

NICE shared decision making guidelines and mental health: challenges for research, practice and implementation

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The National Institute for Health and Care Excellence (NICE) initiated an ambitious effort to develop the first shared decision making guidelines. The purpose of this commentary is to identify three main concerns pertaining to the new published guidelines for shared decision making research, practice, implementation and cultural differences in mental health.

Keywords

Patients; shared decision making; serious mental illness; NICE; policy.

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The National Institute for Health and Care Excellence (NICE) has a rich history of developing guidelines that tend to become ‘gold standards’ for healthcare practices and policies that are being adopted worldwide. The NICE formally adopted shared decision making (SDM) in 2015 as an important practice and goal in healthcare, and formed the SDM Collaborative, making NICE one of the first national health institutes globally to formally support SDM practice and research.¹ SDM aims to facilitate patient-centred care and treatment adherence by promoting joint treatment decision-making between patients with chronic conditions and clinicians.² In mental healthcare, SDM has been recommended for people with serious mental illness (SMI), given that self-determination, choice and autonomy are core aspects of recovery-oriented care.^{3,4}

In December of 2018, NICE initiated an ambitious and important effort to develop the first guidelines for SDM in multiple physical and healthcare contexts. The hope is that the new guidelines, integrating ‘top-down’ theory and recommendations for patient engagement with ‘bottom-up’ patient and public feedback, will result in relevant, usable, acceptable and feasible guidance to facilitate SDM. The guidelines¹ are based on five evidence documents focusing on the following: effectiveness of approaches and activities to increase engagement in SDM and the barriers and facilitators to engagement (Evidence Document A), interventions to support effective SDM (Evidence Document B), decision aids for people facing health treatment or screening decisions (Evidence Document C), risk communication (Evidence Document D) and effective approaches and activities to normalise SDM in the healthcare system (Evidence Document E).⁵ The purpose of this commentary is to share three main concerns pertaining to the implications of the new NICE guidelines on SDM in mental health (based on Evidence Documents A, B and E) that specifically affect the research, practice and implementation of SDM in mental health.

Bias in the selection of qualified evidence for what is considered SDM in mental health

Our main concern is with bias in the presentation of what is considered representative evidence for effective SDM mental health research and practice, and, specifically, in SMI (e.g. schizophrenia, bipolar disorder, major depressive disorder), and its implications for the evolving research on SDM in mental health. The search

criteria adopted by NICE exclude studies conducted with people in ‘situations in which people lack mental capacity to make their own decisions about healthcare at that time’.¹ This is a problematic decision that excludes those considered to be ‘without capacity’ from engaging in the SDM process. It dismisses *a priori* evidence for rich SDM research with individuals with SMI,^{3,6–8} and enhances stigmatic beliefs about the ability of individuals with SMI and other concerns regarding capacity to engage in an SDM process, an assumption that is not yet evidence-based.^{9,10} As a result, the NICE recommendations for effectiveness approaches and activities to increase engagement in SDM (Evidence Document A) are based on only eight quantitative studies of SDM in mental health and ten qualitative studies. Of the included quantitative studies, only six^{11–16} are relevant to SMI and addressed SDM in community mental health settings (the others focused on primary care or patients with behavioural health issues¹⁷ or patients with dementia¹⁸). Only one quantitative study measuring recovery,¹⁶ a primary goal and outcome in mental health that is associated with SDM,^{19–21} was included. Of the included qualitative studies,^{22–31} only four^{24–26,28} involved the perspectives and attitudes of patients or individuals with mental health conditions on SDM (the rest addressed providers’ perspectives^{22–25,27–31}), and most of these qualitative studies were valued by the NICE as having a high^{22,27,28} to moderate^{23,24,26} risk of bias.

SDM research in mental health has evolved rapidly in the past two decades,³ presenting one of the fastest growth curves in SDM research and practice. The first call for clinicians, patients and the scientific community to adopt SDM into mental health was in 2003, with a first overview of SDM in mental health introducing the concept and providing legitimacy of, and justification for, doing SDM in psychiatry.³² In 2010, a second review was published,⁶ identifying two German randomised controlled studies of SDM, one conducted in an acute in-patient psychiatric setting^{33,34} and the other in a community primary care setting.³⁵ In 2017, a third review was published, including 31 unique studies, of which 20 were research articles evaluating SDM interventions.³ The latter demonstrated, for the first time, the heterogeneity of SDM tools and interventions for individuals with mental health conditions, including those with an SMI, and described a wide array of settings, research designs and various SDM in mental health outcomes, calling for an expansion of the narrow view of what can be considered SDM in mental health intervention and outcomes.³

Thus, the limited number of included SDM in mental health studies in the NICE guidelines is not representative of the richness of SDM research in mental health, its focus or its quality. Recommendations drawn on such a small poll of studies lag behind the emerging and developing field of research and practice, create a narrow representation of SDM in mental health, and lead to bias in future research and practice of SDM in mental health when designing and testing interventions, tools and measures.

Bias in the selection of qualified outcomes and study designs for SDM in mental health studies

Compared with the limited number of included SDM in mental health studies, several important studies were excluded owing to a lack of high-quality evidence because of either a failure to present an objective primary outcome of SDM as defined by the NICE,^{36–38} the study design^{38,39} or the involvement of non-certified clinicians (e.g. peer workers) as the SDM providers.⁴⁰

What are the qualified outcomes of SDM in mental health?

The primary outcomes of SDM in mental health are often differ from outcomes in non-mental health studies (such as SDM use, knowledge and conflict level), and involve a focus on goals important to the field, such as empowerment, self-determination and recovery.^{19,41,42} Such outcomes are considered successful goals of SDM in mental health because of the many unique barriers to conducting SDM in mental health that exist at all levels (patients, clinicians, organisations and policy),^{43,44} making the mere act of engaging in an SDM process meaningful for empowering patients and promoting their recovery and self-determination.^{42,45} Therefore, in mental health research, SDM tools and interventions are often used to increase outcomes of empowerment, recovery, self-determination and hope, rather than to reduce decisional conflicts or increase knowledge^{2,8,19,32,38} – the ‘classical’ primary outcomes of interest common in non-mental-health SDM research.⁴⁶ The lack of validated SDM measures uniquely developed to assess SDM in mental health is another factor contributing to the limited use of classical SDM outcomes in many studies of SDM in mental health. Since most existing measures for SDM in mental health were adapted or ‘borrowed’ from SDM studies in chronic physical illness (e.g. diabetes or cancer),⁴⁶ the measured SDM output is often less relevant, meaningful and useful for assessing an SDM process in mental health.

What research designs are appropriate for conducting SDM in mental health research?

Although the NICE inclusion criteria prioritised ‘randomised controlled trials (RCTs), well-designed quasi-experimental studies (quasi-RCTs), controlled clinical trials (CCTs), controlled before and after studies (CBAs) and interrupted time series analyses (ITS)’ (Evidence Document A), only randomised controlled trials or cluster randomised controlled trials were included in this review. We acknowledge the importance of randomised controlled trials as the ‘gold standard’ for causal evidence in health research. However, in health behavioural intervention studies, quasi-experimental designs are often the preferred alternative to generate strong causal evidence when blind randomisation is not feasible (e.g. because of ethical considerations, difficulty of randomising participants, difficulty randomising by location and small available sample size), and this is particularly true for studies of SDM in mental health.⁴⁷ The nature of many SDM interventions in mental health studies,³ which focus on the humanistic live

and interpersonal interaction between two participants (provider and patient), is particularly sensitive to risk of contamination and bias between the intervention and the control conditions because of the inherent processes that alter behaviour over time and may lead to type 2 error.⁴⁸ Therefore, non-randomised quasi-research designs may be preferred and more common for SDM in mental health research. Excluding studies based on their non-RCT research design may contribute to bias in representing the evidence for effective SDM interventions in mental health.

Interestingly, NICE’s focus on ‘primary objective criteria’ had led the committee to conclude that ‘as the primary outcome of “use of SDM” was not shown to be achieved, the secondary outcomes would not help inform the results of this review and therefore on the basis of the quantitative review, the committee were not able to recommend any interventions to increase engagement in SDM as effective’ and ‘based on the lack of robust quantitative evidence of the effectiveness of interventions, and the committee’s lack of confidence in the quantitative data, the qualitative data was used as a guide for creating recommendations’ (Evidence Document A: The committee’s discussion of the evidence). These conclusions provide further support for the bias selecting evidence based on narrow criteria addressing the type of primary outcomes and study design. At least in the mental health field, some of the studies excluded because of their design, outcome and focus could have proved invaluable when summarising the available SDM literature and developing recommendations.

Bias in addressing cultural differences in SDM practice

The articles in Evidence Document B focused on SDM interventions. The search criteria adopted by the NICE exclude ‘non-English language papers’ studies conducted in ‘Non-OECD countries.’ As a result, only nine studies of SDM in mental health conducted in five Western countries, were included: USA,^{14,17} Germany,^{49,50} The Netherlands,^{12,51} Saudi Arabia⁵² and Japan.^{16,53} The majority of study populations included people of White or Northern European descent, or those belonging to a majority group in a given country. Thus, and based on the limited included SDM studies in mental health, there are no practical recommendations on the inclusion of culturally appropriate SDM recommendations for mental health practice. Facing a medical and ethical urgency to include Black, Asian and minority ethnic groups in clinical studies of SDM, randomised controlled trials have been recently cited as a potential source of structural racism and discrimination in healthcare research.^{54–57} Black, Asian and minority ethnic people are often more suspicious of participation in clinical controlled trials because of historic events (e.g. the Tuskegee syphilis study) and more current actions, including socioeconomic and healthcare system inequities.⁵⁷ Expanding the definition of SDM in mental health to additional outcomes, decisions, populations and more naturalistic quasi-research design could have expanded the scope of the included articles, allowing better representation of cultural and ethnic diversity when conducting SDM research.³

To summarise, the upcoming NICE SDM guidelines represent a positive and important effort for patients, healthcare providers and families, policy makers and SDM researchers. We understand that in an effort to draw conclusions, there is a need to define clear boundaries between what is considered the gold standard in SDM evidence, tools and practice. Yet, we feel that with regard to SDM in mental health, the upcoming NICE recommendations are simplified, lag behind the emerging and developing field of research and practice, and create a narrow representation of SDM in mental health. The recommendations are also strongly biased toward Western countries and culture, as well as being White or belonging to a majority group.^{58–61} Considering the international impact of

NICE guidelines on SDM practice, and since many studies of SDM in mental health fall outside of the NICE inclusion criteria, we worry that this narrow representation of SDM will become the gold standard, overlooking other effective research and interventions of SDM in mental health. For example, the NICE guidelines ignore the concept of shared advance decision making in mental health, SDM around decisions about advance care planning^{62,63} and the significant body of literature in mental health around the Joint Crisis Plan.^{64,65}

We call on the NICE to revise their SDM recommendations for SDM studies, or at least to acknowledge that there exist other forms, designs and outcomes important for successful SDM in mental health. We hope that our call will foster an open and diverse discussion about the concept of SDM in mental health, the goals of SDM in mental health, define desired outcomes, support development of appropriate measures, acknowledge the needed diversity in research designs and address issues related to cultural relevancy.

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All authors substantially contributed to the conception of the article. Y.Z.-I. and M.C. reviewed the policy. Y.Z.-I. drafted the manuscript. L.D. and S.R. provided valuable feedback on the manuscript. All authors approved the manuscript before submission.

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