

Spot the difference: shared decision-making and supported decision-making in mental health

M. B. Simmons^{1,2,*†} and P. M. Gooding^{3†}

¹ Orygen, The National Centre of Excellence in Youth Mental Health, Parkville, VIC, Australia

² Centre for Youth Mental Health, The University of Melbourne, Melbourne, VIC, Australia

³ Melbourne Social Equity Institute, The University of Melbourne, Melbourne, VIC, Australia

Respecting a person's choices about the mental health services they do or do not use is a mark of quality support, and is often pursued for moral reasons, as a rights imperative and to improve outcomes. Yet, providing information and assistance for people making decisions about the mental health services can be a complex process, and has been approached in various ways. Two prominent approaches to this end are 'shared decision-making' and 'supported decision-making'. This article considers each of these approaches, discussing points of similarity and difference and considering how the two might complement one another. By exploring the contribution that each approach can make, we conclude by proposing how future application of these approaches can account for the broader context of decisions, including support for ongoing decision-making; the multitude of service settings where decision-making occurs; and the diversity in supportive practices required to promote active involvement.

Received 10 May 2017; Revised 19 September 2017; Accepted 19 September 2017; First published online 23 October 2017

Key words: Decision aids, human rights, mental health services, mental healthcare, shared decision-making, supported decision-making.

Introduction

In recent decades, mental health policies have *generally*, though with some notable exceptions, given greater priority to the will and preferences of the people who use them. This is evident in the rise of 'recovery-oriented' practice over the past 30 or so years (Slade *et al.* 2012), which emphasises the right of people receiving care to make decisions for themselves, including decisions that involve risk (Australian Health Ministers' Advisory Council, 2013). Yet despite the existence of theoretical frameworks and support at a policy level, it is less clear the degree to which these ideals are realised in practice. It seems fair to say that services still generally rely on a medical model of care where the healthcare professional is positioned as the dominant decision-maker. In addition, there are some disturbing signs of an increase in coercive psychiatric intervention. For example, in England between 2014/2015, it was reported that the proportion of 'mental health inpatients' detained under the *Mental Health Act 1983* (England and Wales), which has been increasing over the 21st century, reached 51% (Care Quality Commission, 2015: 6), meaning that people hospitalised for a mental health crisis were more likely to be detained

than not – a situation which likely remains today. It also appears that rates of non-consensual interventions are rising *outside* the hospital in a number of countries, in people's homes and residences via compulsory community interventions (see e.g. Johnson, 2013).

Despite this trend in some high-income countries it seems reasonable to say that recent decades have seen increasing interest among policymakers, service users, service providers and others, in promoting the decision-making of consumers¹ in their own care. There are several drivers for this shift, including: a belief that involving people in making their own decisions is a moral imperative (Drake & Deegan, 2009); increasing respect for human rights and the equal opportunity of people with mental health issues (Minkowitz, 2010; Human Rights Committee, 2016); and mounting evidence that involvement of consumers reduces unnecessary treatment (Veroff *et al.* 2013) and improves clinical outcomes (Clever *et al.* 2006). Two prominent approaches for promoting consumer

* Address for correspondence: Dr M. B. Simmons, Orygen, The National Centre of Excellence in Youth Mental Health, Locked Bag 10, Parkville, 3052, Australia.

(Email: magenta.simmons@orygen.org.au)

† These authors contributed equally to this work.

¹ We acknowledge the contested nature of psychiatric labels, including how we refer to those who seek and provide mental healthcare. For the purposes of this article we use the term 'consumer' to refer to somebody with an experience of mental ill-health, mental health crises, profound distress, psychosocial disability, and so on, who is using mental health services. 'Clinician' is used to refer to a person who provides clinical care. Occasionally, 'mental health professional' is used to refer to clinicians and/or other non-clinical providers of care (e.g. social workers, peer workers, etc.).

decision-making are ‘shared decision-making’ and ‘supported decision-making’.

‘Shared decision-making’ refers to a set of skills and practices that clinicians can learn in order to engage in a collaborative decision-making process for healthcare decisions (Hoffmann *et al.* 2014), though precise definitions are debated and the process is likely to be applied differently in different contexts and for different decisions. Shared decision-making has been applied widely in many areas of health, including throughout the National Health System in the United Kingdom (Joseph-Williams *et al.* 2017), and is referred to in the Patient Protection and Affordable Care Act (2010) in the United States. In 2010, representatives from 18 countries came together for a Salzburg Global Seminar focused on shared decision-making, demonstrating the growing interest and support for shared decision-making in mental health policy and practice worldwide (Alambuya *et al.* 2011).

‘Supported decision-making’ is an idea that emerged from disability and human rights-related activity. It refers simply to decisions, particularly legally recognised decisions, made with support. In crude terms, supported decision-making promotes the idea that just as people who use wheelchairs are entitled to ramps in order to access buildings, so too people with mental health-related disability – or ‘psychosocial disability’² – are entitled to support to exercise choices about their lives. (The same idea holds for people with intellectual disability, or any other disability that may affect decision-making, including the way other people perceive and/or denigrate a person’s decision-making ability). Supported decision-making appears to be driven by issues of power, stigma, discrimination and human rights, and particularly the challenges to the use of non-consensual psychiatric intervention promoted in the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). However, the concept concerns choices beyond mental healthcare decisions, and may relate to housing, finances, relationships, and so on. Nevertheless, the idea of supported decision-making is increasingly being applied in the mental health context, for which practical applications include personal advocacy services, advance directives, and nominated representative schemes (see Minkowitz, 2010; Gooding, 2013; Arstein-Kerslake *et al.* 2017). We will use the term supported decision-making ‘approach’ throughout this paper to describe the range of ideas and practices associated with this term.

² Since the Convention on the Rights of Persons with Disabilities came into force in 2007, the term ‘psychosocial disability’ is increasingly being used, including by the Office of the High Commissioner for Human Rights, the World Health Organisation, the United Nations Committee for the Rights of Persons with Disabilities, various governments and a range of disabled people’s organisations.

Both shared and supported decision-making have developed separately but in parallel, with relatively little consideration given to the similarities and differences between the two (for a notable exception, see Pathare & Shields, 2012). Our paper aims to describe the defining features of both shared and supported decision-making. We will discuss the similarities and differences between the two, and consider points where they may complement one another as strategies for strengthening the self-determination of consumers. Our paper will largely focus on high-income, English-speaking countries.

Shared decision-making

Shared decision-making rose to prominence as a process in healthcare settings for increasing the agency of people receiving treatment, services and care. There are a number of models that describe what this process might look like and involve, but in broad terms proponents suggest that optimal decision-making occurs when a decision is informed by the most relevant evidence and the consumer’s personal preferences and values. Although there is a focus on collaboration between clinician and consumer, according to Edwards & Elwyn (2006), the question of who makes the actual decision is seen as less important than the act of both parties engaging in the decision-making processes. These processes include an initial discussion about the need for a decision and benefits of collaboration; discussion and iterative deliberation about the relevant options, including evidence for potential harms and benefits as well as personal preferences and values about these outcomes; and integration of this shared information into a decision or choice (Elwyn *et al.* 2012, 2013, 2014). Decision aids are tools (e.g. online, paper-based) that convey evidence-based information about the likelihood of potential benefits and harms of relevant treatment options. They also invite users to consider their personal values and preferences in relation to these potential outcomes and in doing so are designed to facilitate shared decision making.

The evidence for shared decision-making

On the whole, evidence to support a shared decision-making model comes from non-psychiatric settings and is mainly based on decision-related outcomes. A Cochrane systematic review and meta-analysis of 115 studies including 34 444 participants across different healthcare decisions (including a small number of mental health-related decisions) demonstrated that decision aids increase knowledge (including more accurate understanding of the likelihood of benefits and harms); help people to feel less confused about what to do; result in more informed, values-based choices; improve communication between consumers and clinicians and help to activate people to be more involved in making decisions (Stacey *et al.* 2014).

Shared decision-making in mental health

There are now at least 13 randomised trials testing shared decision-making intervention for mental health-related decisions. These include for depression (Loh *et al.* 2007; Simon *et al.* 2012; Aljumah & Hassali, 2015; Le Blanc *et al.* 2015); psychotic disorders (Hamann *et al.* 2006, 2007; Woltmann *et al.* 2011; Dixon *et al.* 2014); substance use disorders (Joosten *et al.* 2009); and for a range of disorders (Alegria *et al.* 2008; Westermann *et al.* 2013). In addition to the diversity in the disorder or decision targeted for support, across trials there is a lack of fidelity checking (ensuring shared decision-making did occur, which is not specific to mental health trials) and a lack of consistency in the outcomes measured, meaning that these studies are difficult to compare. Further, almost all trials include only adult participants, leaving a clear gap in our knowledge about how best to promote shared decision-making for young people. Another gap is that although shared decision-making has been studied in inpatient settings, this has been for voluntary treatment decisions.

Despite the research gaps, there have been a number of trials conducted and some sense can be made from these initial findings. In the randomised trials that have been conducted, based on the most consistently measured outcomes, there is emerging evidence to suggest that shared decision-making helps people diagnosed with depressive disorders to feel less confused about what to do (Simon *et al.* 2012; Le Blanc *et al.* 2015; Perestelo-Perez *et al.* 2017); feel more satisfied (Loh *et al.* 2007; Aljumah & Hassali, 2015; Le Blanc *et al.* 2015); adhere more to treatment (Loh *et al.* 2007; Aljumah & Hassali, 2015); and improves knowledge about treatment options in those diagnosed with depressive disorders (Le Blanc *et al.* 2015; Perestelo-Perez *et al.* 2017) and psychotic disorders (Hamann *et al.* 2006; Woltmann *et al.* 2011). Of the five trials that measured reduction in symptoms as an outcome, three showed no effect (Loh *et al.* 2007; Aljumah & Hassali, 2015; Le Blanc *et al.* 2015) and two did (Joosten *et al.* 2009; Dixon *et al.* 2014).

Evidence-based practice

According to Elwyn *et al.* (2012), improving knowledge for both the consumer and clinician is an important goal for shared decision-making interventions, as information about evidence and preferences is considered essential information necessary for the decision-making processes. Without critical knowledge about the decision at hand, including the exchange of evidence-based and preference-based information, a person's preferences are at least partially uninformed and there is a risk of preference 'misdiagnosis', which means that the person would have chosen a different option had they had the necessary information (Mulley *et al.* 2012). In order to make an informed decision, both the clinician

and consumer need access to readily understandable, evidence-based information about the potential harms and benefits of each option, and the likelihood of these potential outcomes. (We will discuss the potential for the evidence-base and the current state of research to devalue the service user and family perspectives shortly). Access to information on current research and practice has mainly been achieved through the use of decision support tools (e.g. decision aids, decision grids) to be used either outside or within clinical consultations. Attempts have been made to include more sophisticated information in these tools, such as an appraisal of the quality of evidence presented, and how similar the trial participants are to the person making the decision, however these inclusions remain challenging. Achieving a balance between including all relevant information and having a tool that is user friendly and readily understandable by a wide range of people is difficult, and is perhaps why shared decision-making may be seen as something only suitable for those with high levels of cognitive capacity. In contrast, as we shall discuss later, supported decision-making is premised on the idea that even those who would not be seen to hold mental capacity, under current standards, can still express preferences, which can help guide decisions, and that such individuals should be afforded the respect and dignity of continuing to have their preferences guide decision-making.

Misconceptions about shared decision-making

A number of misconceptions about shared decision-making have been addressed elsewhere (Hoffmann *et al.* 2014). In short, shared decision-making is unlikely to increase consultation time, result in anxiety or leave people feeling unsupported. It is unlikely that clinicians are already doing shared decision-making, as some commentators have suggested (Loh *et al.* 2006; Goossens *et al.* 2007; Goss *et al.* 2007); and a number of studies indicate that most people want to be involved (McKinstry, 2000; Hamann *et al.* 2005; O'Neal *et al.* 2008; Simmons *et al.* 2011), and are capable of being involved in decision-making (Hamann *et al.* 2006); and it is important not to exclude vulnerable people from decision-making processes as this risks increased health disparities. Efforts have been made to promote shared decision-making for marginalised groups (Muscat *et al.* 2015); however, decision aids often fail to accommodate individuals with low health literacy (McCaffery *et al.* 2013). Decision aids also tend to focus on discrete decisions with defined possible outcomes.

The nature of decision support in shared decision-making

Shared decision-making focuses on the interaction between clinicians and consumers within the clinical

encounter, and decision aids reflect this. Decision aids are usually related to a healthcare decisions, such as whether or not to take a particular medication. However, other interventions, such as prompt questions for consumers (Shepherd *et al.* 2011), have been shown to improve the amount and quality of the information shared within these encounters. Regardless, this focus on specific decisions has also been largely conceptualised within the shared decision-making field as decisions that occur within localised interactions between clinicians and consumers. Morant *et al.* (2016) argue that shared decision-making models, largely devised within non-psychiatric settings, cannot be readily adapted for specialist mental healthcare settings. As they point out, decisions about mental healthcare are embedded in traditionally paternalistic systems of care with an ongoing history of coercion, presumption of lack of insight and decisional capacity and disempowerment. They propose a new conceptual model for shared decision-making in mental healthcare that takes into account the relationship between the decisions made within the clinical consultation with the ongoing therapeutic relationship and the structural, functional and cultural features of the mental health system (Morant *et al.* 2016).

One structural feature of the mental health system is the power imbalance that exists between mental healthcare providers and consumers. One example of the manifestation of this power imbalance is the disjuncture between professional and lay discourses. For example, there remains a well-identified possibility for service user perspectives to be devalued in research. Trisha Greenhalgh *et al.* have argued that 'evidence-based medicine', in general, may 'inadvertently devalue the patient and carer agenda', including through

limited patient input to research design, low status given to experience in the hierarchy of evidence, a tendency to conflate patient-centred consulting with use of decision tools, insufficient attention to power imbalances that suppress the patient's voice, over-emphasis on the clinical consultation, and focus on people who seek and obtain care (rather than the hidden denominator of those that do not seek or cannot access care) (2015: 1).

This is an important consideration in shared decision-making, where the language and evidence used to communicate harms and benefits, and the types of knowledge that are valued and devalued, is most likely going to be more aligned with professional discourse. However, some adaptations of the shared decision model have tried to ameliorate this power imbalance. For example, the use of peer workers employed to facilitate shared decision-making. Patricia

Deegan and colleagues developed CommonGround, a software program delivered in waiting rooms of psychiatric medication clinics (Deegan, 2007 2010). Consumers of the clinic are invited by a peer worker to complete a pre-consultation report about their personal preferences and values before meeting with a medical professional about their medication. This model was designed to address both the power imbalance in the session but also to maximise the amount of information shared in a time limited consultation. CommonGround has since been tested in early psychosis clinics (Dixon *et al.* 2014), and the combination of peer support and shared decision-making has been tested in early intervention services (Simmons *et al.* 2017), demonstrating applicability for younger consumers who may be even more at risk of receiving paternalistic care and experiencing power imbalances due to their age.

Programs such as CommonGround are designed to help involve people with 'serious mental illness' in making decisions about their own care. They go beyond the specific treatment decision they are facing (e.g. 'should I take this medication?') and invite people to explore contextual information with support from a peer worker, which can then be shared with their clinician. Contextual information might include descriptions of 'personal medicine', that is preferred activities that the person engages in to promote wellness and recovery (Deegan, 2005), and whole of life personal goals, reflecting the importance of functional recovery as well as symptomatic recovery. However, the process of shared decision-making that programs such as CommonGround seek to facilitate does not provide the legal mechanism by which individuals can make decisions, for example, through advance directives and nominated persons schemes, as discussed in the following section on supported decision-making.

Supported decision-making

'Supported decision-making' is an approach increasingly used in mental health policy and practice since the coming into force of the United Nations CRPD (United Nations, 2006). The CRPD came into force in 2006 and there are 173 'States Parties' (countries and regions) to have 'signed' and/or 'ratified' the CRPD.

The term 'supported decision-making' does not appear in the CRPD. However, it has become prominent in debates about how to apply human rights to areas of law, policy and practice, in which paternalism and *substituted* decision-making have traditionally dominated, whether formally (e.g. under guardianship or mental health legislation) or informally (e.g. in healthcare settings or family situations in which decisions are made for people) (Gooding, 2013). 'Best interests' decision-making by third parties, where one

person substitutes his or her decision on behalf of another person, is then replaced by an emphasis on adhering to the 'rights, will and preferences' (United Nations, 2006, art 12(3)) of the individual. Supported decision-making is premised on the idea that no one is 'purely' autonomous – and that most, if not all, people are constantly making decisions with support from others. Supported decision-making brings this interdependence out into the open, and invites people to support but not take over the decisions of people in mental health crises or those with ongoing disabilities.

The Office of the High Commissioner for Human Rights (OHCHR, 2007: 89) defines supported decision-making as simply, 'the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters'. We will use this definition throughout the paper. Understood broadly, this definition would seem to encompass shared decision-making. However, elaborated definitions of supported decision-making, and the associated literature, suggests that supported decision-making appears to have a greater emphasis on the decision-maker as the final arbiter of choice (Pathare & Shields, 2012: 4). The OHCHR elaborates:

With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when an individual with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual. (2007: 89)

The OHCHR acknowledges that supporting people to make decisions in practice, will take many forms:

Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realise that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her capacity (2007: 89)

Applied to the mental health context, Pathare & Shields define supported decision-making in the following terms:

supported decision-making ... can consist of organisations, networks, provisions or agreements with the aim of supporting and assisting an individual with a mental illness to make and

communicate decisions. In supported decision-making, the individual is always the primary decision maker, but it is acknowledged that autonomy can be communicated in a number of ways, thus provision of support in different forms and intervals can assist in the expression of autonomous decisions. (2012: 4)

Tina Minkowitz (2006) has argued that 'recovery-oriented practices' can help to understand supported decision-making in the mental health context. She argued that supported decision-making could be understood 'from a user/survivor point of view' as 'an application of the recovery perspective to the situation of decision-making' (Minkowitz, 2006: 19). Given the variety of forms supported decision-making can take, it may be better thought of as an *ethos* rather than a mechanised model to be applied in practice – though again, we will use the term 'approach' here. Nevertheless, it is useful to consider several practical examples of supported decision-making; namely, advance planning, nominated persons (or healthcare decision-making proxies), and personal advocacy.

Practical examples of supported decision-making

Advance planning may consist of formal legal mechanisms (such as advance statements and advance directives) and informal/non-legally binding agreements [such as 'joint crisis plans' (Henderson *et al.* 2004)]. The Committee on the Rights of Persons with Disabilities (2014: para 17), which is the UN body that offers guidance on how countries should interpret the CRPD, has written:

For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others.

Penelope Weller (2008: 102) has argued that advance directives are a practical method for formalising supported decision-making in ways that 'take account of varying mental health conditions and the specific institutional contexts in which mental health treatment is provided'. Advance directives can strengthen self-determination by clarifying a person's will and preference before mental health crises occur. Advance planning tools – both formal and informal – exist in most common law countries, in mental health legislation, and elsewhere (see Weller, 2013).

Nominated representative schemes (or healthcare decision-making proxies) can also offer a practical form of supported decision-making. This entails a person electing a representative to assist them during crises.

Powers of attorney are a widely-known nominated representative scheme in law. In British Columbia, Canada, the *Representation Agreement Act 1996* (Government of British Columbia, 1996), provides for a nominated persons scheme that can be used effectively in the mental health context. The Vancouver/Richmond Mental Health Network Society (2005) describes the potential benefits of representation agreements and advance planning:

Mark had episodes of mood disorder. Each episode created great disruption in his life... Out of desperation, Mark decided to try [advance planning]. He asked four members of his extended family to act as his Representatives. He divided their responsibilities into three major areas: health care, financial affairs and employment. He very clearly described the circumstances that would signal his Representatives to act on his behalf and also said what he wanted them to do. His doctor agreed to help. Mark and his family members executed the agreement. His Representatives have acted on the agreement several times. They've used it to freeze bank accounts and credit cards, to help Mark get treatment and to manage his personal affairs. The banks and professionals who have been called on by the Representatives have honoured the agreement. In retrospect, Mark says that having [this binding advance planning option] 'saved his life'. He no longer has to pick up the pieces and start over after each episode of illness.

Nominated persons schemes are increasingly appearing in mental health legislation in common law countries, though each differs in the extent to which the advanced decisions are binding, and the circumstances in which they can be over-ridden (see e.g. Victorian Government, 2014b; Government of British Columbia, 1996).

The Swedish Personal Ombudsman (PO) Skåne program is another commonly cited example of supported decision-making (OHCHR, 2007: 89). The program is a form of personal advocacy for mental health service users in various areas of life (Gooding, 2013: 14). The Office of the High Commissioner for Human Rights (OHCHR, 2007: 89) recommend the PO Skåne program as an appropriate supported decision-making practice in the mental health context, given its emphasis on being facilitative rather than paternalistic. This vignette offers an example of how the program works:

After a stay in hospital, a client wanted to live in a flat of his own. Since this was the client's wish, he was supported by the PO, while many other professional involved with the client advised against it, saying that it would not work out. This

in fact turned out to be the case: the client eventually moved into housing with special support and was very happy there. Professionals in the social services and psychiatric services thought that this was an unnecessary failure, while the PO's view was that the reason why the client was so happy in the special housing was that he had been given the chance to live in his own flat (Swedish National Board of Health and Welfare, 2008: 10).

The vignette demonstrates the PO's emphasis on respecting the will and preference of the consumer in this case, rather than prioritising risk-aversion or 'best interests'-recommendations by family members or experts. It should be noted that there is little in the way of robust research on the operation of the PO scheme, at least for English language readers, including its application to Anglo-Celtic jurisdictions.

Although supported decision-making has largely developed in higher income countries – to which this paper is focused – there is emerging provision for supported decision-making in low- and middle-income countries (see Special Rapporteur for Disability, 2017; Pathare and Shields, 2012). For example, in 2017 India introduced a new Mental Health Care Act (Ministry of Law and Justice, 2017) that acknowledges that people may need varying levels of support to make decisions about their care, including the provision of a nominated person. India's Mental Health Care Act appears to be the first attempt at implementing such mechanisms (advance directives, nominated representatives) in a low- or middle-income country. In Bulgaria, a supported decision-making pilot program was conducted by various non-government organisations in cooperation with the Canadian Institute for Research and Development on Inclusion in Society (Bulgarian Centre for Not-For-Profit Law, 2014).

Supported decision-making in 'hard cases'

Critics might immediately highlight risks that cannot be said to carry dignity (e.g. a person who thinks jumping off a building will save the world, or someone who perceives no danger in walking onto a six-lane highway). These are important concerns. Yet, emphasising 'hard cases' may overshadow efforts to address the risk-aversion that can so negatively affect the lives of people who come into contact with mental health services (as well as the professionals who endeavour to support them). Supporting someone to take risks does not mean 'turning away' from someone in crisis or being prohibited from intervening in the risky scenarios described previously; instead, it invites supporters to consider the dignity that accompanies risk-taking and the personal growth that can come from making

mistakes (OHCHR, 2007), as captured in the example of the PO Skåne advocacy noted previously. Concerns may also be raised that there will be instances in which a person does not appear to be expressing *any* will or preference, or whose will and preferences are unclear or unknown. In such 'hard cases' the Committee on the Rights of Persons with Disabilities (2014: para 21) advises that respondents should be guided by the 'best interpretation' of the person's will and preference:

Where, after significant efforts have been made, it is not practicable to determine the will and preference of an individual, 'best interpretation of will and preference' must replace 'best interests' determinations.

Applying the 'best interpretation of a person's will and preference' is a work in progress (see Gooding, 2015). It is outside the scope of this paper to elaborate further, but needless to say that such a shift will challenge the traditionally risk-averse terrain of mental health policy and practice, as governments move from the majestic generalities of international human rights law to its implementation in national law, policy and practice.

Supported decision-making as ethos rather than model

As noted, although supported decision-making practices exist, the approach may be better understood as an *ethos* rather than a mechanised model to be applied in practice. In summary, supported decision-making is characterised by:

- support to strengthen self-determination, regardless of a person's apparent cognitive ability; under current laws
- viewing autonomy as relational or interdependent (and recalling that no person makes choices in a purely autonomous or individualistic manner);
- respecting so-called 'dignity of risk';
- providing an alternative to substituted decision-making, paternalism and a 'best interests' approach, and instead, being driven by the 'rights, will and preference' of those concerned;
- upholding principles of equality and non-discrimination; and
- reflecting developing human rights norms.

This list is non-exhaustive, and much has been written about what supported decision-making means in theory and practice (see e.g. Committee on the Rights of Persons with Disabilities, 2014).

Discussion

Both the shared and supported decision-making approaches have begun to appear in mental health

policy and practice throughout the world, and are likely to affect many mental health services, their staff, the people who use services, and others. Clearly there are many similarities between the two. Both emphasise self-determination and the importance of making decisions about one's own life. Both are premised on the view that decisions do not occur in a vacuum; they occur in the context of a person's relationships, whether to experts or others. This is true for people making mental healthcare treatment decisions, as it is for most, if not all, people making decisions in major areas of life, such as financial, education and housing-related decisions.

Both approaches are based on recognition that power imbalances have existed, and continue to exist, in psychiatric and other mental health services. Emergency crises inevitably occur in the mental health context, which will challenge those wishing to authentically apply either shared or supported decision-making – particularly where powers for involuntary psychiatric intervention exist. It is important to note that unexpected, complex decisions requiring rapid responses will arise no matter how well-prepared consumers, families, carers or clinicians are. However, both shared and supported decision-making seem to be premised on the view that mental health service providers should expect to involve consumers and their supporters in all relevant decisions. Ideally, clinicians will be committed to, and skilled in, facilitating this involvement. A range of tools would need to be available to improve the chances that involvement is meaningful to each individual. From a policy perspective, forms of regulation could encourage or even mandate measures to promote active involvement (e.g. service user representation on high-level decision-making bodies; accreditation rules to mandate professional training in facilitative rather than tutelary support; the kind of coalface support reflected in the CommonGround software; or the statutory recognition of advocates under the PO Skåne model). 'Active involvement' in this sense is ambiguous, and will depend on many factors, such as the resources available, the people involved, the specific issue being addressed, and so on. As such, multiple mechanisms are needed across multiple settings, from formal legal mechanisms to informal decision aids, all of which could reasonably appear in different parts of policy and practice, from legislation to healthcare and community service procedures and guidelines.

However, clear differences between the two concepts also appear. Shared decision-making emerged from healthcare provision, and is more targeted to treatment decision-making in specific circumstances. *Supported* decision-making emerged from thinking around disability and human rights, and refers to a collection of various demands for strengthening the self-determination of persons with disabilities, of which people using mental

health services are but one group making decisions in one area of their lives. Each concept brings its own ideas, values, vocabularies, practices, disciplinary leanings, and so on. Such 'baggage' will impact upon the application of either concept to policy and practice, including the measuring of successes and shortcomings.

On this latter point, consider that a randomised-control trial might be appropriate in assessing the utility of shared decision-making for improving patient outcomes. In contrast, supported decision-making is generally advanced by advocates who view autonomy and the necessary support to exercise agency as a good *in and of itself*, borne of rights inherent to all. Utility may be important, or might be important for evaluating the most 'effective' ways to apply supported decision-making, but according to human rights agencies such as the UN Committee on the Rights of Persons with Disabilities, the motive is not proving whether or not supported decision-making *works*; rather, it is about ensuring that consumers, and indeed all people with disabilities, have their rights to make decisions about their own lives respected on an equal basis with others, including being provided with the support needed to exercise that right (see Gooding, 2015: 67–70). This is not to suggest that supported decision-making will not improve outcomes – for example advance planning may well lead to lower rates of crises and hospitalisation, which would be useful to identify – merely that utility is not the driving concern. A number of other differences are noteworthy.

Many of the supported decision-making practices, such as advance planning and nominated persons schemes, require pre-planning, which may not be as useful for people who are first engaging with mental health services. In such cases, shared decision-making can happen the moment a person engages with services, because it provides consumers and clinicians with ready-made tools for collaborative decision-making. It may be that in real terms, such practices fall within the definition of *supported* decision-making – after all, a person is being supported to decide with support from clinicians and other service providers. Yet, shared decision-making tends to emphasise the clinicians role in decision-making, suggesting the decision is *shared* with the doctor. The focus turns to the partnership between the healthcare professional and consumer, advocating for them to work together to exchange the necessary information, deliberate on it and arrive at a decision together. Critics of shared decision-making may argue that this will allow healthcare professionals to have undue influence over the decision-making processes under the guise of collaborative decision-making. In contrast, supported decision-making holds that the person accessing services has the right to make their own decisions

(including refusing treatment), and the right to take risks with their decisions on an equal basis with others, regardless of others perceptions or judgements about the choice.

While this point of difference seems clear, it is important to note that the literature on shared decision-making tends to focus on the information *exchange* (i.e. the decision-making processes) rather than who actually makes the decision (Edwards & Elwyn, 2006). In addition, decision aids present information on possible outcomes if the consumer chooses to do nothing (i.e. natural course of the disorder without treatment) and this is reflected in most models of shared decision-making which stipulate that consumers should be presented with all options, including 'doing nothing'. As such, there may be more overlap here than first appears to be the case. For example, individuals who are initiating supported decision-making methods like advance statements and nominated persons, might benefit from the practical guidance and tools of shared decision-making in order to engage in collaborative processes.

It also bears repeating that the shared decision-making practices discussed in this article tend to presume a level of cognition – as related to presenting different types of research and evidence for treatment options – an emphasis that is given far less priority, if any, in supported decision-making practices. However, this is not always the case; for example, advance directives under current laws often require a certain cognitive capacity at the time of making the directive, particularly where they are authorised within mental health legislation [as is the case, for example, under the Mental Health Act 2014 (Victorian Government, 2014a, s 20(1)(d)(i)), for which accompanying documents explicitly refer to its advance directives as forms of supported decision-making (Victorian Government, 2014b)]. This highlights the contested nature of the term 'supported decision-making' between those who see it as complementary to coercive psychiatric intervention (Victorian Government, 2014b), and human rights agencies who see it as a *replacement* for coercion requiring the abandonment even of the very idea that someone lacks mental capacity (see Committee on the Rights of Persons with Disabilities, 2014). In addition, it does not seem unfeasible for shared decision-making to occur with people who may not be interested or responsive to bodies of health science research (e.g. certain consumers with intellectual disabilities, and many others without). Again, it is important to recognise the diverse uses of the terms 'shared' and 'supported' decision-making, while also recognising the social, historical, legal, political and professional contexts in which the ideas developed and are applied today.

Conclusions

Overall, there seem to be fewer differences than similarities between shared and supported decision-making. In several ways, the issue is terminological, with each concept being used by various parties to refer to a cluster of demands and practices aimed at improving the self-determination of consumers. Szmukler & Rose define self-determination in the mental health context as, 'freedom from forms of control or coercion deriving from external limitations imposed through common treatment practices and social institutions' (2015: 879). It seems reasonable to say that promoting self-determination in this way is common to both the shared and supported decision-making approaches, though the extent to which this is achieved with the specific application of each concept in different circumstances is likely to be debated. At times, the ideas and practices are likely to overlap and complement one another – seemingly, more often than not – while other times they are likely to diverge, such as in relation to coercive intervention, treatment refusal or a preference to completely disengage with services.

Terminological issues aside, there are clear conceptual differences between shared and supported decision-making, which should not be ignored. These differences seem to play out mostly along the lines of the unique history of each concept – one, emerging from health sciences, the other from developments in law and advocacy for the rights of people with disability.

From a purely pragmatic perspective, clinicians and other mental health professionals may be more likely to embrace shared decision-making given its origins in health science, and its emphasis on *sharing* decision-making with consumers. The resulting tools may be more appealing to clinicians than exhortations from human rights advocates, where clinicians are more interested in practical guidance for applying shared decision-making (e.g. checklists, accessible information for consumers, decision-making aids, and so on). In contrast, the emphasis in supported decision-making on tolerating risk, or in guaranteeing a person's right to refuse psychiatric intervention in all circumstances, may raise concerns for some professionals and others for whom assertions about human rights may not be enough to change practice. At present, many jurisdictions do not necessarily permit such an acceptance of risk (nor may professional and ethical guidelines and duties), and clinicians may raise concerns about where their duty to support risky decisions begins and ends. This tension suggests the development of shared and supported decision-making, and the connections between the two will unfold in relation to developments in law, particularly related to the CRPD and international human rights law.

There is clear scope for further research to tease out the connections and differences between shared and supported decision-making, including with more specificity – for example, looking at particular supported decision-making practices, such as advance planning or the use of nominated representatives, and integrating tools from shared decision-making practices. Such efforts, particularly with the input of service user-researchers (see Szmukler & Rose, 2015), are likely to prove fruitful in strengthening the self-determination of consumers across law, policy and practice, and in transforming public perceptions of distress, disorder and disablement more broadly.

Financial Support

P.M.G. has received no funding for the writing of this article, except in his capacity as Postdoctoral Research Fellow at the Melbourne Social Equity Institute and Melbourne Law School at the University of Melbourne. M.B.S. is supported by a Melbourne Research Fellowship from The University of Melbourne.

Ethical Standards

No human research ethics approval was required for this research. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

References

- Alambuya R, Ali S, Apostolidis K, Beinfeld M, Bijwe S, R, Bravo P, Brocklehurst W, Davis R, Dhir A, Dodd CR, Durand MA, Eaton S, Faber M, Fisler CM, Ford PA, Westrick MG, Nikovska DG, Hendy MA, Johnson C, Johnstone R, Laitner S, Lam LS, Lee DM, Lynch HF, Mankeekar PC, Mbaabu LM, McCay L, Monti M, Moulton BW, Muthambi TC, Paguio J, Richards T, Sawicki NN, Talpade MS, Tunick R, Volbracht E, Wade BH, Wexler RM, Xu B, Barry M, Clay K, Coulter A, Dixon J, Edgman-Levitan S, Elwyn G, Gigerenzer G, Mangione C, Moynihan R, Mulley A, Schwitzer G, Stiggelbout A, Wennberg J, Bachleitner K, Lotherington J, Strangmann S (2011). Salzburg statement on shared decision making. *British Medical Journal* 342, d1745.
- Alegria M, Polo A, Gao S, Santana L, Rothstein D, Jimenez A, Hunter ML, Mendieta F, Oddo V, Normand SL (2008). Evaluation of a patient activation and empowerment intervention in mental health care. *Medical Care* 46, 247–256.

- Aljumah K, Hassali MA** (2015). Impact of pharmacist intervention on adherence and measurable patient outcomes among depressed patients: a randomised controlled study. *BMC Psychiatry* **15**, 219.
- Arstein-Kerslake A, Watson J, Browning M, Martinis J, Blanck P** (2017). Future directions in supported decision-making. *Disability Studies Quarterly* **37**, 37.
- Australian Health Ministers' Advisory Council** (2013). *A National Framework for Recovery-Oriented Mental Health Services: Guide for Practitioners and Providers*. Australian Health Ministers' Advisory Council: Canberra.
- Bulgarian Centre For Not-For-Profit Law** (2014). Supported decision making or how people with intellectual disabilities and mental health problems can live independent lives (<http://bapid.com/bapid/wp-content/uploads/2014/08/Supported-decision-making.pdf>). Accessed 9 October 2017.
- Care Quality Commission** (2015). Monitoring the Mental Health Act in 2014/15 (www.gov.uk/government/publications). Accessed 9 October 2017.
- Clever SL, Ford DE, Rubenstein LV, Rost KM, Meredith LS, Sherbourne CD, Wang NY, Arbelaez JJ, Cooper LA** (2006). Primary care patients' involvement in decision-making is associated with improvement in depression. *Medical Care* **44**, 398–405.
- Committee on the Rights of Persons with Disabilities** (2014). General Comment No 1: Article 12: Equal Recognition Before the Law, 11th sess, UN Doc CRPD/C/GC/1.
- Deegan PE** (2005). The importance of personal medicine: a qualitative study of resilience in people with psychiatric disabilities. *Scandinavian Journal of Public Health. Supplement* **66**, 29–35.
- Deegan PE** (2007). The lived experience of using psychiatric medication in the recovery process and a shared decision-making program to support it. *Psychiatric Rehabilitation Journal* **31**, 62–69.
- Deegan PE** (2010). A web application to support recovery and shared decision making in psychiatric medication clinics. *Psychiatric Rehabilitation Journal* **34**, 23–28.
- Dixon LB, Glynn SM, Cohen AN, Drapalski AL, Medoff D, Fang LJ, Potts W, Gioia D** (2014). Outcomes of a brief program, REORDER, to promote consumer recovery and family involvement in care. *Psychiatric Services* **65**, 116–120.
- Drake RE, Deegan PE** (2009). Shared decision making is an ethical imperative. *Psychiatric Services* **60**, 1007.
- Edwards A, Elwyn G** (2006). Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy* **9**, 307–320.
- Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, Cording E, Tomson D, Dodd C, Rollnick S, Edwards A, Barry M** (2012). Shared decision making: a model for clinical practice. *Journal of General Internal Medicine* **27**, 1361–1367.
- Elwyn G, Lloyd A, May C, Van Der Weijden T, Stiggelbout A, Edwards A, Frosch DL, Rapley T, Barr P, Walsh T, Grande SW, Montori V, Epstein R** (2014). Collaborative deliberation: a model for patient care. *Patient Education and Counseling* **97**, 158–164.
- Elwyn G, Tsulukidze M, Edwards A, Legare F, Newcombe R** (2013). Using a 'talk' model of shared decision making to propose an observation-based measure: observer OPTION 5 Item. *Patient Education and Counseling* **93**, 265–271.
- Gooding P** (2013). Supported decision-making: a rights-based disability concept and its implications for mental health law. *Psychiatry, Psychology and Law* **20**, 431.
- Gooding P** (2015). Navigating the "flashing amber lights" of the right to legal capacity in the *United Nations Convention on the Rights of Persons with Disabilities*: responding to major concerns. *Human Rights Law Review* **15**, 45.
- Goossensen A, Zijlstra P, Koopmanschap M** (2007). Measuring shared decision making processes in psychiatry: skills versus patient satisfaction. *Patient Education and Counseling* **67**, 50–56.
- Goss C, Fontanesi S, Mazzi MA, Del Piccolo L, Rimondini M, Elwyn G, Zimmermann C** (2007). Shared decision making: the reliability of the OPTION scale in Italy. *Patient Education and Counseling* **66**, 296–302.
- Government of British Columbia** (1996). Representation Agreement Act R.S.B.C. 1996 c 405.
- Greenhalgh T, Snow R, Ryan S, Rees S, Salisbury H** (2015). Six "biases" against patients and carers in evidence-based medicine. *BMC Medicine* **13**, 1.
- Hamann J, Cohen R, Leucht S, Busch R, Kissling W** (2005). Do patients with schizophrenia wish to be involved in decisions about their medical treatment? *The American Journal of Psychiatry* **162**, 2382–2384.
- Hamann J, Cohen R, Leucht S, Busch R, Kissling W** (2007). Shared decision making and long-term outcome in schizophrenia treatment. *The Journal of Clinical Psychiatry* **68**, 992–997.
- Hamann J, Langer B, Winkler V, Busch R, Cohen R, Leucht S, Kissling W** (2006). Shared decision making for in-patients with schizophrenia. *Acta Psychiatrica Scandinavica* **114**, 265–273.
- Henderson C, Flood C, Leese M, Thornicroft G, Sutherby K, Szmukler G** (2004). Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial. *British Medical Journal* **329**, 136.
- Hoffmann TC, Legare F, Simmons MB, Mcnamara K, Mccaffery K, Trevena LJ, Hudson B, Glasziou PP, Del Mar CB** (2014). Shared decision making: what do clinicians need to know and why should they bother? *The Medical Journal of Australia* **201**, 35–39.
- Human Rights Committee** (2016). Promotion and Protection of All Human Rights, Civil, Political, Economic, Social and Cultural Rights, including the Right to Development, 32nd sess, UN Doc A/HRC/32/L.26 (adopted 29 June 2016).
- Johnson S** (2013). Can we reverse the rising tide of compulsory admissions? *The Lancet* **381**, 1603.
- Joosten EA, De Jong CA, De Weert-Van Oene GH, Sensky T, Van Der Staak CP** (2009). Shared decision-making reduces drug use and psychiatric severity in substance-dependent patients. *Psychotherapy and Psychosomatics* **78**, 245–253.

- Joseph-Williams N, Lloyd A, Edwards A, Stobbart L, Tomson D, Macphail S, Dodd C, Brain K, Elwyn G, Thomson R (2017). Implementing shared decision making in the NHS: lessons from the MAGIC programme. *British Medical Journal* 357, j1744.
- Le Blanc A, Herrin J, Williams MD, Inselman JW, Branda ME, Shah ND, Heim EM, Dick SR, Linzer M, Boehm DH, Dall-Winter KM, Matthews MR, Yost KJ, Shepel KK, Montori VM (2015). Shared decision making for antidepressants in primary care: a cluster randomized trial. *JAMA Internal Medicine* 11, E1–E10.
- Loh A, Simon D, Hennig K, Hennig B, Harter M, Elwyn G (2006). The assessment of depressive patients' involvement in decision making in audio-taped primary care consultations. *Patient Education and Counseling* 63, 314–318.
- Loh A, Simon D, Wills CE, Kriston L, Niebling W, Harter M (2007). The effects of a shared decision-making intervention in primary care of depression: a cluster-randomized controlled trial. *Patient Education and Counseling* 67, 324–332.
- Mccaffery KJ, Holmes-Rovner M, Smith SK, Rovner D, Nutbeam D, Clayman ML, Kelly-Blake K, Wolf MS, Sheridan SL (2013). Addressing health literacy in patient decision aids. *BMC Medical Informatics and Decision Making* 13 (Suppl. 2): S10.
- Mckinstry B (2000). Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *BMJ (Clinical Research Ed.)* 321, 867–871.
- Ministry of Law and Justice (2017). The Mental Healthcare Act (India), 2017 no. 10.
- Minkowitz T (2006). No-force advocacy by users and survivors of psychiatry. Mental Health Commission New Zealand. (www.mhc.govt.nz). Accessed 9 October 2017.
- Minkowitz T (2010). Abolishing mental health laws to comply with the convention on the rights of persons with disabilities. In *Rethinking Rights-Based Mental Health Laws* (ed. B. McSherry and P. Weller), pp. 151–177. Portland: Hart.
- Morant N, Kaminskiy E, Ramon S (2016). Shared decision making for psychiatric medication management: beyond the micro-social. *Health Expectations* 19, 1002–1014.
- Mulley AG, Trimble C, Elwyn G (2012). Stop the silent misdiagnosis: patients' preferences matter. *British Medical Journal* 345, e6572.
- Muscat DM, Morony S, Shepherd HL, Smith SK, Dhillon HM, Trevena L, Hayen A, Luxford K, Nutbeam D, Mccaffery K (2015). Development and field testing of a consumer shared decision-making training program for adults with low literacy. *Patient Education and Counseling* 98, 1180–1188.
- Office of the High Commissioner for Human Rights (OHCHR) (2007). Chapter 6: From provisions to practice: implementing the Convention, Legal Capacity and Supported Decision-Making. In *United Nations Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities*. OHCHR: Geneva. (www.un.org).
- O'Neal EL, Adams JR, Mchugo GJ, Van Citters AD, Drake RE, Bartels SJ (2008). Preferences of older and younger adults with serious mental illness for involvement in decision-making in medical and psychiatric settings. *American Journal of Geriatric Psychiatry* 16, 826–833.
- Pathare S, Shields LS (2012). Supported decision-making for persons with mental illness: a review. *Public Health Reviews* 34, 15.
- Patient Protection and Affordable Care Act (2010). 42 U.S.C. § 18001 et seq.
- Perestelo-Perez L, Rivero-Santana A, Sanchez-Afonso JA, Perez-Ramos J, Castellano-Fuentes CL, Sepucha K, Serrano-Aguilar P (2017). Effectiveness of a decision aid for patients with depression: a randomized controlled trial. *Health Expectations* 20, 1096–1105.
- Shepherd H, Barratt A, Trevena L, Mcgeechan K, Carey K, Epstein R, Butow P, Del Mar C, Entwistle V, Tattersall M (2011). Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial. *Patient Education and Counseling* 84, 379–385.
- Simmons MB, Batchelor S, Dimopoulos-Bick T, Howe D (2017). The choice project: peer workers promoting shared decision making at a Youth Mental Health Service. *Psychiatric Service*, 68, 764–770.
- Simmons MB, Hetrick SE, Jorm AF (2011). Experiences of treatment decision making for young people diagnosed with depressive disorders: a qualitative study in primary care and specialist mental health settings. *BMC Psychiatry* 11, 194.
- Simon D, Kriston L, Von Wolff A, Buchholz A, Vietor C, Hecke T, Loh A, Zenker M, Weiss M, Harter M (2012). Effectiveness of a web-based, individually tailored decision aid for depression or acute low back pain: a randomized controlled trial. *Patient Education and Counseling* 87, 360–368.
- Slade M, Adams N, O'Hagan M (2012). Recovery: past progress and future challenges. *International Review of Psychiatry* 24, 1–4.
- Stacey D, Legare F, Col NF, Bennett CL, Barry MJ, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L, Wu JH (2014). Decision aids for people facing health treatment or screening decisions. *The Cochrane Database of Systematic Reviews* 1, CD001431.
- Swedish National Board of Health and Welfare (2008). A New Profession is Born – Personligt ombud, PO. Västra Aros, Västerås (www.personligtombud.se).
- Szmukler G, Rose D (2015). Strengthening Self-Determination of Persons with Mental Illness. In *Handbook of Neuroethics* (ed. J. Clausen and N. Levy), pp. 879–895. Springer: London.
- United Nations (2006). *The Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, Doc. A/61/611 (entered into force 3 May 2008). United Nations: Geneva.
- Vancouver/Richmond Mental Health Network Society (2005). Representation agreements and supported decision-making (<http://francais.camhr.ca/communications/repagreements.html>). Accessed 8 October 2017.
- Veroff D, Marr A, Wennberg DE (2013). Enhanced support for shared decision making reduced costs of care for patients

- with preference-sensitive conditions. *Health Affairs (Millwood)* **32**, 285–293.
- Victorian Government** (2014a). Mental Health Act 2014, No. 26.
- Victorian Government** (2014b). Recovery and supported decision-making. In *Mental Health Act 2014 Handbook*. (<https://www2.health.vic.gov.au/mental-health/practice-and-service-quality/mental-health-act-2014-handbook>).
- Weller P** (2008). Supported decision-making and the achievement of non-discrimination: the promise and paradox of the disabilities convention. *Law in Context* **26**, 85–110.
- Weller P** (2013). *New Law and Ethics in Mental Health Advance Directives: The Convention on the Rights of Persons with Disabilities and the Right to Choose*. Routledge, London.
- Westermann GM, Verheij F, Winkens B, Verhulst FC, Van Oort FV** (2013). Structured shared decision-making using dialogue and visualization: a randomized controlled trial. *Patient Education and Counseling* **90**, 74–81.
- Woltmann EM, Wilkniss SM, Teachout A, Mchugo GJ, Drake RE** (2011). Trial of an electronic decision support system to facilitate shared decision making in community mental health. *Psychiatric Services* **62**, 54–60.