<u>Recovery from Psychosis: physical health, antipsychotic medication and the daily dilemmas</u> <u>for mental health nurses</u>

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Introduction

This paper considers some of the dilemmas experienced by Mental Health Nurses everyday when faced with the seemingly conflicting relationships that exist between recovery, antipsychotics and the physical health of people experiencing psychosis. We examine the role of antipsychotics in the process of recovery from psychosis and argue that Mental Health Nursing's laudable shift away from the medical model towards the concept of self-defined personal recovery should not result in overlooking the importance of physical health and medication management. Mental Health Nurses have a responsibility to help services users make an informed choice about treatment; this exchange of information should be based on the best available evidence rather than philosophical values or personal opinion.

The shift from a medical to a recovery model

The recovery model (or concept) first emerged during the 1980's from the narratives of people with personal experience of a diagnosis of mental illness (Houghton, 1982; Deegan, 1988). Their accounts of successfully negotiating mental health services highlighted the importance of the conditions required to facilitate a process of personal recovery. These conditions include hope, healing, empowerment, personal identity and a connection with the social world (Jacobson and Greenley, 2001; Leamy et al., 2011).

This concept is at odds with the clinical view of recovery, which is medically dominated, paternalistic, illness-based, diagnostically determined and focussed heavily on treatment compliance (Cavelti et al., 2012; Lieberman et al., 2002; Bellack, 2006). In contrast, the recovery approach aims to support people to meet their life potential whilst facilitating greater involvement in person-centred care through personal choice (Deegan, 1996; Hogan, 2003). The

model helps to challenge assumptions that serious mental health disorders take an inevitable path of progressive deterioration (Farkas, 2007). These shifting perspectives were reinforced by observations that people with a diagnosis of schizophrenia were able to regain functioning over the longer term (Harding and Zahniser, 1994; Farkas, 2007).

The recovery concept has since been adopted by mental health services and policy makers throughout the world (Davidson et al., 2005; Jacobson and Greenley, 2001). However there are still significant levels of confusion about how clinical services can embrace the concept of recovery as being truly self-defined. This ambiguity remains (in part) due to service-level requirements for measuring clinical outcomes in an objective manner whilst more meaningful recovery outcomes are more likely to relate to self-reported functioning (Green et al., 2014). It seems that policy makers and clinicians have adopted the language of recovery, but uncertainty about the actual implementation of recovery-oriented mental health systems persists (Kidd, McKenzie and Virdee, 2014).

Mental Health Nurses (MHNs) shift away from the medically dominated view of recovery places greater emphasis on psychosocial and alternative treatment approaches to promote optimism, reduce fostered dependence and facilitate meaningful recovery. The move away from a reliance on the medical model raises questions about whether a recovery-orientated approach should adopt a pro or anti-medication stance. But, the fact remains that the majority of people who experience psychosis are prescribed antipsychotic medications over the long term (Royal College of Psychiatrists, 2014). Furthermore, administering or supporting self-administration of medication is a daily clinical intervention for most MHNs. We also know that antipsychotics can cause physical health problems and that many people experience distressing side effects (Lambert et al., 2004).

This highlights a dilemma; the process of recovery is often helped by the use of antipsychotics to reduce the impact of distressing psychotic experiences. But, how likely is meaningful recovery if people develop serious physical illnesses, or if they are so sedated and overweight (as a result of taking medication) that they cannot leave their home or participate in meaningful social interaction. As such we have a moral, legal and ethical duty to ensure that people who take antipsychotics to aid their recovery, or those who choose to discontinue them, do so based on an informed decision. They should also be able to rely on us to try to minimise their undesired effects and ensure their long term physical safety (Nursing and Midwifery Council 2007; 2010).

Mental Health Nurses and Physical health

It is clear that people with a diagnosis of psychosis still experience very poor physical health (DeHert, et al., 2011; Khaw et al., 2008). Life expectancy is reduced on average by 10 - 30 years in comparison to the general population (DOH, 2006 & 2009; Colton and Manderscheid, 2006; DeHert et al. 2011; Happell et al., 2011). These physical health disparities have worsened over the last few decades (Brown et al., 2010; Saha et al., 2007). The reasons for this are multifactorial (DeHert et al., 2011) and include health behaviour, poor socioeconomic status (Cunningham, Peters, and Mannix, 2013) and a reduced likelihood of spontaneously reporting physical health concerns (Phelan et al., 2001; van Os and Kapur, 2009). There are also many service–related issues which reduce the effective utilization of health care. For example ineffective clinician communication (Colton and Manderscheid, 2006), stigma (Kane, 2009), access barriers (DeHert et al., 2011) and adverse effects of psychotropic medication, including those experienced when medication is discontinued (Foley and Morely, 2011; Moncrieff et al, 2013).

MHNs worldwide should now be aware that they are well-placed to monitor and try to help improve the physical health of service users. A systematic review of the literature (Happell, Davies and Scott, 2012) identified a generally positive effect of health behaviour interventions for people with a diagnosis of severe mental illness. The review concluded that a focus on such interventions by nurses might lead to significantly improved health outcomes. However, only 16 randomised clinical trials were identified and the overall methodological quality of the 42 studies included in the review was rated as moderate (Happell, Davies and Scott, 2012). There is also some limited evidence from case-series and pilot studies suggesting that programmes that focus on assessing both physical health parameters and health behaviours can inform individualised care and may result in health improvements (Ohlsen et al., 2005; Eldridge et al., 2011; Shuel et al., 2010; Bressington et al., 2014; van Meijel et al., 2014).

A large survey of MNHs (Happell, Platania-Phung, & Scott (2014) reported great support for nurse-led physical health improvement initiatives, but far less enthusiasm for minimising the side effects of medication or appropriately reducing the amount of antipsychotics used. Perhaps this is because some MHNs still lack the knowledge, confidence and skills to have discussions about the potential adverse effects of antipsychotics on physical health and facilitate related physical health improvement interventions (Bressington et al., 2012; Robson and Haddad, 2012). In a survey of over 500 UK MHN (Robson et al., 2013) the vast majority acknowledged the importance of a physical health role, but over 80% felt that they would benefit from additional training. A third of respondents also felt they lacked the ability to deliver health care relating to the physical adverse effects of treatment and around 20% believed that providing information about the possible physical health risks of medication would reduce treatment adherence. Similarly, a recent qualitative study (Brown and Gray, 2015) reports that some mental health professionals in the UK held a "paternalistic fear" about providing information about some of the negative aspects of medication. Therefore, the current literature indicates that despite good intentions some MHNs still seem to have unmet training needs. They also have little appetite for providing information about the iatrogenic effects of medication, supporting a reduction in the use of antipsychotics, or for managing their associated physical health consequences.

Physical health problems - the risks of taking antipsychotics

Although current treatment guidelines and the empirical evidence suggest that antipsychotic drugs have an important role to play in recovery, they are associated with the development and exacerbation of a wide range of physical health problems (Lambert et al., 2004; Lean and

Pajonk, 2003). Cardiometabolic disorders including type 2 diabetes, weight gain, hypertension and lipid abnormalities which contribute towards the development of cardiovascular disease have a significant impact on the shortened lifespan of people with SMI (Hennekens, 2007; Brown et al., 2010). Although the causes of these serious physical disorders are multi-factorial, they are certainly closely linked with the use of antipsychotic drugs (Lambert et al., 2004; Sernyak et al., 2004). A systematic review of health outcomes amongst people with psychosis who had never taken medication (Foley and Morely, 2011) demonstrated that an increased cardiovascular risk occurs after the first exposure to any antipsychotic drug. The review also concluded that changes in BMI, waist circumference and weight were obvious after only one month of treatment.

So-called "atypical" antipsychotic drugs are often thought to be the worst culprits in causing these issues. However, it is becoming more apparent that the use of the term "atypical" is not particularly useful as it assumes that all drugs in this class have similar properties whilst there are great differences in tolerability and adverse effects within the same groups (Rummel-Kluge et al., 2012; Crossley et al., 2010). These include the risk of weight gain and other metabolic problems (Tschoner, et al., 2007) in addition to other physical health issues such as prolongation of the heart rate-corrected QT interval (QTc), anticholinergic effects, hyperprolactinaemia, seizures, cerebrovascular risk, sexual dysfunction and sedation (Haddad and Sharma, 2007; Correll et al., 2014; Sernyak et al., 2004). A large meta-analysis comparing the efficacy and tolerability of 15 different antipsychotic drugs (Leucht et al., 2013) reinforces this view; all the medications were more effective than placebo, but there were relatively small (but significant) differences in efficacy and large variations in adverse effects within the same typical/atypical classes. Unfortunately some of the drugs with the best efficacy are those most associated with the worst side effect profiles (Rummel-Kluge et al., 2012; Leucht et al., 2013; Perera and Taylor, 2014). The importance of all health professionals refocusing attention on physical health was nicely summed up by an editorial published in the Lancet entitled: "No mental health without physical health" that highlighted the need to improve the cardiometabolic health of people taking antipsychotics (Tiihonen et al., 2011).

Recovery – how essential are the role of antipsychotics

It is possible for people who develop a psychosis to fully recover without the need for long-term maintenance antipsychotic treatment. A study exploring the 32 year outcomes of people diagnosed with schizophrenia in the 1950s showed that 68% of 82 participants had considerably improved or clinically recovered despite half not using antipsychotic medications at follow-up (Strauss and Breier, 1987). Other long-term naturalistic studies involving small numbers of people diagnosed with schizophrenia (i.e. Harrow and Jobe, 2007; Bola and Mosher, 2003) have demonstrated that those people who were not receiving antipsychotics at follow-up had better level of functioning than participants who were still taking medication. Of course, it is quite possible that the reason people in these studies stopped taking medication was because they had less severe psychotic experiences and better coping resources than those who felt they needed to continue.

Clearly the studies exploring recovery without antipsychotics should instil some degree of optimism in service users, carers and professionals that there is life without antipsychotics. And some studies show that around 74% of people prescribed antipsychotics will discontinue them within 18 months (Lieberman et al., 2005). But, it should be considered that the vast majority of evidence from controlled antipsychotic efficacy trials and effectiveness studies demonstrates that all antipsychotic drugs are significantly more effective in reducing psychotic symptoms and relapse rates than placebo (Leucht et al., 2012., 2012a, 2013; Gilbert, Harris and McAdams, 1995). Psychiatric medications have also been shown via large meta-analyses to be generally no less efficacious than many drugs commonly prescribed within general medicine for physical health conditions (Leucht et al., 2012). We should also remember that there are more people with psychosis that report a good outcome over three-years (42%) than the 27% with a poor prognosis (Menezes, Arenovich and Zipursky, 2006). Despite the potential benefits of treatment some studies show that antipsychotics exert only a moderate (0.5) effect on symptoms (Leucht

et al., 2009) and therefore MHNs need to ensure that service users' and their families have realistic expectations of treatment benefits.

If antipsychotic medication is required at some point (and it usually is, at least during an acute phase), it should be taken sooner rather than later. Studies show that early treatment with antipsychotics for people with a first episode of psychosis results in better clinical and functional outcomes than delaying treatment for more than one year since prodromal symptoms have developed (Novak et al., 2008). It is also reported that the discontinuation of antipsychotics in first episode psychosis within the first two years of onset results in persistent symptoms, and significantly higher levels of relapses and readmissions (Robinson et al., 1999; Morken, Widen and Grawe, 2008). In line with these findings the WHO recommend that antipsychotics should be taken regularly for at least one year after the start of remission from a first episode (WHO, 2014) and for people with multiple episodes a treatment duration of at least 2-5 years is recommended (Hasan et al., 2013).

The effects of reducing or stopping medication

We MHNs need to keep at the forefronts of our minds that supporting service users' personal choices about treatment is extremely important, but we must also be open with people when sharing the potential risks and benefits of stopping medication. Non-adherence with antipsychotic medications has been shown to be the most powerful predictor of relapse in schizophrenia (Robinson et al. 1999; Lacro et al., 2002 Subotnik et al., 2011;). A study of medication discontinuation in 53 people that had been stable on antipsychotics for two years following a first episode of psychosis found that 78% experienced an exacerbation of symptoms within one year (Gitlin et al., 2001). However, only 6 people in this study required an admission to hospital; suggesting that although the majority of people are likely to experience a reemergence of psychosis after stopping medication, re-hospitalisation can possibly be prevented by close monitoring and a reinstatement of antipsychotic treatment at the appropriate time (Gitlin et al., 2001).

In some cases the re-emergence of psychosis may be associated with the discontinuation of the drug rather than the underlying condition. A meta-analysis found the emergence of psychotic symptoms more likely in cases where antipsychotic medication is abruptly stopped (Viguera et al, 1997). A systematic review concluded that Clozapine is the most likely to be associated with psychotic symptoms on withdrawal, possibly related to its relatively short half-life. (Moncrieff, 2006). Re emergence of psychotic symptoms tends to peak in the first three months after stopping medication but then tails off to levels below that expected after 6 months, suggesting a discontinuation effect (Moncrieff, 2006). Recovery is not just about symptom remission and social and vocational functioning is arguably just as (or even more) important to the service user. Wunderink et al., (2013) found that a reduction or discontinuation of antipsychotics 6 months after remission from first episode psychosis resulted in better functional outcomes than maintenance treatment independent of the re emergence of symptoms. The findings of all these authors suggest that a very slow and closely monitored withdrawal is optimal and those who remain stable over six months after stopping antipsychotics are likely to do so over long periods.

The characteristics of service users who are most likely to recover over the longer term without the need to take medication constantly seem to be people with good pre-morbid developmental achievements, higher levels of self-esteem and perception of internal rather than external locus of control (Harrow and Jobe, 2007; Bola and Mosher, 2003). Phamocogenetic factors may predict the effects of psychotropic medication in individuals, including discontinuation effects but genotyping is rare (Bray et al., 2008). Knowledge to inform best practice (including information exchange with service-users about the safest method of withdrawal) has been identified as absent from core MHN education texts (Salomon and Hamilton, 2014). There are currently no professional guidelines to help health professionals support people who want to reduce or discontinue their antipsychotic medication. In the absence of such guidance a harm reduction approach that allows the person to learn from their own experience of stopping medication is recommended (Aldridge, 2012).

Alternatives to antipsychotics

Although there is increasing suspicion among purveyors of the recovery model about the value of antipsychotic medications there are only very few studies which investigate the effects of interventions that can be used as alternatives (rather than adjunct treatments). One such study is a randomised controlled clinical trial of cognitive therapy for people diagnosed with schizophrenia who chose not to take antipsychotic drugs (Morrison et al., 2014). This feasibility study involved 74 people and the results demonstrated that the symptoms and functioning of people in the cognitive therapy group improved in comparison to treatment as usual (with both groups not receiving medication). However, this promising study should not be viewed as conclusively demonstrating that cognitive therapy is a potential alternative to antipsychotics for people experiencing an acute psychotic episode; participants were excluded if they were being treated within inpatient units, there were a small number of people studied and interestingly 10 participants in each group started taking antipsychotics during the course of the trial (Morrison et al., 2014).

Due to the lack of studies exploring alternatives to antipsychotic medications it is difficult for MHNs to be able to share evidence-based information with service users about what works in the absence of pharmacological treatment. This is disappointing because medication-free studies in early-onset psychosis have the potential to provide extremely useful information about the processes and outcomes of psychosis without the confounding effects of medication (Schooler, 2006). In addition, understandable ethical and safety concerns have necessitated that such studies adopt very strict inclusion/exclusion criteria. These criteria typically result in including only people who are viewed as being "clinically low risk", hence seriously limiting the generalisability of findings (Francey, et al., 2011).

Models of care that focus on the social aspects of peoples' lives aim to empower service users by moving away from more reactive clinical interventions towards maximizing strengths (Burns et al., 2009). These approaches recognize the crucial importance of relationships in service users' recovery and reinforce the need for a comprehensive and holistic care package (Beresford, 2002). Although social models of care are clearly meaningful and helpful, it is problematic for MHNs to be able to share evidence about their effectiveness with service users. This is because the evidence is clouded by a number of issues, including the wide variety of research methodologies utilized, difficulties with the comparability of interventions and the fact that self-defined recovery outcomes are conceptually different to clinical outcomes (Tew et al., 2011; Shanks et al., 2013).

A further example of non-pharmacological interventions is the "Hearing Voices Movement". This began in the 1980's and is involved in facilitating peer-supported hearing voices groups in many international settings (Romme and Escher, 1989). The network is an excellent illustration of how people with the lived experience of voice hearing come together to support each other through coping and self-management strategies in order to re-frame and normalise voice hearing (Corstens et al., 2014). In addition to the "Hearing Voices Movement" there are also a variety of other group-based interventions designed to empower people to manage distress associated with voice hearing which are well-adopted internationally. Despite their popularity, a comprehensive systematic review of the literature (Muddle, Mason and Wykes, 2011) concluded that there is still a paucity of evidence from robust studies demonstrating the effectiveness of hearing voices groups that adopt mindfulness, cognitive-behavioural, Hearing Voices Network or skills-training approaches. However, this lack of evidence may also relate to the difficulties in conducting the research and measuring recovery-focussed outcomes which are conceptually removed from traditional clinical outcomes (Corstens et al., 2014).

In keeping with the "personal recovery" concept some studies have also investigated the clinical effectiveness of interventions which are based on the concept of illness self-management and improving hope (Schrank et al., 2012). Characteristically, such approaches are not designed to be used as alternatives to medication. A good example is the "Wellness Recovery Action Planning" (WRAP) self-management intervention for improving depression and

anxiety in people with a diagnosis of severe mental illness (Cooke et al., 2012). The results of the WRAP randomised controlled trial show that the intervention was more effective than a waiting list control in enhancing perceived recovery and reducing self-reported levels of depression/anxiety over the 8 month trial duration. However, the trial had a number of methodological limitations, including not recording medication use, using an inactive control intervention, the reliance on self-reported outcomes measures and inability to establish fidelity to the WRAP treatment (Cooke et al., 2012).

Many MHNs and people with a diagnosis of psychosis now place great emphasis on the use of professional-facilitated person-centred psychosocial treatment approaches and these are also highly recommended for all people at all stages of psychosis in current NICE guidelines (NICE, 2014). These guidelines should not be misinterpreted to mean that recovery-focussed approaches do not include the use of medication. The recommendations make it clear that psychosocial interventions such as Cognitive Behaviour Therapy (CBT) and family work should be offered in conjunction with medication in many cases. Despite the enthusiasm of NICE for psychosocial interventions, the efficacy of CBT in the treatment of schizophrenia is still hotly debated; a recent robust meta-analysis (Jauhar et al., 2014) concluded that CBT for psychosis has at best only a small effect on psychotic symptoms. There has rightly been criticism of some clinical guidelines that are based on research conducted or sponsored by the pharmaceutical industry as being inherently biased due to conflicts of interest (Citrome et al., 2014). But, potential conflicts of interest in non-pharmacological research may be overlooked as they are often not explicitly stated (Clarke et al., 2015). The NICE 2014 schizophrenia guidelines have also been criticised as over-emphasising the benefits of psychosocial interventions and too closely reflecting the research interests of many of the guidance development project team (Perera and Taylor, 2014).

Conclusion:

MHNs and people making a decision about which (or any) antipsychotic drug to take need to be aware that the distinction between typical and atypical antipsychotics is false, and that the choice of drug should be tailored to the needs, hopes and concerns of the individual concerned. The choice of service users to not take antipsychotics which is based on an informed costbenefit analysis should be viewed as understandable rather than pathological. Promoting a recovery focused approach should not entail the adoption of an anti-medication stance based purely on philosophical values rather than evidence. There is some promising evidence that supporting people through a gradual reduction in medication after acute psychosis may result in positive outcomes, but more research is needed. Similarly, the results from studies which utilize personal recovery focused self-management approaches and peer-support are encouraging, but the quality of evidence is still debatable. The process of helping people on the road through recovery should involve the sharing of facts and entails MHN's being confident to have open discussions about available treatments and approaches. However, if drugs are chosen, MHN's need to involve people in the active management of their medication, including the close monitoring of physical health in order to detect and prevent iatrogenic physical illnesses.

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