in a PAD. Autonomy and empowerment are fundamental to making independent choices. Our findings suggest, based on the narratives of individuals with mental illness, that there is a desire for a stronger voice to negotiate medication and hospitalization preferences with doctors through a shared decision-making approach (Laugharne & Priebe, 2006). Trust and level of social support are critical to understanding the content of instructions included in PADs. Future research should explore to what extent PADs can improve the lines of communication between doctors, hospital staff, patients, and family. Several participants also identified as important the issue of accessing PADs during a crisis otherwise such documents are hardly useful. PADs may be helpful not only to communicate preferences but also to help individuals re-examine their values, develop insight into mental health and wellness, and improve trusting relationships between doctors, families, and friends.

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