1 Mental Health Pharmacists views on Shared

Decision-Making for Antipsychotics in Serious

Mental Illness

INTRODUCTION

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At least one in four people in the UK will experience a mental health problem and up to two percent of the population will be diagnosed with a serious mental illness (SMI) during their lifetime (1). For the purposes of this research SMI is considered to include diagnoses that are treated with antipsychotics, typically schizophrenia and bipolar affective disorder (2). The adverse effects of antipsychotics can decrease adherence rates (3). Adherence, the currently accepted term used for medication-taking behaviour, is defined 'as the extent to which the patient's action matches the agreed recommendations' (4). Adherence presumes agreement about the proposed medication, between the prescriber and the person taking the medicine, emphasising the importance of shared decision-making (SDM; 4). A third to a half of all medications for long-term conditions are not taken as recommended, and treatment adherence is one of the biggest challenges in mental health (4,5). Adherence in SMI is very poor; estimated nonadherence rates for people diagnosed with schizophrenia range from 40 to 75% (6,7). Studies have found that 75% of people with chronic schizophrenia discontinue their medication within 18 months (8) and non-adherence rates in bipolar disorder ranges between 20 to 60% with a mean of 41% (9,10). Antipsychotic prescribing lends itself to SDM, because the adverse event profile is the main factor in the choice of antipsychotics (11). SDM is defined by the NHS as 'the conversation that happens between a patient and their healthcare professional to reach a healthcare choice together', where both parties consider what is important to the other when selecting treatment. There are ethical, clinical and economic arguments for SDM (12); it represents a method of healthcare communication that promotes patient-centred care and sharing expertise between clinicians and service users (13,14). The most accepted model is that of Charles and colleagues, which emphasises patient autonomy, informed consent and empowerment (15). SDM is founded on partnership and opposed to a paternalistic model of healthcare (16). A recent Department of Health White Paper stated that 'care should be personalised to reflect peoples' needs, not those of the professional or the system' and patients

39 should be involved in treatment decisions (17). People diagnosed with SMI can be fully engaged 40 with making decisions and seek a more collaborative approach, thus treatment decisions should be 41 made by the service user and the healthcare professional working together and considering both the 42 likely benefits and possible adverse effects of the medication (11,18). 43 SDM has been linked to improved quality of care and service user satisfaction (19,20). However, 44 the evidence base supporting the use of SDM for chronic conditions, notably mental health (21) 45 and the use of SDM for decisions made on multiple occasions over the longer-term is limited. 46 Hamann (2006) found that SDM increased knowledge and perceived involvement in treatment in 47 inpatients with schizophrenia (22). However, SDM failed to show long-term benefits in the same 48 study (23). A Cochrane review found that no conclusions could be drawn regarding the 49 effectiveness of SDM interventions for people with mental health problems and highlighted the urgent need for more research (13). A more recent study found that although a pharmacist 50 51 intervention based on SDM significantly improved adherence, treatment satisfaction and beliefs 52 about medication in people with depression, it had no significant effect on depressive symptoms 53 (24).54 Both service users and clinicians appear to support SDM (25). However, only 32% of service users 55 report that their views about treatment were considered 'to some extent' and less than half (43%) 56 were informed about adverse effects, suggesting clinicians are not engaging in SDM (26). The lack 57 of a multi-disciplinary approach and the perceived difficulty of implementing SDM with service 58 users who may lack insight are barriers to SDM across mental healthcare (21,27). In addition, there 59 are structural obstacles to collaborative care in psychiatry which include timely access to relevant, 60 reliable clinical information, and therefore research is vital to understand the practicalities of SDM 61 in practice (21,28,29). 62 Whilst experiences of and attitudes of consultant psychiatrists towards shared decision making in 63 antipsychotic prescribing have been studied, qualitative data on the views of other key groups of 64 healthcare professionals involved in medication management across mental health services, 65 including pharmacists, is lacking (21). This study aimed to understand the views and opinions of

mental health pharmacists in the UK who are increasingly developing clinical roles. These clinical roles include; advising prescribers and clinicians on the most appropriate medication after interviewing patients; patient education and advocacy; attending and directly inputting into multidisciplinary meetings. These roles are generally independent from the prescribing process although a limited number of pharmacists may have a caseload with a prescribing role.

AIM

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- 72 To elucidate the experiences and opinions of mental health pharmacists about implementing SDM
- in the process of antipsychotic choice and prescribing in SMI.

74 ETHICS APPROVAL

75 The project received approval from the Aston University Ethics Committee.

76 **METHODS**

77 Design

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- An exploratory qualitative study design that followed COREQ (Consolidated Criteria for
- 79 Reporting Qualitative studies) guidelines (30) was employed.

Participant Recruitment and Consent

Mental health pharmacists with a minimum of 12 months experience in mental health pharmacy practice were recruited, on the basis that they are more likely to have an understanding of SDM and be undertaking advanced clinical roles. Participants were recruited from the Midlands region of the UK. Initially convenience sampling was used; known contacts meeting the inclusion criteria were identified (31). Further participants were recruited through active snowballing (32). Potential participants were emailed with the project aims and participation requirements. Written informed consent was obtained prior to participation.

Inclusion Criteria

Mental health pharmacists with a minimum of 12 months experience in mental health pharmacy practice.

Interview Structure and Collection

A semi-structured interview was used to allow the interviews to be participant-led and participants to express their views openly (33,34,35). An initial interview topic guide, based on the literature on research into SDM in mental health, was constructed to focus the interviews (36). This guide was reviewed and amended by the academic supervisor (IM) and two practising mental health pharmacists (NH, DS; see appendix 1 for schedule). The schedule was adapted following each interview, using an iterative approach (37,38). Participants were given a chance to provide feedback and suggest questions to be included in the topic guide. Eleven face-to-face and two phone interviews were conducted; each lasted between twenty and thirty five minutes. These 13 interviews were deemed sufficient to provide the necessary identification of themes. The transcripts were reviewed after each interview and data saturation was perceived to have been met as no new themes were identified in the last set of interviews (39). Interviews were audio recorded and a verbatim account produced from these recordings (40). The recordings were checked against the transcripts several times (41).

Data Analysis

Thematic analysis, based on the identification of themes, was conducted by MY (34). The transcripts were independently reviewed by IM; any disagreements on the coding scheme were resolved by discussion between IM and MY.

The constant comparison method informed by grounded theory was used whereby the data analysis takes place alongside data collection (42,43). Each interview was reviewed before the next commenced to identify emerging patterns in the data and assist structuring of further interviews (33). Coding took place in three stages (35,44), as follows:

114 Open coding was used to identify themes; coding and categories were refined. Axial coding was then used. Extracts were photocopied from the original data and 115 116 arranged with the codes together in files. 117 Selective coding was used; data was analysed and re-organised. Themes were arranged 118 according to their relation to the research question. 119 Reflexivity 120 Qualitative research as a process necessitates and acknowledges the key role of reflexivity, and the 121 important role played by any researcher's background, perceptions and interests in the topic 122 (72,73). Within this study, the interviews were conducted by a female pharmacy undergraduate 123 student of Indian sub-continent descent. In preparation for the study, the student received training 124 in research methods including qualitative research, supervisory guidance during the development 125 of the interview schedule and support from the research team in relation to the interpretation and 126 analytic process. 127 128 **RESULTS** 129 Fifteen participants were recruited but two interviews didn't take place due to time constraints. Of 130 the 13 participants interviewed the majority were aged between 30 and 40 years old (six of the 11

135 <u>1. Attitudes to Shared Decision Making</u>

and the role of mental health pharmacists.

136 Pharmacist Attitudes

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participants who reported this information). Ten participants were female and three were male.

Four main themes were identified: attitudes to SDM; barriers to implementation; benefits of SDM;

137 Almost all the pharmacists felt SDM was a positive concept and supported its use in antipsychotic prescribing. 138 139 'I totally support the idea...they're powerful drugs therefore....patients should have the 140 opportunity to articulate what factors are most important to them and this should be taken into 141 consideration when choosing treatment'. (In01) 142 The complexity of antipsychotic use was recognised, with reference in particular to side effects and 143 the impact on adherence rates. For these reasons, patient choice was highlighted as being 144 particularly important: 145 'The choice should be dependent on what the patient will tolerate in regards to side effects'. (In13) 146 The pharmacists believed that it was important to involve service users in the discussion, even if 147 agreement could not be reached. 'We get that quite a lot. We have involved them in the treatment plan but they might not agree still 148 with the decision that we have tried to involve them with'. (In06) 149 150 However, some pharmacists viewed SDM as a tool to achieve adherence, to persuade the patient to take the medication, rather than an agreement negotiated between two equal parties. 151 152 'A few cases it has helped but we still need to persist in getting them to take their medication so it's 153 still an issue. Once they realise that medication is important they feel better then hopefully...sometimes when we have given them a lot of choice the patient seems to change their 154 155 mind a lot'. (In06) 156 The views of Pharmacists on the Attitudes of Prescribers 157 Pharmacists believed that attitudes towards SDM amongst prescribers were variable. 'There's a very broad church amongst (prescribers)...some are excellent and some have the view 158 the patients should do as they're told'. (In04) 159

160	The majority, however, felt that there had been a positive cultural shift, with attitudes moving
161	towards greater service user involvement.
162	'Attitudes have definitely changed in my 16 years in mental health, early on it was very muchI'm
163	the doctor and this is what's right. I think health as a whole has shiftedengaging with the patient
164	a lot more. At one timeit wasif you tell patients about side effects they won't take the
165	medication'. (In03)
166	However, some pharmacists felt that SDM was not practised as widely as it should be due to the
167	perceived difficulties in relation to patient engagement:
168	'I'm not sayingthey don't want to involve patients but I think it's because of the difficulty of
169	engaging patients'. (In11)
170	The views of Pharmacists on the Attitudes of Service Users
171	The pharmacists also believed that the attitudes of service users towards SDM were variable; some
172	service users were seen to want involvement in the decision-making process whereas others
173	preferred the clinicians to make the decisions.
174	'Some patients want to be told what to do; other patients wantto make the decision themselves'.
175	(In04)
176	There was, however, a general consensus amongst the pharmacists that service users, particularly
177	younger service users, were increasingly wanting to be involved in the decision-making process
178	and have more choice, partly due to changes in society.
179	'They crave that involvement andempowermentin a largely consumerist society people want
180	and expect choice andmore autonomy'. (In01)
181	2. Barriers to Implementation of SDM

Capacity and Insight

183	A lack of service user insight was seen by the participants as an obstacle to SDM.
184	'If they don't have insightit doesn't matter what decision you make or information you give
185	(them)(if they believe that) there's nothing wrong with them they don't need to take treatment.'
186	(InO4)
187	Several pharmacists highlighted the fact that when treatment decisions (initiation, dose change or
188	switching) are frequently made, that service users are often acutely unwell and so these are times
189	of difficulty in relation to SDM. Moreover, if they are detained under the mental health act then
190	treatment decisions may be imposed on the service user as being in their best interests rather than
191	attempting to overcome the barriers associated with SDM at these points:
192	'They might be acutely unwellthey might not be in a position to make a decision they might be
193	forced to have treatment against their wishes so in that scenario you're not going to be able to
194	provide them with SDM'. (In03)
195	When medication regimes were working well, there was often hesitancy from clinicians to make
196	changes.
197	'Switching a treatment when they have been stabilised a long period of time is actually a very
198	scary thing to do.' (In13)
199	However, the majority of pharmacists felt that SDM could be implemented with most of the
200	service users, most of the time:
201	'If you are flexible in your approachbut nevertheless you can still have some degree of
202	conversation to enable them to be a part of the SDM process the vast majority of the time.' (In07)
203	Time
204	Time was a key barrier to SDM. Pharmacists believed that clinicians often did not have the
205	opportunity to speak to service users or time to fully implement techniques of SDM:

206 'It takes a lot longer than just writing a prescription.' (In06) 207 Such time pressures were increasingly problematic with services experiencing high demand: 'There's always a demand for beds, it does have an impact on SDM.' (In05) 208 209 'Not having the time in outpatient clinics.' (In13) 210 3. Potential Benefits of SDM **Adherence** 211 212 Pharmacists felt that if service users were genuinely involved in the prescribing decision, this could 213 improve adherence. 'If they're taking part in the decision they have an interest in the outcome...if you don't involve 214 215 them and you are imposing something, as soon as they go out of the door they won't actually be 216 interested in continuing with it.' (In05) 217 Mental health was viewed as similar to any other chronic illness management in that giving more 218 autonomy to service users improved adherence to medication. 219 'I think it's like any other condition...the more autonomy you give the patient...the more likely they 220 are to comply.' (In10) 221 Importantly, the absence of SDM was believed to result in non-adherence and high rates of re-222 admission to hospitals. 223 'It's not as high as it ought to be otherwise...they wouldn't have so many patients relapsing, we 224 have these revolving door patients that keep coming in again and again, people just don't take 225 their medication'. (In02) 226 However, there was recognition that those service users who were engaged and interested in SDM 227 could be those who were more likely to be adherent regardless of approach. 228 'Those patients who can actually engage are more likely I think to actually be concordant'. (In11)

229	Service User Satisfaction
230	Service users were said to respond well to SDM, and appreciate being involved in decisions about
231	their care, improving the therapeutic alliance. One pharmacist who believed that SDM had a
232	positive effect on the therapeutic alliance quoted one service user saying:
233	'You were one of the few people who saw me as a human being and gave me a choice, when
234	everyone else was just telling me what to do.' (In07)
235	SDM could help service users feel more valued and respected, and work towards removing some
236	of the stigma that is associated with mental health.
237	'It's huge stigma all around so if you treat them like every other human being they're going to
238	feel valued and respected definitelythere's definite improvement, they feel at the centre of their
239	carethey will respect you for giving them that rather than being domineering and telling them
240	I know better than you.' (In02)
241	4. The Role of the Mental Health Pharmacist
242	Service User Counselling
243	The pharmacists felt that service users were often more open about medication issues with them
244	than other health professionals, particularly about sensitive side effects such as sexual dysfunction
245	'I've had a patient discuss sexual dysfunction with myselfwhere they didn't discuss it on the
246	ward review because they felt embarrassed to talk about it with the consultant.' (In13).
247	Pharmacists felt they were often seen as an independent person compared to the prescriber and
248	therefore able to have an open conversation with service users about medication.
249	'I do think we're in a very good position to discuss things because we areseen as independent.
250	(In10)

251	More research into the impact pharmacists can have upon clinical outcomes such as relapse rates
252	was suggested.
253	'I think we could reduce (the) relapse rate. Somebody needs to do a study into pharmacist
254	inputand the impact it has on non-concordance.' (In13)
255	Multi-Disciplinary Team (MDT) Working
256	The level of input that mental health pharmacists have in SDM was dependent on the leadership of
257	the MDT, with some clinical teams more collaborative than others, and resourcing within
258	pharmacy services.
259	'Some of the clinical teams I'm in are very collaborative and very collegiate I've also worked in
260	teams where there's very little conversation apart from between nurses and doctors, me as the
261	pharmacist has to almost fight to say something.' (In07)
262	Mental health pharmacists clearly felt that they had more to offer and were often underutilised.
263	'I think they have a really difficult job, but if they let us help them, a bit more in recognising we
264	have a resource here, that we can actually use that we have the knowledge.' (In11)
265	Pharmacists believed that a more inter-disciplinary approach with a referral system could support
266	their involvement in SDM.
267	'Some way of referring patients to a pharmacist clinicbut there's no actual referral process'
268	(In13)
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270	DISCUSSION
271	Pharmacist participants were supportive in principle for SDM, particularly when considering the
272	use of antipsychotic medication, and believed that practising SDM was a key part of stigma-free
273	clinical care. Like previous research, the pharmacists felt SDM increased service user satisfaction,

275 success and positive outcomes by improving adherence to medication (19,45-50). 276 The pharmacists perceived that attitudes of both services users and prescribers to SDM varied. 277 Some pharmacists felt that a minority of service users were happy with the clinician making 278 treatment decisions on their behalf. Other research has also identified this group who believe 'the 279 doctor knows best'; perhaps because they undervalue their expertise in relation to clinicians and 280 want to be 'a good patient' (47,51). Most service users, however, particularly those in younger age 281 groups, were said by the pharmacists to increasingly crave involvement, which is in line with 282 previous research (27,46,52). This change may reflect an increasingly consumerist society, where 283 choice was expected (53-55). 284 A strong, trusting relationship, with health care professionals and service users both accepting an 285 active role, is essential to the success, or otherwise of SDM (47). Yet service users often describe 286 mixed feelings, that they are both helped and misunderstood by healthcare professionals, and 287 commonly report experiencing discrimination (56,57). SDM involves the clinician respecting the 288 right of service users to make treatment decisions, even if they disagree with this decision (58). 289 However, like other research, we found a mixed picture; the pharmacists perceived that some 290 prescribers adopted an authoritative approach, dominating consultations and failing to take into 291 account the views of service users (26,59-62). 292 The participants perceived a lack of service user insight as the main barrier to SDM. Service users 293 suffering from acute illness were said to lack capacity precisely when medication was most likely 294 to be initiated or changed and, therefore, when SDM was important. However, when the illness 295 being treated was well controlled, and the service user may be more likely to be able to be engaged 296 in SDM, the pharmacists perceived that clinicians would be reluctant to change medication due to 297 concerns about the illness becoming less well-controlled. 298 Generally the pharmacists reported that SDM was not possible with service users treated under the 299 Mental Health Act without their consent (63). This act is designed to protect the rights, health and

which in turn improved the therapeutic relationship and was key to achieving long term treatment

safety of people with a mental health disorder and the safety of others; it covers the circumstances in which someone can be detained for treatment (63). Unlike other studies, some pharmacists in this study did not view capacity in absolute terms (21). They felt more should be done to engage service users and that SDM should be attempted with all service users to varying degrees depending on the level of insight and capacity. This echoes other research, which has found that service users with SMI value the opportunity to collaborate with those providing their care and are prepared to engage with SDM within the current patient-professional relationship (47). SDM can also improve treatment knowledge amongst service users with schizophrenia potentially reducing the risk of medication errors (18,64-66).

However, rather than focus on individual barriers, it may be more relevant to consider structural barriers to SDM in mental health practice such as a lack of time, poor communication between clinicians and service users, and limited access to evidence-based information (28,58). SDM can be seen to be a time consuming activity to undertake (22,27). In this research pharmacists reported the lack of time of both pharmacists and prescribers to be a barrier, with pharmacists identifying that other duties were seen to override SDM; other research has found that lack of time is a commonly reported barrier by both health professionals and service users (27,51,59,60).

The pharmacists felt they were able to play a vital role in SDM partly because their independence from the prescribing process enabled them to engage in SDM. Previous research has identified the need for an inter-disciplinary approach involving autonomous clinicians to engage service users in SDM (67-70). However, many of the pharmacists felt that they did not always get the opportunity to be involved in the SDM process due to the lack of a structured referral system and multi-disciplinary approach or resources issues within pharmacy departments.

Implications of Study

Services should be structured to support SDM with a more inter-disciplinary approach. This could include a formal referral system to pharmacists or implementation of pharmacist clinics. Training

for pharmacists (and potentially other clinicians) should highlight that SDM should be adapted depending on the state of illness at the time, but not abandoned.

Further Study

Further qualitative research on SDM, and more specifically the potential role of pharmacy, involving pharmacists, other clinicians and service users is required. Research is also required on the impact of SDM on outcomes including adherence to medication (19,48-50,71). Future research should investigate whether clinicians use SDM differentially depending on various characteristics including how long they have known the service user for and what the medication is being utilized for. It could also cover service users' views on the role of family members as advocates. Previous research has identified a role for healthcare professional 'coaches' not involved in treatment to actively support service users in engaging in SDM (58). Therefore, future research could investigate the impact of 'pharmacy medication management coaches' on key outcomes.

Limitations

All the participants recruited for the study came from the Midlands region and may not be broadly representative of attitudes and experiences of mental health pharmacists nationally and internationally. Moreover, we cannot be sure how long the participants had worked in mental health for (other than more than one year), whether they have a formal mental health qualification or their area of practice. We relied on convenience and snowballing sampling and relatively small sample sizes; however we found data saturation with consistent themes identified and no new themes identified in the last set of interviews. Additionally, identifying participants via known contacts may have influenced the interview responses in relation to socially desirable responses. This research project only sought the views of mental health pharmacists; a future project should triangulate the data collection methods and also interview other clinicians and more importantly service users. Pharmacists are increasingly becoming prescribers and therefore a future research

should also compare and contrast the views and experiences of prescribing and non-prescribing (who are independent from the prescribing process) pharmacists.

CONCLUSION

In keeping with previous research in this area, SDM was seen as a positive concept by the mental health pharmacists interviewed. SDM should take into consideration the service user's ability to tolerate adverse effects and their preferences regarding medication. The pharmacists believed that such an approach could improve service users' satisfaction with medication management services and ultimately adherence to medication. The pharmacists perceived that the attitudes of prescribers and service users, although noted as variable, were considered to be increasingly in favour of SDM.

The pharmacists identified that the use of SDM was limited by barriers, particularly the difficulties perceived by clinicians of engaging people with SMI who lack insight and mental capacity in the process. Greater effort is seen to be needed to work around these issues and try to engage service users as much as possible. Structural issues, such as time pressures may also limit the use of SDM. Pharmacists clearly feel they can play a vital role in SDM but their skills and knowledge in this area being underutilised, limiting their opportunity to contribute. SDM is clearly seen as one way to improve outcomes, and more research on how it be effectively implemented in mental health is required.

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Conflict of interest

No conflicts of interest were identified.

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