

Supported decision-making: The expectations held by people with experience of mental illness

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Abstract

Supported decision-making (SDM) is a principle guiding mental health service provision which aims to improve people's ability to make informed decisions about their care. Understanding diverse individual needs is vital to its success. Based on 29 narrative interviews with people diagnosed with mental illness in Australia, we examine how participants reflected on their own experiences of SDM. We find that participants' conceptualization of mental health expertise, their own experiences and sense of agency, and their varying needs for dependence and independence influenced their relationships with mental health practitioners. These factors in turn shaped their expectations about SDM. Four narrative positions emerged: the 'Inward Expert', the 'Outward Entrustor', the 'Self-Aware Observer' and the 'Social Integrator'. These positionings influenced the type or style of support that participants expected and considered most useful. Our findings are relevant to developing effective approaches to SDM that take into account service users' needs and preferences.

Introduction

Engaging health service users in treatment decision-making has been shown to promote personal recovery (Kreyenbuhl, Nossel & Dixon, 2009; Serobatse, Du Plessis & Koen, 2014). In mental health research, there is a long history of encouraging respect for the autonomy of service users in making decisions about treatment and care (Armstrong, 2014; Weiss, 1985). Shared and supported decision-making¹, as part of person-centered care, have become well recognized as the foundations for good practice in health care internationally (Duncan, Best & Hagen, 2010; Carney, 2014). Supported decision-making (SDM), the focus of this article, has been promoted in Australia, most notably by the disability rights movement (Mental Health Australia, 2016). SDM requires attention to how people with a ‘disability’, including people with experiences of psychiatric diagnoses, can be supported to make decisions on an equal footing with others about their care.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (CRPD 2017) provides a basis in international law for requiring states to provide support to people receiving mental health treatment in exercising their legal capacity on an equal basis with others. It emphasizes positive rights in requiring countries to provide the services and support needed to enable people diagnosed with mental illness to participate more fully in society as equals, and also states that people should not be detained and treated without informed consent. The CRPD represents a move away from substitute decision-making² in asserting that people with psychosocial disability in the context of a mental illness should remain central in all decision-making.

SDM can refer to a variety of models ranging from informal support to organizational assistance, and from civil society schemes to legally mandated ones (Carney, 2014; Davidson

et al., 2016). SDM requires that the person with a psychiatric diagnosis be at the center of decision-making, and that every attempt be made to ensure that they can exercise their legal rights to the greatest extent possible. Efforts by mental health practitioners (hereafter ‘clinicians’) to develop strong and considerate relationships with health service users with psychiatric diagnoses, especially by sharing information and working towards consensus about treatment and life decisions, are foundational to SDM (Charles et al., 1997; Chong, Aslani & Chen, 2013; Delman et al., 2015; Goscha & Rapp, 2015).

Introducing SDM in the context of a rights-based approach requires substantial reorganization and innovation in mental health service delivery, and the full participation of people with experiences of mental illness, family carers, clinicians and other service providers (Wallcraft et al., 2011; Freeman et al., 2015). Minimizing the use of substitute decision-making remains an aspiration in many countries, with most jurisdictions that are signatories to the CRPD continuing to authorize widespread substitute decision-making, particularly the involuntary treatment of people experiencing severe mental illness (Davidson et al., 2016). Even so, governments in many countries are seeking to improve the quality of mental health services and ensure that associated support systems are in place. Supported decision-making is being embedded in the principles underlying mental health service provision in several countries, including in Victoria, Australia (Davidson et al., 2016). Substitute decision-making is used only as a last resort in these jurisdictions, and various safeguards are employed.

However, even where clinicians follow best practice for SDM, service user engagement is not guaranteed (Quirk et al., 2012). Engagement can be affected by a range of factors, including the person’s age, their trust in clinicians, the level of distress involved, and the availability of broader family and social support systems linked to housing, employment and other rights

(Simmons et al., 2011). Further, users' 'self-confidence' (Delman et al., 2015) or personal preferences (Himmerich & Wranik, 2012), and anxiety or fear over treatment decision-making processes (Pantalon et al., 2013) can all affect their engagement with SDM. Nevertheless, a shared understanding of the primary concerns of the person with experience of mental illness is considered a critical starting point in good psychiatric care (Bonfils et al., 2014), and therefore in facilitating SDM.

We aim to build on existing knowledge about SDM by enquiring about expectations of SDM held by people diagnosed with mental illness. Our focus is on understanding the experience of people with psychiatric diagnoses, and in particular the range of preferences they have with respect to treatment and support, their reflections on the mental health services with which they have engaged, and their interactions with clinicians. We anticipate that the findings will be relevant to developing effective supported decision-making models and support systems, in turn fundamental to the implementation of the CRPD, and guide the development of mechanisms to aid clinicians in achieving these respectful relationships and excellence in clinical care.

The Australian context

In Australia, as internationally, psychiatrists and other mental health practitioners are given the power to make decisions on behalf of a person diagnosed with mental illness who is seen as not having the relevant decision-making capacity. Generally this form of (substitute) decision-making occurs in the context of concerns about the need to protect that person or others from harm, the perceived need for that person to receive treatment, and the lack of a less restrictive option (McSherry & Wilson, 2015). However, under the influence of the CRPD, mental health law is changing to emphasize greater respect for individual choices about treatment, the

promotion of autonomy, and a presumption of legal capacity on an equal basis with others (McSherry, 2014).

Mental health law reforms in the Australian state of Victoria have sought to bring legislation into greater alignment with the CRPD, as well as with the concerns of the user-led personal recovery movement (Australian Health Ministers' Advisory Council, 2013). Victoria's Mental Health Act (2014) outlines a commitment to the importance of respecting the views and preferences of the person diagnosed with mental illness in all decision-making (Mental Health Act 2014). Voluntary treatment is promoted wherever possible. Mechanisms to facilitate SDM include Advance Statements, a nominated persons scheme and an Independent Advocacy Service (Mental Health Act 2014). An Advance Statement allows a person to outline her or his treatment preferences prior to becoming unwell and requiring treatment. Their preferences must be taken into account in all psychiatric care provided. The nominated persons scheme allows a service user to appoint a person to receive information about their condition and related treatments, and support them should they require psychiatric care. A nominated person should be consulted at every key moment of a person's treatment and recovery. The Independent Advocacy Service enables service users to contact advocates who are able to provide information and support them to understand and exercise their rights in relation to treatment. This advice is free and independent of government. These mechanisms have been criticized as being insufficiently progressive, especially when psychiatrists and others still retain substitute decision-making powers (Maylea, 2016). Nonetheless, the implementation of the 2014 Act requires clinicians to re-orient their practice to facilitate people receiving mental health services to be active participants in decision-making about their treatments and other aspects of their lives (Cross et al., 2014).

Listening to the accounts of people diagnosed with mental illness is essential to facilitate greater understanding of SDM, and the development of effective SDM models. The findings reported in this article about Australian mental health service users' expectations of SDM are derived from interviews conducted for a larger study of experiences of mental illness and supported decision-making. The research reported in this article investigated the processes that can facilitate the participation of people with experience of mental illness (and their families where appropriate) in meaningful supported decision-making about clinical treatments, and about the use of other services and types of support.

Methods

Participants

We investigated the narratives of 29 people with experience of a mental illness (hereafter 'participants') living in Victoria, Australia. Participants were recruited via advertising through mental health community support services, newsletters and online advertising. A maximum variation sampling approach was used to ensure inclusion of people from diverse backgrounds, and to capture a wide range of experiences (e.g. diagnosis, disclosure, treatments, social support, recovery, and experiences of supported decision-making). The research was conducted using rigorous qualitative methods developed by the Health Experiences Research Group (HERG) at the University of Oxford (Ziebland & Hunt, 2014).

We interviewed 18 women and 11 men, aged between 22 and 65 years, between February and December 2014. Most participants were Australian-born, with diverse self-reported ethnic backgrounds including Australian, British, Irish, Aboriginal Australian, Punjabi Indian, Greek/Egyptian, Maltese, Italian, Australian-Brazilian, Portuguese, and 'European'. Sixteen participants were in paid employment, and all worked part-time in the mental health sector.

Several were studying or volunteering, engaged in caregiving roles, retired, or not engaged in any of the aforementioned activities at the time of the interview. Eighteen participants were single, divorced or separated, and eleven were partnered or married. Nine had children. Participants' diagnoses were self-reported. Seventeen people reported receiving more than one diagnosis in the course of their encounter with mental health services. The most common diagnoses participants recalled were bipolar disorder and schizophrenia. Many participants had experienced involuntary treatment (a community treatment order or involuntary hospitalization). All participants provided informed, written consent to be involved in the interview and self-identified as being able to fully participate.

Interviews

The interviews explored experiential aspects of and interpretive practices situated within personal narratives (Andrews et al., 2013). In the first part of the interview, participants were asked to provide an account of their experiences of being diagnosed and living with a mental illness. The second part of the interview comprised discussion of other research-related themes if these had not already emerged in the initial narrative, including diagnosis, hospitalization, involuntary treatment, medicines and other voluntary treatments, experiences of making decisions about treatment and other matters affecting participants' personal lives, experiences of being supported to make one's own decisions, ideas about personal recovery, and hopes for the future. Interviews lasted one to two hours and were conducted at locations convenient for participants, mostly in support organizations. They were video or audio recorded with written informed consent, transcribed verbatim, and returned to participants for review and approval. At this point, participants could opt to delete sections of their interviews if they so wished. After being returned by participants, transcripts were de-identified and entered into NVivo 10 for data management and primary coding. Thus the materials analyzed were transcripts that

had been checked and approved by the participants themselves. Ethics approval was granted by Monash University Human Research Ethics Committee (CF13/2980:2013001607). The data and findings were used to create a Healthtalk Australia online resource (healthtalkaustralia.org) detailing participants' experiences. Renata Kokanović was the lead investigator, Lisa Brophy and Helen Herrman were co-investigators, Fauzia Knight, Nicholas Hill, and Kate Johnston-Ataata were members of the research team and Damien Ridge was a member of the project advisory group.

Analysis

Primary coding had already been carried out for the original research to produce content for the online resource detailing participants' experiences of mental illness and supported decision-making (<http://research.healthtalkaustralia.org/supported-decision-making/overview>). In this article we report on the analysis focusing on participants' experiences of supported decision-making (SDM). This analysis explored how participants positioned themselves in their narrative accounts in describing interactions with clinicians (predominantly psychiatrists but also psychologists, psychiatric nurses, and other mental health practitioners). We also took into account other aspects of these encounters, such as expectations of care, family practices of support, and how people's support needs changed over time. Theoretically, we were interested in the relational nature of SDM – participants' relations with others and with themselves, and drew on a rich history of literature and research in the field of narrative and phenomenological research of illness experience (Andrews et al., 2013; Carel, 2008; Frank, 2012; Hyden & Brockmeier, 2008; Kokanović & Stone, 2018). Narrative positioning analysis was used to explore how people located themselves within their accounts. Subject positions are informed by the social, cultural, linguistic, political and interpersonal resources available to a person (Davies & Harre, 1990; Harre & van Langenhove, 1999; Squire et al., 2014). Focusing on how

a person locates themselves draws attention to the performative dimension of identity production (Bamberg 2012). That is, how a person wants to be perceived, and by extension, treated.

In a move away from mental health service research that assumes fixed identities for professionals (professional roles) and fixed subjectivities for service users (according to diagnosed conditions), we understood narrative identities as fluid and dynamic, as variously imposed/resisted and/or willingly taken up, as different actors compete for power. While we accept Silverman's (2017) position that interview narratives cannot be relied on to fully represent subjectivities, they can nevertheless be revealing in terms of what people want and desire, allowing us to uncover the narrator's intentions (explicit and implicit) as they construct their subjectivities through their stories (Schachter, 2010).

We began our analysis by reading transcripts in full to map out narrative themes relevant to supported decision-making. Narrative analysis revealed significant differences across the transcripts in the meanings given to experiences, and a relationship between those meanings and the person's descriptions of the self (Andrews et al., 2013; Squire, 2013). A detailed chart was constructed of the language and concepts used in each transcript under the following headings: (a) attributes of self; (b) description of medical professionals; (c) experience of decision-making process; and (d) references to subjectivity. These were analyzed and key concepts such as control, trust, expertise and support identified across the four domains. Four main narrative positions emerged that were investigated with reference to the full coding reports.

Findings

Participants' accounts of themselves and their aspirations with respect to SDM varied. Some presented themselves as independent 'experts' on their experience of mental illness while others described high levels of dependence on support from others. Most narrative accounts featured a range of approaches, depending on timing of the experience of support discussed and its context. However, our analysis revealed that people's accounts of themselves tended to be framed predominantly within one of four narrative positions. We termed these positions: Inward Expert; Outward Entrustor; Self-Aware Observer; and Social Integrator.

The 'Inward Expert' and 'Outward Entrustor' positions were dominant in the narratives of most participants, with fewer people constructing their experiences in terms of the 'Self-Aware Observer' (five participants) or 'Social Integrator' (three participants). Narrative positions exhibited complex dimensions, including positive (e.g. honest, caring) or more challenging (e.g. fearful, helpless) qualities. As indicated, there was also a degree of overlap between narrative positions, with some qualities appearing in more than one narrative type (e.g. helplessness). Furthermore, participants aligned themselves with their dominant position to various degrees. While some people more strongly affiliated with one particular narrative position, a few moved between different positions. We propose that, rather than being a way of categorizing people and their experiences, these categories are positions that people can take up, and therefore require acknowledgement of fluidity. Although the participants ranged in age from 22 to 65 years, age did not seem to influence the narrative position with which participants aligned – the average age of participants within each of the four positions was 41, 44, 46 and 35 respectively.

Inward Expert

‘Inward Expert’ was a common narrative position taken up by our participants, entailing the presentation of the self as an expert in relation to one’s own experience, indicating a strong sense of agency. Women in particular adopted the narrative position of the ‘Inward Expert’, often early on in their narrative account. For men (and a few women), self-expertise was mostly described as emerging over time, through learning about themselves through experience. Accounts presented by ‘Inward Experts’ focused on self-reflection, revealing a tendency to look inwards for answers, and featured claims about valuing the self (“I am worth caring about”). These accounts articulated inner strengths (“I’m also very self resourceful”) and self-care, and tended to highlight the progress people had made in relation to personal recovery. Assistance by others was frequently acknowledged, but in these accounts, people predominantly noted their own agency: “This is a recovery thing that *I’ve developed for myself* through the help of psychiatric disability services” (emphasis added).

However, the agency portrayed in these accounts was framed by perpetual struggles for outside validity and attempts at gaining control. Sometimes interactions with clinicians corroborated people’s sense of agency. For one woman, being discharged from hospital provided confirmation of her ability to care for herself: “They discharged me because they said I have a lot of insight and they think I could cope.” In contrast, involuntary treatment, usually in hospital, was experienced as loss of prized autonomy for the ‘Inward Expert’. During involuntary treatment, some described themselves as struggling with loss of freedoms, as clinicians (perceived as the ‘other’) appeared to take over. The apparent re-categorization of the person, from voluntary/capable to involuntary/incapable, imposed by the ‘other’, jarred with the inner agentic self:

And quite often if I've gone in as a voluntary patient, they make me involuntary because I don't agree to their treatment. So – and of course being an involuntary patient, they can do what they like with me.

Reclaiming some level of control narratively in the face of lost agency could be important for reinforcing the image of the expert and agentic self, as evident in one participant's account. While reflecting on her resistance to a diagnosis of 'personality disorder', she re-storied her "restrictive eating behaviors" as agentic. The account below demonstrates the participant's strong resistance to (and rejection of) the diagnosis, a deeper understanding of herself compared with what clinicians could possibly know, and a particular perception of what recovery meant for her.

But yeah, they weren't sure, like at first it was either borderline or schizoaffective disorder... So then it was decided like yep, it's borderline personality disorder. Which I was – I was actually quite upset about because I refused to have borderline personality disorder. I refused. I refused. I hated it. I've never gotten along with people with it and there's – to be honest I think that's where the maj– majority of the restrictive eating behaviors came from. I think it became a way to un-borderline myself.

Trust in the self, self-awareness, a level of honesty with oneself and self-care were considered important aspects of 'Inward Expert' approaches. These attributes created high expectations of relationships with families and friends, and of interactions with clinicians: "You [clinician] have to care about someone and if you don't... you're not doing your job." In comparison to the attention and effort that 'Inward Experts' directed towards self-care, clinicians could be perceived as relatively inattentive – "She [psychiatrist] couldn't be bothered listening," – or as

unable to understand adequately the experience of mental illness: “I’ve read my medical record... and some of the things they’ve written... are way out of touch with my experience.”

‘Inward Experts’ positioned their self-knowledge as equal in importance to, or sometimes superior to, clinicians’ knowledge. Yet mostly people attempted to gain recognition from health professionals, who were seen as authoritative “others”. They hoped to gain respect and secure partnerships with professionals in decision-making. Participants’ accounts demonstrated that if clinicians did not recognize their inner knowledge, interactions could be experienced as a site of psychiatric dominance and loss of control. However, there was evidence in participants’ accounts of finding alternative ways to exercise agency when perceived control over decision-making was lost. Examples included approaches to taking medication. Some participants reported unilaterally changing dosages or timing of medication:

I would keep [the medicine] under my tongue and then go into the bathroom once the nurse had left, and decide what I wanted to do. Whether I wanted to take the medication or break it in half or just spit [it] down the sink... I guess I always had to feel in control of that process.

Others described valuing ‘compliance’ with medication regimes as a way of demonstrating ‘good behavior’ to medical practitioners, to enable subsequent negotiation around dosages or types of medicines:

I only had my GP and I said... “I don’t, you know, I don’t like side effects.” I said to her, “I’m very compliant at taking medication every day, like I’m supposed to, but I’m not happy...” She reduced it by over a hundred, so I was happy with that.

For the ‘Inward Expert’, trust in and respect for clinicians could only develop when they felt assured that the clinicians, in turn, trusted and had respect for them as ‘experts by experience’. Trusted clinicians were allowed more control, on the assumption that they would likely endorse participants’ preferences.

The ‘Inward Expert’ expected to be treated with respect, and have their experience and self-knowledge acknowledged as being at least equal with biomedical/psychiatric expertise. This was not just a matter of exercising control but of ‘dignity’ – a confirmation of their autonomy and sense of self.

Outward Entrustor

In contrast to ‘Inward Experts’, those participants’ whose narrative positions we categorized as ‘Outward Entrustor’ predominantly looked to medical expertise for guidance on how to interpret – and cope with – their experiences of mental illness. ‘Outward Entrustor’ accounts were dominated by descriptions of needing (bio)medical care. They were less likely than ‘Inward Experts’ to question treatment decisions, including Compulsory Treatment Orders (CTOs). However, dependency on medical expertise was not necessarily fixed, as these participants also sought to recover agency, over time, through the medical treatments and other assistance they received.

Experiences of mental illness were narrated as a major life disruption (Bury, 1982), described by some as a “lifelong battle”. Whereas the ‘Inward Expert’ demonstrated a strong agentic narrative in spite of their illness, the ‘Outward Entrustor’ narrated a loss of agency caused by their illness. For many this became synonymous with a ‘lost life’, as highlighted by one

participant: “I was sort of grieving that it was sort of out in the open and my life was not going to be perhaps what I thought it was going to be.”

In contrast to the self-reliance of the ‘Inward Expert’, lack of certainty in dealing with mental illness characterized most ‘Outward Entrustor’ narratives. Thus, help was expected and frequently sought from clinicians. If assistance wasn’t forthcoming, some participants described taking desperate steps to get help: “And I actually stood in front of a car and just ran over my foot, you know and that was another suicide attempt that I had. But I just don’t think that they put the whole picture together of exactly what was going on with me.”

The urge to get help, when distress was acute, could be all-encompassing. In these circumstances, receiving care from a clinician was framed by some as ‘being rescued’: “When you get to that lowest point, you really need someone to step in.” In retrospect, for one participant, receiving involuntary treatment was welcomed:

I didn’t find it that onerous. I, I think that the community treatment order [worked] well for me, all it was, was just getting an injection every two weeks... I didn’t fight it because I didn’t want to go back to the voices.

In ‘Outward Entrustor’ narratives, psychiatrists, case managers and social workers were often expected to take responsibility and make decisions on behalf of their patients. As one participant commented: “I pretty well never bothered about writing it all down [in an Advance Statement], but I’d just go and see staff if I had to.” A few participants’ accounts indicated they held high expectations of what psychiatrists could achieve on their behalf. When treatment expectations were not met, such participants could become bitterly disappointed, as indicated

by one participant who said that when he was told he was leaving hospital, he thought it premature:

I obviously had a look of shock on my face because I thought, well, I didn't think anything had been fixed. I guess I was feeling that there should be some kind of resolution here, because I didn't feel any different to when I first was admitted.

In several accounts it was clear that clinicians were expected to provide more than just medical treatment (diagnosis and therapies). Participants were hoping for, and desired, empathic and insightful companions on their journey to deal with their distress. Here, many looked for a long-term relationship. Continuity of care from someone with whom a good therapeutic alliance had been, or could be, forged was identified as one of the most desired components of care by many, including when people were feeling relatively well.

Most participants across narrative types discussed wanting to share their experiences of mental illness with (and have them recognized by) their treating clinicians. This was strongly emphasized within 'Outward Entrustor' narratives in particular. One participant contrasted his rewarding relationship with one clinician (a psychologist) who appeared to take the time and care to engage closely with his experience, with his less satisfactory interactions with another treating clinician (a psychiatrist) who focused more on prescriptions:

...with [the psychologist] I could get into detail with it... give them more of a chance to know exactly what's going on. Like exactly how you're feeling and what, what the actual symptoms are... Like with me, the symptoms would make me insomniac. Like I wouldn't get sleep till like 3:00 in the morning, 4:00 in the morning because of the symptoms.

Like, like the voices and stuff... I never got to like tell my psychiatrist that or whatever and he [psychologist] went into detail and, and said, "Oh okay and what, what do you do about it?" And he goes, "No you should do this."... Whereas the psychiatrist would just hear you out and, and not really do much about the situation besides maybe looking at your medication or something or putting on a PRN for a, a sleeping tablet.

Positive and rewarding therapeutic alliances were valued, with such relationships considered by some participants as friendship-like. When relationships were perceived as trustworthy and caring, some participants showed understanding of clinicians' decisions, even where treatment seemed suboptimal: "With my anxiety, that was hard to treat and when the schizophrenia came it was even more complex... So it was all, very difficult for them to treat." Caring for practitioners and showing understanding of their actions was itself a rewarding relational experience for some of our participants.

Within 'Outward Entrustor' narratives, as participants felt better over time and regained a greater sense of agency, some described gaining more independence, although based within a "strong" sense of connection to a (trusted) clinician.

So I feel I guess I'm probably at a point now where I've got a strong relationship with my psychiatrist, that I can advocate a little bit more strongly for myself. Whereas before, whether I was too unwell or I didn't feel confident enough in my own, understanding my own mental state, I didn't have those advocacy skills. But now I feel like I can take a bit more of a lead with that sort of stuff.

For the ‘Outward Entrustor’, trust in the clinician’s expertise was crucial. Medical expertise was expected to be all-encompassing – including detailed knowledge and understanding of the experience of participants. Continuity of care and quality of therapeutic alliance was very important. Participants experienced care that nurtured and guided people towards wellness (and supported personal recovery) as supporting them in actively engaging in their own decision-making and in self-advocacy. The psychiatrist, GP or other mental health practitioners were expected to be empathetic and consistent companions in this process.

Self-Aware Observer

While for the ‘Outward Entrustor’, perceived needs while acutely unwell subsumed agency, in ‘Self-Aware Observer’ narratives, agency was reconstituted in the context of the illness. There was a strong narrative of being self-aware in these accounts, but rather than the notion of self-expertise requiring external validation as characteristic of the ‘Inward Expert’, participants had greater confidence in their personal decisions regardless of expert advice. As one participant said: “[I realized] I can’t manage this on my own anymore... So I went to the hospital and was sectioned immediately because they were expecting me.”

In these narratives, the illness experience transformed the participant’s sense of self-identity, creating a space for acknowledgement and acceptance of a ‘self’ that existed in the context of their ‘illness’, as one person’s account demonstrated: “I am a crazy woman.” Rather than a loss of self, there was an acceptance of a different type of personhood emerging in the context of illness. This is not to say that this new personhood was easy to assimilate: it could be jarring for participants to integrate the unwell self into their life story.

Despite a high level of independence, the accounts of participants who took up the ‘Self-Aware Observer’ position indicated that support was considered important, and having medical care in place was part of the narrative of ‘the good life’: “I’ve seen my doctor. I’m back on my meds. I’m seeing my psychologist and life is good.” Medical intervention was also relied on and trusted to ensure wellbeing would be maintained in the future: “I would hope that if it ever happened again, I would be able to seek that help quickly and in a way that didn’t cause me to get so unwell again.”

Although a sense of helplessness and dependency on medical intervention featured in these narratives, the narrator’s relationship to those experiences differed in important ways from the ‘Outward Entrustor’ and ‘Inward Expert’ positionings. Accepting help seemed to be part of the agentic process. In strong ‘Self-Aware Observer’ narratives, the participant seemed to take responsibility for themselves, even when most unwell. While there was recognition of the need for help from mental health clinicians, this did not seem to be accompanied by expectations that others would make them ‘well’, as with ‘Outward Entrustor’ narratives. ‘Self-Aware Observer’ stories suggested an implicit ownership of the mental illness as the participant’s own challenge:

I just remember going to my psychiatrist this one day and being really, really agitated and I think I was probably in tears and I just said, “Well, look, I think I’ve hit rock bottom...” But I do remember feeling a – a great sense of relief, like someone has presented *me* with an option beyond like a weekly, hourly appointment kind of thing in order to help – to assist or to help *me* with *my* mental health (emphasis added).

As with all participants, for the ‘Self-Aware Observer’, trust in relationships with clinicians was important. For most, trust meant achieving collaboration. Maintaining some control over the decision-making process was important, but the ‘Self-Aware Observer’ did not need medical practitioners to ‘give’ them ultimate control, as with the ‘Inward Expert’ narrative, for collaboration to work.

For the ‘Self-Aware Observer’, agency emerged through the integration of experiences of illness with self-identity. The ‘Self-Aware Observer’ accepted support from psychiatrists, GPs and other clinicians through a collaborative interaction in which she or he was the instigator, seeking out help, and being given choices in her or his care. While experience and self-awareness were important for these participants, they also internalized the logic of the advice and expertise of clinicians.

Social Integrators

A few participants’ narratives placed great importance on how their psychiatric diagnosis impacted on their social integration. In these accounts, there was less focus on receiving a diagnosis and the medical treatment that followed than in the three other narrative positions. For ‘Social Integrators’, the language of ‘illness’ belonged to clinicians who were portrayed as being in a position to define the ‘problem’, in contrast to the person with experience of a mental illness, who was in a position of ‘not knowing’.

Interviewer: ... would you describe yourself as having an illness?

Participant: An illness? it’s hard to say because yeah at times it could be but, I don’t fully know if that’s kind of what’s the thing, what’s going on like. You kind of have to accept

it because all – there are people who are, you know, in charge that, who are telling you what to, what's, what's going on, so yeah, you probably don't know yourself, so.

Not 'knowing', in the biomedical sense, was not especially problematic for the 'Social Integrator', and narratives featured a strong but tacit sense of agency that was separate from the experience of being diagnosed with a mental illness. Taking advice was important, so being agentic could mean listening to what medical practitioners had to say, although ultimately self-help was key: "Well I've learnt to, to listen carefully to what doctors have to say and try to do the best that, oh do the best you can for yourself."

Mental distress, rather than 'illness', was experienced as one of many life challenges. Experiences of distress did not define or alter the 'Social Integrator's' sense of self:

I know [laughs], I think, look seriously, I think whether you've got a mental illness or not, everybody has issues of some sort don't they? I mean life doesn't go smoothly for anyone, and we just have to, you know, sort of take mental illness away from us and just look at us as people with different needs, and you know, different abilities, different capacities to do things as well. And not be too hard on ourselves about that, yeah.

However, a sense of agency was tied in with these participants' social identity, and if a label of mental illness challenged their social identity, this could feel like an attack. One participant described how she felt when she read that she had been put on a Compulsory Treatment Order:

I read it and... I felt like I was a criminal... I thought I didn't do anything wrong... It was talking about... being a threat to the community, the local, the local, local community or something like that, and I've never had that happen to me before.

For the 'Social Integrator', developing good interpersonal relationships and being perceived as a part of a community was considered an important part of life. Help and advice offered by friends or family were often highly valued, and support and self-care were the cornerstones of getting better: "If I am getting over the top or out of hand, I try and listen to family and friends, because they might know a bit more than me"; "Surround yourself with people that... are good to you... taking care of yourself and being positive."

Engagement with clinicians seemed less important for 'Social Integrators' than for 'Outward Entrustors', who sought lots of support, and 'Inward Experts', who desired validation. 'Facilitative' interventions by clinicians ("sort of pointed me in the right direction...") were more likely to be highly valued.

And always my shrink would – like I remember once he, he was very handy to have, because like I was generally not doing well some weeks or whatever and I said to him, "Look, I'm a bit anxious about going back to work... I don't know if I'm still unwell." He just said, "Well we'd better not send you to work then." He said – that was just nice of him... he's very professional.

The 'Social Integrator' did not fully identify their distress as 'illness'. Their primary concern was with acquiring wider support for themselves through advice, facilitation, and peer and social support. The 'Social Integrator' valued social integration to the point where treatment

decisions that were socially endorsed, or carried out in communion with others, were more readily accepted.

Temporality, experience and shifting narrative positions

While most people's accounts were framed predominantly within one of the four narrative positions outlined above, there was fluidity within each position. The way people's accounts were emplotted (Ricoeur, 1991) illustrates how their self-confidence and capacity to engage in decision-making altered over time, and could move back and forth. For instance, a participant could move between narrative positions depending on how unwell they felt at different times. In some 'Inward Expert' accounts, when participants described feeling more acutely unwell, their narratives took a turn towards the 'Outward Entrustor' position. There was more reference to dependency and finding a balance between feeling in control and being able to accept the clinician as expert. Some 'Inward Experts' were more expert than others (with higher levels of self-expertise), and some 'Self-Aware Observers' could associate emotionally more closely with some events in their story than others.

As mentioned earlier, a few people whose narratives were predominantly aligned with the 'Outward Entrustor' position also seemed to have made a transition over time as they became more experienced. A narrative of self-awareness and self-care emerged as they became more able to articulate their feelings and needs for themselves. One participant, for example, spoke about gaining confidence over time in asking for what he needed:

And these days I, I, I go in there and I say, "Well, this isn't working." You know. "Can we do something about this?" Or, I'm getting – I'm much more articulate with the way I describe how I'm feeling. And in those days I was, I was probably fearful that they'd put

me in the hospital or something, you know. And I was, I was young and a bit naive and so it was a – it was more difficult.

Such fluidity did not take away from the underlying narrative position but demonstrated that these positions were flexible rather than rigid. Narrative positions provided a way for participants to make sense of their lives, and these developed in response to experiences and relationships as well as their own world view.

Discussion and implications for practice

We investigated expectations of supported decision-making in narratives of 29 people with experiences of psychiatric diagnoses including bipolar disorder, borderline personality disorder, psychosis and schizophrenia living in Australia. In our analysis, we explored how the world around participants influenced their subjective judgment and the stories they told about themselves, and how their world-view informed their expectations of support in making decisions about their treatment and other aspects of life. Positioning our participants as meaning-making social actors, we examined the patterns in their descriptions of interactions (Guidry-Grimes, 2015) with others, what this told us about the role they attributed to themselves and others, and the expectations that emerged from these perceived roles.

We explored participants' expectations of clinical encounters and clinicians, including psychiatrists, other mental health practitioners and GPs, with a particular focus on people's expectations of how they could be best supported to participate in their medical treatment and other important life decisions. The data did not allow for an examination of how participants navigated structural boundaries (gaining access, waiting times etc.) during moments of action or responses to external influences, such as those studied by Pescosolido et al. (1998).

However, it did allow for a study of the mechanisms by which people related to others, including medical practitioners, to themselves and to their ‘illness’.

Four distinctive types (with some overlapping characteristics) of narrative positioning emerged in our analysis. The description of each type indicates how participants related to their diagnosis of mental illness, and suggests how health professionals could most fruitfully engage with them. People’s sense of agency emerged as an important factor. ‘Inward Expert’ accounts conveyed an overt sense of agency that continued after a diagnosis of mental illness was made and was expressed through a strong, though potentially fragile, sense of expertise through experience. ‘Outward Entrustors’ experienced a loss of agency and loss of self in the face of living with a psychiatric diagnosis and looked to clinicians for biomedical expertise as well as a comprehensive understanding of their experience. Those participants with a strong ‘Self-Aware Observer’ narrative maintained or reconstituted their sense of agency after being diagnosed with a mental illness and in the context of interacting with health professionals. Finally, ‘Social Integrators’ had a tacit agency that was detached from their diagnosis and the expertise of clinicians.

During interactions with psychiatrists and other clinicians, control was important for most participants. Having or losing control could have a direct impact on participants’ sense of self and sense of agency. Two separate but inter-related aspects of control were identified as relevant: what participants sought control over, and how they imagined this control could be achieved.

Narratives of ‘Inward Experts’ focused on whether people had control over their treatment decisions. For most, this was mediated through the therapeutic alliance and trust in their

relationships with clinicians. However, the perceived trust the clinician had in them as patients (e.g. the psychiatrist trusting them to take their medication rather than putting them on a CTO) was a crucial component. Clinicians were expected to ‘validate’ the ‘Inward Expert’s’ sense of expertise in their own illness, as an expert by experience. The ‘Outward Entrustor’, on the other hand, used a strong relationship with their psychiatrist or other clinician as a way to take control over their illness (even if this sometimes meant relinquishing at least some degree of control over treatment decisions). Their sense of not being able to help themselves on their own led them to look to others, primarily clinicians, for assistance. The clinician was not necessarily expected to take control, but to be a ‘companion’ in the illness journey and, eventually, to nurture the participant’s capacity for self-advocacy.

Control and trust were also factors for the ‘Self-Aware Observer’. ‘Self-Aware Observers’ sought control over their future, in which the illness seemed to be an unwanted, dominant force. Medical care was a vital ingredient in taking back control. Participants described seeking assistance from clinicians as collaborators in this process. The ‘Social Integrator’ also wanted control over their life and future. The distress associated with their condition was not necessarily perceived as an ‘illness’ but as another life challenge. Control came through support from others and through self-care, and clinicians who facilitated this were valued. Trust and support from family and friends was crucial, as was having a meaningful social identity.

Our analysis builds on empirical and theoretical studies of illness narratives, which study the ill self at moments of interaction (Bury, 1982, 2001; Carel, 2008; Charmaz, 1983; Estroff et al., 1991; Hyden & Brockmeier, 2008; Kokanović & Stone, 2018). In illness studies, an understanding of the self emerges through the lens of the illness (Carel, 2008). In the context of supported decision-making, however, it is more instructive to examine how a construction

of the self is developed in interaction with others. This examination is likely to help in understanding what makes decision-making processes effective. Rather than beginning with the ‘ill self’ – the two-way interaction of self with illness – we began with the ‘interactional self’ in a social context – a three-way interaction of self, illness, and others. To facilitate this, our analysis drew on theoretical understandings of the subject that recognize subjectivity as shaping (and shaped by) the world around it, habitually relating to and responding to forces in the environment (Blackman et al., 2008; Kokanović & Flore, 2017). Health service users are not neutral recipients of ‘evidence-based’ treatments. Thus, we looked at ways in which participants are agentic subjects, maneuvering and self-positioning in relation to changing contexts, including navigating power relations as they perceive them.

Pescosolido et al. (1998) discuss the importance of the social dimensions of experiences of mental illness, including not just the individual, but the individual in interaction. Relationships, and the events that surround them, are critical to understanding the elements of good decision-making. In the context of decision-making in mental health service provision, the relationship between service user (person diagnosed with a mental illness) and service provider (medical practitioner) is characterized by a power imbalance and mismatched expectations. For most service users, psychiatrists and other clinicians are seen as distant (speaking a different language, having different priorities or values) and portrayed as ‘the other’. While this does not necessarily impede effective communication, it forms a baseline for the interactional event.

The relationship between clinicians and people with experiences of psychiatric diagnoses traverses the line between professional and interpersonal relationships (Ljunberg, Denhov & Topor, 2015; Newman et al., 2015). Working out how the service user’s self relates to this has a bearing on the ‘emotional climate’ (Denhov & Topor, 2012) of the interaction (whom the

service users want to help them, and how). Following Himmerich and Wranik's (2012) recognition that physicians' values and beliefs influence SDM, it is not too big a leap to suggest that users' values and beliefs do too. These in turn are influenced by their experiences of the attitudes and actions of those they encounter in treatment and support systems.

Our findings also demonstrate the precariousness of narrative positioning. Based on a study of experiences of people diagnosed with psychosis, Tidefors and Olin (2011) argued that participants' 'wishes and needs' regarding psychiatric care changed over time. During 'periods of psychosis', people wanted staff to offer 'care and safety' from the outside world and to act as 'parental figures'. Later, when they sought support for a 'liveable life', they wanted information, and for staff to give time and share their sense of hope. Our findings indicate that while people's expectations of supported decision-making could change from periods of 'illness' to periods of 'wellness', their personal preferences for care were not so predictable. Care preferences were affected by participants' understanding of their own expertise, their sense of agency and perceptions of need for control, and not by timing alone.

We also found that people's expectations of decision-making could shift over the course of an episode of being unwell and getting better, and over their lifetime. Trust, self-expertise and self-confidence were important features in understanding how participants' expectations changed over time. This accords also with the practical recognition that past experience, including the attitudes of clinicians and the support and understanding of families, employers and community organizations, has a strong influence on function and coping.

To facilitate supported decision-making, psychiatrists and other mental health clinicians (of all disciplines), GPs and other health professionals may need to act in a variety of roles: as

facilitators (including trusting their patient to self-manage where appropriate and facilitating self-care and processes of recovery); as companions (getting to know their patients well and ‘being there’ when needed); and as collaborators (providing options and information and, where possible, a speedy resolution). The findings also point to the value for most people of family and peer support and social networking for supported decision-making. These will be discussed in future articles.

The characteristics of the interactions that facilitate SDM as identified here are also the fundamental elements of a good clinical interaction: the engagement of both parties, active listening, commitment and concern, and a shared understanding of the primary concerns of the person with experience of a diagnosis of mental illness (Bonfils et al., 2014). The development of the therapeutic relationship requires that the clinician takes a good history, which remains the cornerstone of clinical practice.

The results of this study therefore emphasize the need for clinicians and other service providers to enquire about and take note of the nature of the service user’s interaction with them during the current and any previous episodes of care. These topics also need to be prominent discussion points with the person and their treating team. The relevant aspects of history taking, team interaction, and considering in collaboration with the service user how to act on the understandings derived can facilitate SDM and contribute to recovery.

Our findings are consistent with developments in mental health practice and service provision including the personal recovery paradigm that emphasizes connectedness, hope, identity, meaning and empowerment as cornerstones of recovery (Leamy et al., 2011), and the related increased use of advance statements, joint crisis planning and wellness recovery action plans

(WRAP) (Henderson et al., 2008). Lofgren et al. (2015, p. 483) suggest that clinicians need to be mindful of the impact of their language on people experiencing mental distress. Moreover, positive interpersonal encounters in healthcare settings, as Moran and Russo-Netzer (2016) argue, can enhance agency and meaning making, thereby facilitating service users' personal recovery. The recognition that people may view decision-making in different ways, and that their preferences may change over time, enables a more nuanced approach to practice which might facilitate more positive and empathetic clinician and service user interactions.

New approaches may involve assessing what people require from professionals at the outset (e.g. collaboration, expertise, trust, autonomy) and building this into service provision. For example, a WRAP might be developed collaboratively when a person is in the 'Inward Expert' phase. People's own understanding of their needs and challenges could be worked into planned changes and new life-routines aimed at maintaining their wellness and maximizing their autonomous functioning. Alternatively, if a person is in (or moves into) the 'Outward Entrustor' mode, it would be more appropriate for people to have regular contact with a named support person who could work with them more gradually to facilitate SDM in relation to treatment or other life decisions through the use of mechanisms such as advance statements or joint crisis plans. While in the short term this approach would fulfill people's need for someone dependable to oversee their care, in the medium term it could ease them into a position of greater independence. This could include strategies for informal care or self-care during a period of being unwell so as to stay safe, nominating a support person, and, for some, arranging planned short stays in hospital or other care environments. Those who take up 'Self-Aware Observer' and 'Social Integrator' positions might benefit more from peer support and personal recovery oriented practice that promotes positive understandings of self-identity and the role of illness in peoples' lives (Leamy et al., 2011).

Attending to people's views and preferences regarding supported decision-making can lead to positive therapeutic encounters that foster meaning, agency and trust, and in turn facilitate personal recovery. These outcomes are likely to be enhanced by awareness of and sensitivity to how these views and preferences differ from person to person, and for each person may shift at different stages of their illness trajectory.

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The Authors declare that there is no conflict of interest.

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Data: Data are available from the Health, Society & Medicine Research Hub, RMIT, or by contacting the authors, for researchers who meet the criteria for access to confidential data. Ethics approval for this project does not include provision for making full interview transcript data publicly available, so as to preserve participant anonymity. Ethics clearance for the project limits transcript access to only members of the research team. Data will be made available for researchers who meet the criteria for access to confidential data. Requests for access can be made to Dr Kate Johnston Ataata, Co-Lead, Health, Society & Medicine Research Hub.

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¹ ‘Shared’ decision-making tends to refer to clinical guidance for physicians to involve users in treatment decisions.

² Where someone is appointed to make a decision (e.g. about healthcare, accommodation or financial matters) on behalf of another who is deemed to lack mental capacity (Davidson et al., 2016 p. 32).