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Young people's experiences with mental health medication: A narrative review of the qualitative literature

ABSTRACT

Background: With the growing prevalence of mental illness in young people, healthcare professionals require an understanding of the social and psychological implications of medication use in this population.

Aim: To characterize the qualitative literature regarding the perceptions and experiences of young people taking medication for mental illness.

Methods: A narrative review of qualitative studies involving young people (13-24 years) taking any medication as treatment for a mental illness. The Medication Experience Model guided analysis of quotes related to medication use.

Results: Of the 27 included studies, the majority involved participants with depression and utilized interviews. Young people reported a wide range of mental health medication experiences, both negative and positive, which could influence medication acceptance. Lack of autonomy and the influence of family members were challenges faced by this population.

Conclusions: Young people reported that medications had affected them in various ways across multiple dimensions. Lack of involvement in decision-making and a loss of autonomy were of particular relevance to young people, issues which should also be of interest to healthcare professionals.

Key words: Mental illness, adolescent, young adult, medication, review

INTRODUCTION

The use of psychotropic medication such as antidepressants and antipsychotics as a treatment option for managing mental illness is well established. While an important treatment choice, taking mental health medication is fraught with complexity; consumers have to negotiate the medical world and understand their medicated selves (Malpass et al., 2009). A thoughtful synthesis of consumer experiences of taking antidepressants was constructed by Malpass and colleagues (2009), which highlighted the tension placed on a person's sense of self when medication was effective. For example, a return of functioning can be tempered by a questioning of one's normality (Garfield et al., 2003). Perceptions and attitudes towards psychotropic agents appear to fluctuate throughout the medication-taking journey, and are influenced by many variables such as relationships with healthcare professionals, consumer knowledge, illness severity and medication tolerability (Gibson et al., 2014). The highly stigmatised nature of mental health medication (Kranke et al., 2010), alongside the condition/s for which it is intended to treat (DeLuca, 2019; Kaushik et al., 2016), is reported.

The views and experiences of adults taking mental health medication are well explored (Bulow et al., 2016; Morant et al., 2017; Morrison et al., 2015; Schofield et al., 2011), yet minimal qualitative research has focused on young people. As evidenced by Bulow et al. (2016) and Morant et al. (2017), while many studies have eligibility criteria over the age of 18 years, the majority of participants are middle-aged adults with few young people included. Although young people may encounter similar medication experiences to older adults, they also face unique circumstances. This includes a process of identity formation (Choudhury et al., 2015), the influence of peers and a desire to fit in, enhanced sensitivity

towards body image and appearance, and experimentation with alcohol and recreational drug use (Steinberg et al., 2001).

Young people must also deal with the challenges involved with balancing treatment autonomy with the opinions of parents/guardians; their own involvement in medication-related decisions may be limited (O'Brien et al., 2013). Being 'forced' (Aselton, 2010) or placed on medication without input from the young person concerned was aptly referred to as "getting pillled" by Davidson (2003). In a study by Delman et al. (2015) many 18 to 30 year-olds reported that, as adolescents, decisions were made by their parents and/or psychiatrists, thereby minimising opportunities for the young person to learn how to make informed choices and become an active participant in their own healthcare. While there are legal safeguards, e.g. the Convention on the Rights of the Child (The United Nations, 1989) and the Disabilities Convention (United Nations Department of Economic and Social Affairs, 2007), and an active change towards a human rights-based approach to the treatment of young people with mental illness (Kotzmann et al., 2018), further attention to the application of these legal safeguards is warranted. This is particularly relevant to those young people receiving a compulsory treatment order (Kotzmann et al., 2018). Indeed, there are benefits to be gained from young people managing their medication in terms of increased responsibility and self-care (Choudhury et al., 2015), which are required skills for functioning and autonomous adults.

Some reviews have targeted young people within the context of mental health, such as their perception of mental health services (Goodwin et al., 2016), stigmatisation (Kaushik et al., 2016), barriers and facilitators to help-seeking (Gulliver et al., 2010) and the effect of help-seeking interventions for depression and anxiety (Gulliver et al., 2012). While

important insights were provided from two recent systematic reviews focused on the qualitative experiences of young people living with mental illness (Chernomas et al., 2017; Woodgate et al., 2017), the search strategies indicated that medication was not a key focus. Other studies have focused on surveying young people about mental health medication either separately or alongside other treatment options; apart from Jordan et al. (2017) these surveys did not include open-ended qualitative questions (Bradley et al., 2010; Caporino et al., 2012; Edlund et al., 2015; Foltz et al., 2014; O'Brien et al., 2013). Floersch and colleagues (2009) referred to the limited knowledge about how young people subjectively experience medication use for mental illness. Whilst we appreciate that this research is now rather dated, we are unaware of more recent work that has reviewed the qualitative experiences of young people using medication for a range of mental illnesses. Furthermore, this work needs to go beyond the experiences of young people with Attention Deficit Hyperactivity Disorder (ADHD) which has been extensively studied (Avisar et al., 2014; Charach et al., 2014; Knipp, 2006; McCarthy, 2014; Singh et al., 2010).

The aim of this review was to characterize the qualitative literature regarding the perceptions and experiences of young people taking medication for mental illness and map these findings to the Medication Experience Model (Werremeyer et al., 2017). The increasing prevalence of mental illness in young people (Mission Australia et al., 2017; NHS Digital, 2018), together with suicide as the leading cause of death in 15 to 29 year-olds (World Health Organization, 2014), is of serious concern. The prescribing trends for many psychotropic medications for young people have also shown an increase (Brijnath et al., 2017; Hartz et al., 2016; Karanges et al., 2014; Tsai et al., 2017). A review of studies exploring the broader social and psychological implications of medication use in young

people with various mental illnesses is thus timely and necessary. Hence this review of the qualitative literature.

METHODS

Search Strategy

A review of the available literature was conducted using the following key electronic health-related databases: PubMed, Embase, CINAHL and Google Scholar. The search for articles was conducted between July and September 2017, with an updated search conducted in March 2019. The initial primary search terms and the final search strategy are outlined in Table 1; reference lists and citations of relevant publications were reviewed for additional studies. Keywords associated with stigma, medication compliance or adherence were not utilised as these were beyond the scope of this review. For example, adherence can be an outcome of medication experience in the event a consumer ceases medication due to side effects. Readers are referred to the work of Timlin et al. (2014), Goldstein et al. (2016) and Kaushik et al. (2016) for further information.

[Insert Table 1 here]

Inclusion and Exclusion Criteria

The full-text of any qualitative study involving young people, i.e. adolescents and young adults between 13-24 years of age, taking any medication as treatment for a mental illness (except ADHD) was reviewed for eligibility by two study authors (BW and SM). No time-frame for study inclusion was applied to ensure that all relevant articles were identified. See Table 1 for an overview of the study inclusion and exclusion criteria.

Studies which encompassed ages outside of 13 to 24 years were reviewed and included if sufficient data (e.g. quotes) were identified to be from a young person. For example, the average age was specified in the demographic results by Gray and Deane (2016), however, specific ages were reported alongside participant quotes, leading to study inclusion. A number of articles were excluded as participant ages could not be identified from reported quotes (Bjornestad et al., 2017; Garfield et al., 2003; Harding et al., 2015; Inder et al., 2010; Lorem et al., 2014; McCann et al., 2004). Quotes were not provided as evidence in Sung et al (2006), and although participant ages were reported in Harding et al. (2015), aligned quotes were not related to medication use. Knudsen et al. (2002) was excluded as only one of the eight participants was within the 13-24 year age range and it was unclear whether the study results were relevant to this participant. Lastly, the adolescents interviewed by Maroun et al. (2018) were not all taking or using medication; these participants were part of a randomized controlled superiority trial comparing the effectiveness of psychological therapies.

Studies were included if they were written in English and involved young people diagnosed with a mental illness other than ADHD. However, if a published article had a mixed sample which included participants with ADHD this was not excluded providing equal attention was placed on participants with other mental illnesses. Mental illnesses included anxiety and panic disorders; mood disorders (e.g. depression and bipolar); psychotic disorders (e.g. schizophrenia and schizoaffective disorder); eating disorders; personality disorders; and trauma-related disorders (e.g. post-traumatic stress disorder). Bluhm et al. (2014) was included even though six of the 37 participants had a suspected, rather than diagnosed, mental illness.

Study participants were required to be using prescription medication to manage their mental illness, within any setting. If a young person discussed their medication experience within the context of medication adherence or stigma, the study was included. Research exploring the views of parents, the general public or healthcare professionals were excluded.

Data Extraction and Analysis

Study data was entered into an Excel[®] spreadsheet: author/s (year), study location, study aim and methodology, participant sample (including age and diagnosis), medication and treatment duration, and key findings related to medication experiences. All quotes related to medication were extracted and initially coded as positive or negative experiences or management strategies. Data extraction and quality checking tasks were shared between two researchers (BW and SM) for this initial stage.

Following the initial stage of data extraction, the Medication Experience Model (Werremeyer et al., 2017) was identified and subsequently used to guide the coding of the key findings for this narrative review. The Medication Experience Model emerged from the thematic analysis of interview and focus group transcripts of psychotropic medication experiences of adults using photovoice methodology (Werremeyer et al., 2017). This conceptual framework involves three key concepts: i) the illness experience; ii) medication acceptance; and iii) the medication experience. Werremeyer and colleagues (2017) posit that these concepts are inter-related, for example, perceived benefits from medication use increased medication acceptance, which in turn mitigated negative connotations associated with a diagnosed mental illness. In the pilot work of the same study, the authors identified that discussions relating to medication use were superseded

by other areas of importance, such as dealing with the mental illness itself (Werremeyer et al., 2016). While this is an important finding, the aim of our review was to focus specifically on the reported medication experiences of young people using psychotropic medication. Thus, only two of the three components of the Medication Experience Model, i.e. medication experience and medication acceptance, were relevant and hence referred to when analysing the qualitative data from the included studies. Although Werremeyer et al (2017) focused on adult consumers (mean age 35.9) using psychotropic medication, the depth of information obtained about medication experiences closely reflected the findings from the studies in our narrative review, thereby demonstrating its utility as a framework for our analysis. Furthermore, a range of medications was reportedly used, including antidepressants, mood stabilisers and anti-anxiety medication, also of relevance to this review.

The key findings (i.e. themes and/or relevant quotes) from the included studies in our review were independently coded by one researcher (SM) with reference to medication experience and medication acceptance as explained by the Medication Experience Model (Werremeyer et al., 2017). This researcher was a registered pharmacist who, at the same time as this review, was conducting interviews with young people about their psychotropic medication experiences. Hence, the author was constantly reflecting on these themes throughout the analysis process. Any quotes referring to willingness to use medication and influencing factors such as the level of support from family members, were coded as medication acceptance. Although perceived stigma was an integral aspect of the illness experience in the Medication Experience Model, in our review, concerns or experiences relating to stigma with medication use were coded under medication acceptance. The sub-themes explaining the components of the medication experience by

Werremeyer and colleagues (2017) were used to define the five additional themes presented in this review; additional context used by the authors when coding is presented in italics:

1. *Medication benefit*: involved medication-related improvement (and frustration when this did not occur), hope and goal setting. *Any positive comments regarding medication use.*
2. *Medication side effects*: included the impact on functioning and quality of life, fear of long-term effects, questions as to whether effects were disease-related, and risk versus benefit analyses. *Any reference to a negative impact on mental or physical wellbeing from medication use.*
3. *Routine and adherence*: recognised the importance of establishing and keeping routines to take medication, as well as *instances of non-adherence and influencing factors.*
4. *Burden/responsibility*: related to the effort involved in using medication daily *and the ease/difficulty with managing routine administration.*
5. *Non-medication therapies as medicines*: non-medication approaches used to manage mental illness, such as a supportive other and self-care strategies.

All themes encompassed the need for additional information, as outlined by Werremeyer et al. (2017). This coding was confirmed by a second researcher (BW).

RESULTS

Study Selection

Twenty-seven studies (including two doctoral theses) were included in this review and are summarised, and numerically annotated, in Table 2. Where more than one study is cited, the in-text reference includes only the assigned number (see Table 2).

[Insert Table 2 here]

Six studies used data from the same participant data-set (Table 2, References 7-8, 11-13, 15); this was also the case for both studies by Murphy et al (22-23). The majority of studies were conducted in the USA ($n=14$) (Table 2, References 2-3, 7-8, 10-15, 20, 24, 26-27). Marcus et al. (2012) included participants (internet bloggers) from multiple locations such as England and the USA; this was one of only two studies that did not involve interviews (10, 17); unlike other researchers who conducted interviews using more conventional methods, Aselton (2010) employed email correspondence. Nine studies provided a topic/interview guide or sample questions (Table 2, References 3, 5, 15-16, 18, 20, 24, 26-27), of which four did not involve medication-specific questions (5, 16, 18, 24). An adapted version of the Subjective Experience of Medication Interview was used in nine studies (Table 2, References 2, 6, 7-8, 11-15).

Study sample sizes ranged from three (Kranke et al., 2015) to 52 participants (Narendorf et al., 2015); 13 studies involved participants under the age of 16 (Table 2, References 5-6, 7-8, 11-15, 20, 22-23, 27), with the youngest being 12 years of age (Moses, 2011). Most studies included participants with depression ($n=21$; Table 2, References 1, 3-4, 6-8, 10-12, 14-20, 22-24, 26-27), followed by bipolar disorder ($n=17$) (Table 2, References 4-5, 7-8, 10-12, 14-20, 22-24). Three studies did not report participant diagnoses but were included because they specifically focused on psychotropic medication management (2, 21, 25).

Minimal information was provided about the types of psychotropic medication used by participants, with only 12 studies providing class (3, 11, 20, 24, 26-27), or specific,

medication names (6, 9, 14, 19, 22-23). No average treatment duration was reported for participants. Limited ethnic diversity across all studies was observed, although it should be noted that publications in languages other than English were excluded.

Key Themes

As previously explained, the following information is organised according to themes from the Medication Experience Model (Werremeyer et al., 2017). Key quotes from the included studies illustrating these themes are presented in Table Three.

[Insert Table 3 here]

Medication benefit

The majority of studies referred to some benefit of medication use, including improved emotional stability (8-9, 21), feeling calmer (20, 23), reduced anger or grouchiness (13, 15) and feeling proud of oneself (Floersch et al., 2009). Other cognitive benefits included a reduction in disorganised (Leavey, 2005), or negative, (Gray et al., 2016) thoughts, improved functioning (12, 25) and academic performance (11, 26), increased capacity to manage life events (McKinney et al., 2010) and to problem solve (Narendorf et al., 2015). Improvements in relationships with significant others, including peers, friends and/or family, were also acknowledged as positive outcomes (7, 14); some participants spoke of feeling more attractive (Venarde, 1999) and looking forward to the future (Marcus et al., 2012).

Other young people spoke positively about their medication-related mood changes including feeling more like their previous (normal) self (Narendorf et al., 2015) or the return of their familiar identity (Venarde, 1999). In Murphy et al. (2015) a participant

described that while any “weirdness” had been muted, they nonetheless felt somewhat “below-par” with medication use. Some young people had pre-conceived ideas about the impact of medication on their sense of self, with concerns about “acting differently” (Floersch et al., 2009). For one participant, this resulted in fear and apprehension to use treatment, which was only alleviated when they realised that their sense of self remained unchanged (Bluhm et al., 2014). A positive effect of medication was sometimes undesirable however, because it did “not represent one’s authentic self” (Moses, 2011).

Feelings of hope that medication would be effective were highlighted (Venarde, 1999) with the journey to finding the right medication acknowledged in multiple studies (1, 3-5, 10, 20, 23-24). Prescriber willingness to try a range of medications was appreciated (Jivanjee et al., 2011), however, waiting for medication to take effect was sometimes frustrating (1, 4) as there was a general expectation that medication would act quickly. When medication did work, this increased hope that the mental illness could be effectively managed or treated (Bluhm et al., 2014), or that the participant could cope better (Anderson et al., 2013). However, there was sometimes also a sense of ambiguity in terms of whether medication was the primary reason for the difference felt (Choudhury et al., 2015). For some young people, beneficial effects of medication were less apparent (Moses, 2011); medications either did not meet their expectations (Gray et al., 2016) or questions were raised as to whether medication really helped them (Aselton, 2010). For others, medication seemed to stop working (Jivanjee et al., 2011). Benefits were not mentioned in four studies (2, 18, 22, 27); although three papers did not specifically focus on medication experiences (1, 18, 27), and research by Murphy et al. (2013) explored weight gain as an exclusive side effect of antipsychotic use. Although medication benefits

were not discussed, side effects were reported by McCloughen et al (2016) and Murphy et al (2013).

Medication side effects

Eighteen studies described participants experiencing side effects (1, 3, 5, 7-11, 17-26). Encountering side effects was one reason why some participants disliked medication; in-depth exploration of this phenomenon was not possible by Marcus et al. (2012) as they collected post-hoc data from internet blogs. Overall, a range of side effects were noted, such as dry mouth, sleep disruption, reduced energy and, particularly with antipsychotics, weight gain. Suicidal ideation after starting antidepressants was acknowledged in one study (Aselton, 2010). Sedative effects added a layer of complexity for homeless young people, who needed to remain constantly alert to stay safe within their often-unpredictable environment (Muir-Cochrane et al., 2006). Questions were sometimes raised about whether side effects were related to the medication or due to the mental illness itself (Anderson et al., 2013).

Other unwanted effects included feeling numb and slow (Moses, 2011) and experiencing hallucinations (Steffenak et al., 2015). Feeling like a “zombie” was identified by Floersch et al (2010) and Murphy et al (2013). Medication-related flattening of emotions contributed to some young people ceasing their medication in an attempt to regain their full emotional range (3, 24); experienced discontinuation side effects when they did this abruptly (McKinney et al., 2010). Conversely, one participant described continuing medication use because they were scared of discontinuation side effects during the ‘wash-out’ period (Moses, 2011), i.e. the time when a medication dose is reduced or ceased and is gradually eliminated from the body. Another participant disclosed using illicit

substances to manage side effects (Murphy et al., 2015), which was also reported by Narendorf et al (2015) as a treatment alternative for young people diagnosed with mood disorders. Young people described a range of concerns related to side effects, such as becoming medication dependent (Kranke et al., 2012), feeling “high” or too happy, and, as previously described, acting differently (Floersch et al., 2009). Increasing reliance on medication was a concern for one 19-year-old female (Venarde, 1999), although older adults also commented on this issue. A lack of medication-related information provision was reported (Steffenak et al., 2015) alongside a need for further detail about expected treatment outcomes, including benefits and side effects (Anderson et al., 2013).

Routine and adherence

Having to remember to take medication, and the disruption in daily activities in order to accommodate this, was annoying for some young people (12, 20). This was particularly difficult for homeless youth, resulting in sporadic medication use (Muir-Cochrane et al., 2006). Feelings of shame were reported, with young people avoiding medication use at school, or in front of peers, because of the fear of being bullied (Kranke et al., 2010). Other strategies included hiding medication out of sight (Kranke et al., 2011) and accessing a lockable dorm room in order to take medication without drawing attention from others (Anderson-Fye et al., 2011).

Students who had been persuaded to take medication by family and friends did not like taking it (Aselton, 2010). Being coerced to take medication was a common theme (Moses, 2011), with feelings of disempowerment and a need to take control by the limited means available to participants, e.g. medication non-adherence. In some instances, medication refusal was one method available for young people to demonstrate their autonomy,

particularly if they perceived medication as not working (Choudhury et al., 2015). Steffenak et al (2015) reported that some young people stopped medication use without consulting a healthcare professional. It was not until benefits were felt that one participant accepted medication that was previously imposed upon them by their parents (Floersch et al., 2009). Young people also revealed that they changed or ceased medication use depending on their mood, or to manage side effects (19, 22). For example, one participant described using medication for no longer than two weeks as medicating beyond this time led to a perceived placebo effect (McKinney et al., 2010). Only one study, which specifically focused on the views of African-American adolescents, identified that it was a ‘duty’ to take medication, as this was thought to be ‘God’s will’ (Kranke et al., 2012).

Burden and responsibility

Paying for and storing medication was a particular burden for homeless young people (Muir-Cochrane et al., 2006), which could influence adherence. The support of healthcare professionals was emphasised by one participant who obtained sample medication packs from a doctor; for others, lack of engagement with a supportive health professional was a problem (Muir-Cochrane et al., 2006). Anderson-Fye and Floersch (2011) identified regulatory barriers to obtaining prescription medicines when American students travelled between home and college in different states. This resulted in prescriptions expiring or lapsing, and for some students, finding a new prescriber in their local area was challenging. One participant solved this issue, at least in the short-term, by arranging with her mother to send medication at regular intervals, underscoring the importance of family support (Anderson-Fye et al., 2011). An easier medication regimen was desired by participants in another American study, such as once-a-day dosing and alternative

medication formulations (Floersch et al., 2009). For other young people, taking medication was simply viewed as a mundane, everyday task (Moses, 2011).

The need, or desire, by young people to be active participants in their own care, such as being involved in treatment choice, was a feature of some studies (4, 23-24). Taking personal responsibility, for example, by asking questions or obtaining medication information, was viewed as integral to the recovery journey (Leavey, 2005). Only one study outlined the sources participants used to obtain medication information, such as the internet, peer groups and physicians (Murphy et al., 2015). Young people generally wanted to work in collaboration with their healthcare team rather than have medication prescribed to them, resulting in more positive experiences (24, 27).

Non-medication therapies

Supportive others, such as families, were a major influence on young people's perceptions of mental health medication (Kranke et al., 2010). Supportive social environments were characterised by good communication, medication knowledge and emotional support; these features neutralised negative stereotypes and promoted feelings of normalcy (Kranke et al., 2015). By comparison, family environments with poor communication and emotional support contributed to feelings of embarrassment, rejection and social withdrawal (Kranke et al., 2010).

Medication was not necessarily viewed as the sole contributor to achieving improvements in mental wellbeing (5-6). Other self-care strategies, such as deep breathing, exercise and connecting with others, were used by American college students to manage emotions (Aselton, 2010). Participants in some studies suggested that medication should be used in

conjunction with other treatments or therapies (Narendorf et al., 2015), such as psychotherapy (Bluhm et al., 2014), or expressed a preference to try alternative or other treatment options instead (19, 23, 26).

Medication acceptance

Stigma related to medication use was referred to in twelve studies (2-5, 11-12, 14, 20, 23, 25, 26-27). Taking medication was associated with “abnormality” (Wisdom et al., 2006); medication was for “sick” (Kranke et al., 2010) or “weird” (Venarde, 1999) people. Some young people were thus reluctant to take medication as they perceived this as reinforcing their diagnosis; they did not want to identify, or to be identified, as a sick person (Bluhm et al., 2014). Ambivalence towards medication use was emphasised by participants questioning the need for medication (23, 26). Two participants thought they were “too young” to take medication although limited detail was provided about this viewpoint (Bluhm et al., 2014). Other young people assumed that talking to a health professional would ultimately lead to being prescribed medication, and that their mental health was something they should be able to control without the need for medication (Wisdom et al., 2006). A level of mistrust in prescribers was also recognised; a participant who had trialled multiple medicines described this as being akin to a lab “rat” (Moses, 2011), which was acknowledged elsewhere (24-25). Concerns about the over-use of medication to manage mental illness were noted (Wisdom et al., 2006); suspicions about the influences on prescriber practices, such as monetary gain, were also raised (Jivanjee et al., 2011).

Some young people chose not to disclose their medication use (11-12, 20, 26) as an attempt to avoid social rejection. However, for one participant this was explained by a

desire to avoid discussing a personal matter, rather than from concerns about embarrassment (Bluhm et al., 2014). Not all young people experienced stigma with respect to medication use; the majority of college students in Kranke et al.'s (2013) study chose to disclose this information to break down barriers and help others. For some, mental health medication was viewed no differently from medication prescribed for other long-term conditions such as asthma (Kranke et al., 2013), and there were benefits from identifying or knowing others using similar medications (20, 26). Limiting social interactions to trusted peers or other young people using mental health medication reduced the risk of being stigmatised (Kranke et al., 2010). An exploration of the experiences of participants who did not report feeling stigmatised identified related factors, including supportive family and friends, school success, positive outlook and treatment involvement (Kranke et al., 2015).

Stigma did not just come from peers, but also from healthcare professionals and family members. Feeling judged by healthcare professionals resulted in feelings of humiliation and disrespect (Anderson-Fye et al., 2011), although specific details about the types of medication or mental illness involved were not reported in this study. The negative impact of intrusive checking by healthcare professionals on medication compliance was mentioned in a New Zealand study of young people's experiences with treatment for psychosis (Cadario et al., 2012). Stigma was identified amongst other family members (11-13) who may not have wanted their siblings or children to use medication (Floersch et al., 2009). One 20-year-old stated that her parents were not supportive of medication use due to the risk of dependence (Venarde, 1999); other young people perceived this caused their families to be ashamed of them (Steffenak et al., 2015). Conversely, having

a parent with a positive lived experience of antidepressant use facilitated medication acceptance by the young person (Venarde, 1999).

DISCUSSION

The findings of this review indicate that a lack of involvement in decision-making and a loss of autonomy can be detrimental to the mental wellbeing of young people using psychotropic medication; it is essential that this vulnerable group are better supported by health professionals and family members. Young people had a wide range of experiences with their mental health medication. Negative experiences included side effects, a loss of sense of self, stigma, lack of involvement in decision-making, and loss of autonomy; positive experiences included supportive environments and relationships with family, friends and schools, and involvement in treatment decisions. These experiences impacted significantly on medication acceptance; in some cases, refusing to take medication was a direct response to feeling coerced, and a need to demonstrate a sense of autonomy. There are several key challenges experienced by young people when accessing healthcare such as navigating a complex health system (Institute of Medicine and National Research Council, 2015 ; Robards et al., 2018); additional challenges for this more vulnerable population warrants increased attention, such as the stability of their home environment or family support.

The influence of family members and the family environment was evidenced by our review; young people lacking family support were more likely to report a negative medication experience. Instances of being forced to take medication, with limited input into the decision-making process, were identified (Choudhury et al., 2015; Moses, 2011; Murphy et al., 2015). Parents' attempts to 'protect' their children by hiding their own

medication use, such as antidepressants, could reinforce stigma (Thomas, 2016). Although concerns related to medication side effects and stigma have been acknowledged by other mental health consumers (Ridge et al., 2015), lack of autonomy and the adverse views of family members on medication use are key challenges faced by young people living with a mental illness. Building autonomy from an early age via involvement in therapy decisions, alongside family support and reinforcement of the benefits of medication use, are likely to improve acceptance of medications by young people living with a mental illness. Lack of engagement with a supportive health professional was a problem identified in this review; the authors of one study recommended a greater level of dialogue between the two parties (Muir-Cochrane et al., 2006).

The impact of the learning environment is another consideration. Further exploration as to whether there is greater acceptance in a college/university setting, where young people are likely to live away from parental influence and have greater autonomy, compared to primary and secondary schools, is needed. It may be that time and experience are required to become more comfortable with disclosing medication use as a young adult. Additional qualitative research exploring the complexities of medication acceptance and disclosure as young people transition to adulthood is needed, particularly when there is increased focus on mental health promotion within society.

Medication-related discussions need to be tempered by realistic expectations that medication may not work immediately (Anderson et al., 2013; Bluhm et al., 2014). The paradox of medication use should also be noted: effective treatment can minimise symptoms of mental illness yet taking medication and experiencing possible side effects are reminders of an existing illness (McDonagh et al., 2016). Discussions about progress

might usefully consider the ambiguity expressed by some young people about whether the effects they were experiencing resulted from medication, or their mental illness, or both. Furthermore, this review identified that a reduction in illness-related symptoms enabled young people to forget the positive impact of medication use (Gray et al., 2016), which should be considered when reviewing medication effectiveness.

Other research has indicated that young people living with a mental illness (Simmons et al., 2011), or other long-term health conditions (Jordan et al., 2018), want to be involved in collaborative decision-making processes. Healthcare professionals who are respectful, non-patronising, encourage engagement, and provide continuity with appointments, were identified as particularly important aspects of a service that was friendly towards youth or “youth-friendly” (McCann et al., 2012). It is evident that the knowledge, skills and attitudes of health professionals influences youth engagement with health services (Robards et al., 2018). Given the ease with which the authors of this paper were able to apply the Medication Experience Model (Werremeyer et al., 2017), we recommend its use as a guide for other healthcare professionals wishing to explore the expectations and experiences of young people using medication for mental illness. It is unclear from this review where young people obtained medication information; only one study described sources, such as the internet, peer groups and physicians (Murphy et al., 2015). The offering, or provision, of information is essential to support young people to make informed decisions about their own healthcare.

Lastly, this is the first review to our knowledge that has utilised aspects of the Medication Experience Model to report key findings. While this review did not focus on the illness experience of young people, it is reasonable to suppose that a person’s medication

experiences, or how well they accept medication use, would influence their illness perceptions and vice versa. Further qualitative exploration is required to ensure that this model sufficiently captures the psychotropic medication experiences of young people, particularly given that the model originated from adult experiences. Greater attention on medication-related stigma is also needed, which was not referred to by Werremeyer and colleagues (2017) as a specific theme or subtheme of medication experience.

Strengths and Limitations

To our knowledge, this is the first narrative review of qualitative research which focused on young people's experiences with medication use for a mental illness. Data extraction was extensive and involved a quality checking process by a second researcher, and results were coded with reference to a previously established model (Werremeyer et al., 2017) which met the aims of the review. While we acknowledge the limitations to using an established framework for data analysis within a deductive approach, we are confident that all relevant information was captured, as the final coding was checked by a second researcher. It should be noted that many of the included studies did not report on the duration of treatment and hence, comparisons between the experiences of new and established medication users was not possible. There are also limitations pertaining to this narrative review. While the review included studies from any country, publications in languages other than English were excluded and thus issues of diversity and possible cultural differences were not examined. For example, all of the identified studies were from western countries and thus findings have limited generalisability to young people living in other countries. Only selected quotes are presented in Table 3; for additional evidence, readers are referred to the original studies. The literature search was restricted to four health-related databases; a more exhaustive database search, including the grey

literature, could have identified further relevant studies or reports. This also applies to the chosen search terms; MeSH terms relating to educational facilities such as schools and universities were not utilized and therefore some studies may have been missed. While some papers were identified that Lastly, details of the number of citations found and articles excluded cannot be provided; while systematic in its search strategy, this was not a systematic review and thus a specific methodological framework was not followed by the study authors.

CONCLUSION

Overall, this review provides important insights for healthcare professionals involved in the prescribing and supply of mental health medications. Young people reported that medications had affected them in various ways across multiple dimensions. Although both positive and negative medication experiences were identified, there was a perceived lack of involvement in decision-making and a loss of autonomy that is of particular relevance to young people and their care providers. Healthcare professionals have an obligation to work collaboratively with young people in the same way as they do with older adults; an exploration of young people's experiences taking mental health medication is needed to validate their concerns and facilitate care. Much more work is required in this area to further explore the nuances of this topic, particularly in culturally and ethnically diverse groups.

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Table 1: Search Strategy and Criteria	
Initial keywords	“Mental Health,” “Mental Illness,” “Mental Disorder,” “Adolescents,” “Teenagers,” “Young Adult/s,” “Experience/s,” “Attitude/s,” “Perceptions,” “Opinions,” “Thoughts,” “Beliefs,” “Medication,” “Medicines,” “Drug,” “Antidepressant Medication,” “Antidepressant Agents,” “Antidepressant,” “Antipsychotic Agent,” “Antipsychotic Medication,” “Antipsychotic,” “Psychotropic Drug,” “Qualitative,” and “Qualitative Research”
PubMed	(adolescent OR children OR young adult) AND psychotropic drugs AND qualitative research [all MeSH Terms] (adolescent OR children OR young adult) AND psychotropic drugs AND health knowledge, attitudes, practice [all MeSH Terms] (adolescent OR children OR young adult) AND health knowledge, attitudes, practice AND (mental disorder OR mental health) [all MeSH Terms] AND qualitative [TI/ABS] adolescent AND mental illness AND qualitative [all Text Words]
Embase	(adolescent OR young adult [Emtree term – exploded]) AND mental disease [Emtree term – exploded] AND medication AND qualitative research [TI/ABS/KW] drug therapy AND qualitative research [Emtree term – exploded] AND (adolescent OR young adult) [limit] AND mental disease [limit]
CINAHL	(medication OR medicine OR drug) AND (mental illness OR mental health OR mental disorder) AND qualitative [Word in Subject Heading] AND (adolescents OR teenagers OR young adults) [all text]
Inclusion Criteria	<ol style="list-style-type: none"> 1. Qualitative study (original research) 2. Young people taking any prescription medication for a diagnosed or suspected mental illness/es (other than ADHD) 3. Medication-related quotations specific to participant age range of 13-24 years (even if the study included older participants) 4. Written in English in any country or study location
Exclusion Criteria	<ol style="list-style-type: none"> 1. Studies focused solely on young people living with ADHD, mental health related stigma or medication adherence 2. Review articles, commentaries, book chapters, conference papers 3. Studies in which the age of young people could not be identified (and no-response from authors) 4. Studies written in languages other than English 5. Quantitative studies

Table 2: Relevant literature on young people's experiences with mental health medication													
Reference		Study Design	Country	Participant details	Ethnic diversity	Mental Illness	Medication and Duration	Coding Framework					
								Benefit	Side effects	Routine/ adherence	Burden/ Responsibility	Non-medication therapies	Medication Acceptance
1	Anderson & Roy, 2013	Secondary analysis of interviews	UK	n=32 23 females 17-24 years	Y (n=2)	Depression	Not reported	x	x				
2	Anderson-Fye & Floersch, 2011	Adapted SEMI Interviews	USA	n=17 18-25 years	Not reported	Not reported	Not reported			x	x		x
3	Aselton, 2010	Email interviews	USA	n=13 8 females 19-22 years	Y (n=3)	Depression	Antidepressants > 4 weeks	x	x	x		x	x
4	Bluhm et al., 2014	Interviews	Canada	n=37 27 females 16-24 years	Not reported	Anxiety Bipolar Depression Eating disorders Substance abuse	Not reported (n=32 received treatment)	x			x	x	x
5	Cadario et al., 2012	Interviews	NZ	n=12 5 females 15-18 years	Y (n=5)	Bipolar Psychosis Schizophrenia	Not reported	x	x			x	x
6	Choudhury et al., 2015	Modified TeenSEMI interviews	Canada	n=14; 8 females 14-18 years	Not reported	Depression ADHD Other	Mixed Duration not reported	x		x	x	x	
7	Floersch et al., 2009	TeenSEMI interviews	USA	n=20 11 females 12-17 years	Y (n=20)	Anxiety Bipolar Depression ADHD Eating Disorder	Only reported the mean age when medication started	x	x	x	x		x

						Substance abuse Other							
8	Floersch et al., 2010	TeenSEMI interviews	USA	n=24/30 12-17 years	Y (n=15/30)	Bipolar Depression Schizophrenia	reported ages when started medication	x	x	x			
9	Gray & Deane, 2016	Interviews	UK	n=20 6 females average age 26 years	Y (n=4)	Psychosis	Antipsychotic Duration not reported	x	x				
10	Jivanjee et al., 2011	Focus groups	USA	n=16 2 females 17-24 years	Y (n=2)	Bipolar Depression ADHD OCD Other	Not reported	x	x				x
11	Kranke et al., 2010	TeenSEMI interviews	USA	n=40; 24 females 12-17 years	Y (n=21)	Mood disorder (e.g. bipolar, depression) ADHD Anxiety Schizophrenia Other	Mixed Medication taken at least once in the past 30 days	x	x	x		x	x
12	Kranke et al., 2011	TeenSEMI interviews	USA	n=27 18 females 12-17 years	Y (n=12)	Mood disorder (e.g. bipolar, depression) ADHD	Not reported Medication taken at least once in the past 30 days	x		x			x
13	Kranke et al., 2012	TeenSEMI	USA	n=17 11 females 12-17 years	Y (n=17)	ADHD Mood disorder Eating disorder Schizophrenia	Not reported Medication taken at least once in the past 30 days	x	x	x			x
14	Kranke et al., 2013	Adapted SEMI interviews	USA	n=17 13 females 18-21 years	Y (n=3)	Anxiety Bipolar Depression ADHD	Mixed Duration not reported	x					x

						OCD Other							
15	Kranke et al., 2015	TeenSEMI	USA	n=3 2 females 12-17 years	Y (n=1)	Bipolar Depression ADHD	Not reported	x				x	x
16	Leavey 2005	Interviews	Canada	n=13 6 females 17-23 years	Not reported	Anxiety Bipolar Depression Psychosis Eating disorder OCD Schizophrenia Other	Not reported	x			x		
17	Marcus et al. 2012	Internet blogs	Mixed	n=8 6 females 18-25 years	Not reported	Anxiety Bipolar Depression Eating disorder Other	Not reported	x	x				x
18	McCloughen et al., 2016	Interviews	Australia	n=12 7 females 16-24 years	Not reported	Anxiety Bipolar Depression Schizophrenia	Not reported		x				
19	McKinney & Greenfield, 2010	Interviews	Canada	n=22 19-24 years	Not reported	Anxiety Bipolar Depression ADHD Eating Disorder Substance abuse	Mixed Duration not reported	x	x	x		x	
20	Moses., 2011	Interviews	USA	n=50 21 females 12-17 years	Y (n=22)	Anxiety Bipolar Depression ADHD OCD Other	Mixed Duration not reported	x	x	x	x		x

21	Muir-Cochrane et al., 2006	Interviews	Australia	n=10 Specified 5 females and 3 males 16-24 years	Not reported	Not reported	Not reported	x	x	x	x		
22	Murphy et al., 2013	Interviews	Canada	n=18 8 females 13-26 years	Not reported	Anxiety Bipolar Depression ADHD Psychosis OCD Schizophrenia Other	Mixed Prescribed antipsychotics within the last 2 years		x				
23	Murphy et al., 2015	Interviews	Canada	n=18 8 females 13-26 years	Not reported	Anxiety Bipolar Depression ADHD Psychosis OCD Schizophrenia Other	Mixed Prescribed antipsychotics within the last 2 years	x	x		x	x	x
24	Narendorf et al., 2015	Interviews	USA	n=52 37 females 18-25 years	Y (n=35)	Bipolar Depression Other	Mixed Duration not reported	x	x		x	x	x
25	Steffenak et al., 2015	Interviews	Norway	n=8 6 females 17-24 years	Not reported	Not reported	Mixed. Duration not reported	x	x	x			x
26	Venarde, 1999	Interviews	USA	n=4 3 females 19-24 years	Y (n=1)	Anxiety Depression ADHD	SSRIs Otherwise not reported	x	x			x	x
27	Wisdom et al., 2006	Individual and focus group interviews	USA	Interviews n=15 8 females 14-19 years	Interview Y (n=2)	Depression	Antidepressant Duration not reported				x		x

				Focus Group n=7 5 females 15 years									
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Table 3: Selected quotes pertaining to themes from the Medication Experience Model					
Theme	Quote	Reference	Theme	Quote	Reference
Medication Benefit	<i>I don't really feel like I'm bipolar now. Like with my medicine, you know, I feel like a normal person</i> (Male, 19 years)	(Narendorf et al., 2015)	Side Effects	<i>...it just amazed me that forgetting to take a tiny little pill could make me feel so awful the next day...</i> (Male, 23 years)	(McKinney et al., 2010)
	<i>...I have a hard time remembering what kind of person I was prior to taking the SSRI. I feel as if I am a numbed version of myself...</i> (Female, unknown age)	(Aselton, 2010)		<i>And then they swapped me to [antipsychotic] which was good but had quite big side effects on me. I put on quite a lot of weight</i> (Gender, Age unknown)	(Cadario et al., 2012)
	<i>Antidepressants, they aren't a quick fix to make you better, but they help you to cope better with what you're going through</i> (Female, 19 years)	(Anderson et al., 2013)		<i>...I don't want my body depending on medication for me to feel better or for me to do better. I don't want my body to need medication for the rest of my life</i> (Gender, Age unknown)	(Kranke et al., 2012)
Routine and Adherence	<i>...another reason I didn't want to do the med wash, I'm just scared of what might happen...I just don't want to feel so crappy...</i> (Female, 16years)	(Moses, 2011)	Medication Acceptance	<i>Yeah, it's really nothing different than...the pill I take for asthma...</i> (Gender, Age unknown)	(Kranke et al., 2013)
	<i>...it doesn't really seem to work properly so I just take it now and then when it kind of builds up and it seems to work out that way.</i> (Gender, Age unknown)	(Muir-Cochrane et al., 2006)		<i>"I feel I was a guinea pig. They tried me with everything that came out."</i> (Gender, Age unknown)	(Narendorf et al., 2015)
	<i>I...refused my meds every day. I was going through withdrawal so my eyes were bloodshot and I was getting like abusive so then I started taking it again...I was just trying to prove a point...'cuz they can't force you to take it.</i> (Male, 16 years)	(Moses, 2011)		<i>There is a stigma with antidepressants, and I don't want to be that person who carries around pills in their purse and like can't have too much to drink because it interferes with the medication...</i> (Female, early 20s)	(Venarde, 1999)

Theme	Quote	Reference	Theme	Quote	Reference
Burden and Responsibility	<i>"...I think it was mostly enforced on me. I was told I had to take this medication..."</i> (Female, 23 years)	(Murphy et al., 2015)	Non-medication therapies as medicines	<i>Half the reason I'm feeling better is because of the Zoloft [Sertraline] and the other half is because just of myself</i> (Female, 16 years)	(Choudhury et al., 2015)
	<i>"...not having a place of your own doesn't give you a stable anything whether it be just somewhere...to keep your medication and take it..."</i> (Gender, Age unknown)	(Muir-Cochrane et al., 2006)		<i>...it seemed like it meant admitting I had a bigger problem than I did...I was more interested in and accepted to the idea of a talking type therapy than medicating therapy.</i> (Male 24 years)	(Venarde, 1999)
	<i>"A normal everyday thing...like popping a vitamin"</i> (Female, 12 years)	(Moses, 2011)		<i>I think that maybe some of the doctors shouldn't be dependent on the medicines...A lot of depression may stem from loneliness or being singled out, so instead of pushing them towards drugs maybe you should push them toward a YMCA or a summer camp or something...</i> (Male, 17 years)	(Wisdom et al., 2006)