



Experiences of taking neuroleptic medication and impacts on symptoms, sense of self and agency: a systematic review and thematic synthesis of qualitative data

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Abstract

Purpose Neuroleptic (antipsychotic) drugs reduce psychotic symptoms, but how they achieve these effects and how the drugs' effects are experienced by people who take them are less well understood. The present study describes a synthesis of qualitative data about mental and behavioural alterations associated with taking neuroleptics and how these interact with symptoms of psychosis and people's sense of self and agency.

Methods Nine databases were searched to identify qualitative literature concerning experiences of taking neuroleptic medication. A thematic synthesis was conducted.

Results Neuroleptics were commonly experienced as producing a distinctive state of lethargy, cognitive slowing, emotional blunting and reduced motivation, which impaired functioning but also had beneficial effects on symptoms of psychosis and some other symptoms (e.g. insomnia). For some people, symptom reduction helped restore a sense of normality and autonomy, but others experienced a loss of important aspects of their personality. Across studies, many people adopted a passive stance towards long-term medication, expressing a sense of resignation, endurance or loss of autonomy.

Conclusions Neuroleptic drugs modify cognition, emotions and motivation. These effects may be associated with reducing the intensity and impact of symptoms, but also affect people's sense of self and agency. Understanding how the effects of neuroleptics are experienced by those who take them is important in developing a more collaborative approach to drug treatment in psychosis and schizophrenia.

Keywords Antipsychotics · Neuroleptics · Psychosis · Schizophrenia · Qualitative research

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Introduction

Neuroleptic medication (also known as 'antipsychotic' medication) is the primary treatment for people with a diagnosis of schizophrenia or other psychotic disorders [1, 2]. There is evidence that it reduces acute psychotic symptoms and risk of relapse [3]. However, neuroleptics have many adverse effects and recent accounts suggest they may be overused [4–6]. The action of neuroleptics is thought to be mediated through their effects on neurotransmitters, but the manner in which they modify symptoms remains uncertain. Early pioneers of neuroleptic treatment suggested that the ability of neuroleptics to reduce the intensity of emotional responses and motivation was relevant to their neuroleptic effects [7, 8], and this idea has been reiterated more recently [8–10]. These effects are also likely to impact on other areas of people's experience, such as their sense of self and agency,

including their sense of choice and power over treatment decisions. Indeed, research has shown that people's sense of self and agency are affected by the use of other mind-modifying medicines, such as anti-depressants [11, 12].

Several qualitative studies have been conducted that describe the experiences of taking neuroleptics [13]. The rich nature of qualitative data means these studies can highlight the complex alterations to conscious experience, mental functions and behaviour that neuroleptics produce, arguably more successfully than quantitative approaches (e.g. use of side effect scales). It can also clarify how such effects interact with symptoms of psychosis, and how they impact on people's sense of self and agency. The current study is a systematic review of the literature that is aimed to explore these issues using qualitative methods. Specifically, our research addresses the following questions:

1. What does qualitative research indicate about the mental and behavioural alterations produced by neuroleptic drugs and how do these impact on symptoms?
2. How do neuroleptics affect people's sense of self and agency?

The first question aims to establish the particular experiences induced by neuroleptic drugs, and how these might interact with symptoms. In relation to the second question, we define the sense of self as an individual's view of the distinctive features of their own character [14], and agency can be summarised briefly as having the ability to influence what happens in one's life [15].

Methods

The systematic review was conducted in accordance with PRISMA (Preferred Reporting Items for Systematic Reviews) guidelines [16] (protocol available at: https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=55646. Registration number; 55646).

Eligibility criteria

Studies were included if they reported qualitative data about the experiences and views of people taking neuroleptic medication for a mental health condition and were written in English. Unpublished data were included and no date of publication range was specified. Studies only describing the views of clinicians or carers were not included.

Search

Repeated searches of the following electronic databases were conducted from inception of the project in 2017 until

7 March 2019: Ovid MEDLINE, EMBASE, PsycINFO, PsycARTICLES, the Cochrane Library, CINAHL, Scopus and AMED. OpenGrey was also searched for unpublished literature. Hand searching of citations was also conducted. The following search terms were used: ("neuroleptic*" OR "atypical antipsychotic*" OR "neuroleptic*" OR "major tranquiliser*" OR "psychotropic*" OR "depot injection*" OR "psychiatric medication*") AND ("attitude*" OR "experience*" OR "subjective*" OR "opinion*" OR "side-effect*" OR "compliance*" OR "adherence*" OR "satisfaction*" OR "perception*" OR "understanding*" OR "interpretation*" OR "view*" OR "tolerability*" OR "perspective*" OR "insight*" OR "quality of life*" OR "personal account*").

Study selection

All titles and abstracts identified in the searches were screened to see whether they fulfilled eligibility criteria, and the full papers selected through this process were assessed by two reviewers (JT and JS). Queries about inclusion were resolved through consultation with two other reviewers (JM, RC).

Quality review

Study quality was assessed by two reviewers (JT and JS) using the Critical Appraisal Skills Programme (CASP) qualitative checklist [17]. The CASP was chosen since it is recommended by the Cochrane Collaboration [18] and is widely used in qualitative synthesis. Before commencing independent quality assessments, reviewers assessed the same five papers, with high interrater reliability (96%).

In line with recommendations for qualitative research synthesis, we did not set quality criteria for inclusion [19, 20].

Data extraction, analysis and interpretation

All parts of the results and discussion sections of included papers that described or analysed study participants' experiences of taking neuroleptics were extracted and imported into the qualitative analysis software NVivo 11. We used thematic synthesis [20] to analyse this material (referred to in the process described below as 'data'). Thematic synthesis is an established method that uses the basic principles and practices of thematic analysis [21] to draw together key themes from across studies, and in so doing develop further interpretations or new analytic insight [20]. Similar to thematic analysis, thematic synthesis offers a standardised but flexible approach that can be used to integrate relatively large numbers of qualitative studies and is recommended for topics in mental health [19].

Our analysis proceeded as follows: Initially, the first reviewer (JT) and last reviewer (JM) read all the papers in detail to obtain an overview of the issues covered. Then the first reviewer coded the data from each of the papers line by line, with the second reviewer (JS) coding a sample of papers. The data were initially coded into descriptive themes, which directly described the findings of each of the included papers. Themes and sub-themes were collated in tables and a hierarchical descriptive tree, to compare and match themes across articles. This process went through several iterations with input from the whole research team. Descriptive themes were then grouped into analytic themes which were refined collaboratively through a further process of iteration. This step involves “going beyond the descriptive synthesis to produce a more conceptual line of argument” [19] (P 7). As with thematic analysis, we endeavoured to enhance validity through reflexive and collaborative working, in which we discussed and questioned theoretical and personal positions held by team members [22]. The detailed coding process, iterative consideration of descriptive and analytical themes and constant input of the whole research team ensured that there was strong consensus across the research team about the conceptualisation of themes and their relationships to the data.

Results

The search strategy identified 11,292 references. Of these, 103 full text articles were assessed for eligibility and 69 were excluded (see Fig. 1 for reasons for exclusion). A total of 35 studies were included in the review, including 34 published studies and 1 unpublished doctoral thesis.

Study characteristics

Of the 35 included studies, participants were recruited from a variety of settings across 11 different countries, including inpatient facilities, community-based services, first episode psychosis services, general youth services and one was conducted in a prison. Twenty-one studies were restricted to people with a diagnosis of schizophrenia, a psychotic disorder or bipolar disorder. One study included people with borderline personality disorder and eight did not specify diagnoses. Data were mainly collected via face to face interviews ($N=21$) with other studies using a mixture of focus groups, interviews and diary entries ($N=8$), questionnaires/surveys ($N=3$) and data from Internet fora ($N=1$) (see Table 1). One study explored the effects of clozapine specifically [23], and

Fig. 1 Preferred Reporting Items For Systematic Reviews and Meta-Analyses (PRISMA) flow diagram

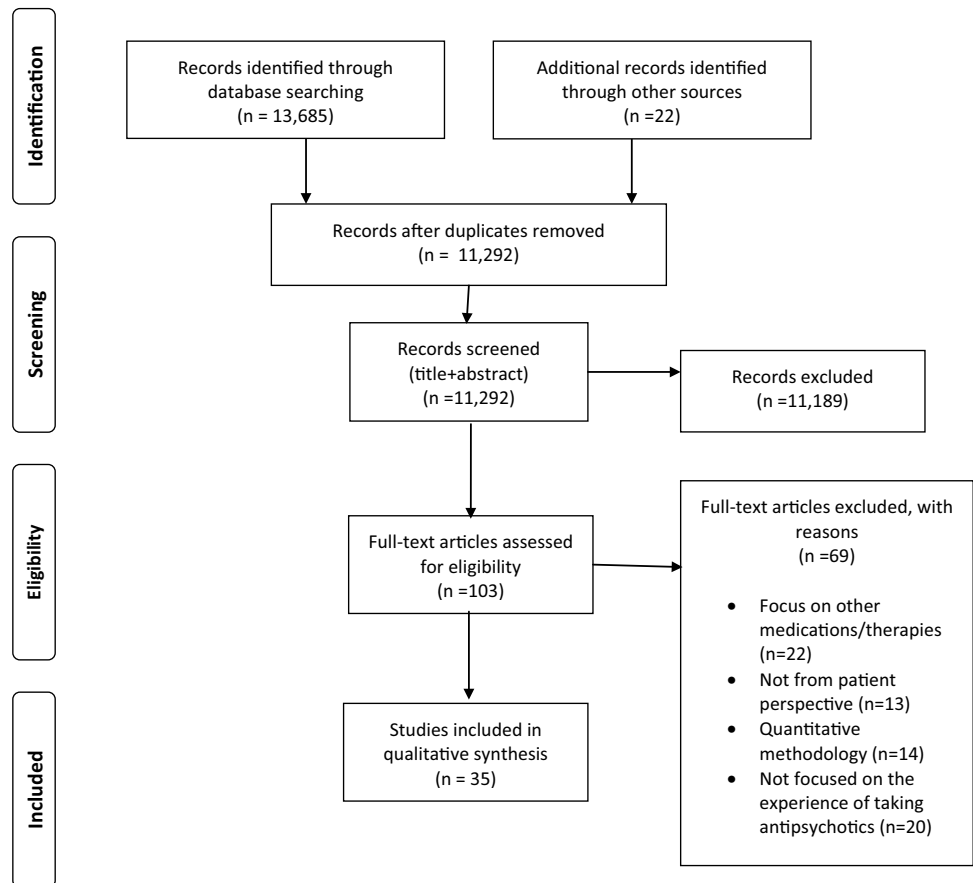


Table 1 Study characteristics

Author (year)	Country	Aim	Sample size, characteristics, setting and diagnoses	Analytic approach	CASP score (maximum 10)
Angermeyer et al. [23]	Germany	Qualitative exploration of attitudes towards clozapine treatment	80 48 M, 32 F One-third of the sample was: under 30; 30–40; and over 40 years Inpatient or day hospital services Schizophrenia	Content analysis, semi-structured interviews	9
Bülwö et al. [33]	Norway	Qualitative exploration of neuroleptic medication management and adherence	19 10 M, 9 F 20–69 years (median 41 years) All psychiatric services Psychosis	Not specified	9
Carrick et al. [42]	UK	Qualitative exploration of experience of taking neuroleptics	23 13 M, 12 F 24–70 years (mean 43.3 years) Local day centres and author caseload Schizophrenia, schizoaffective disorder, psychotic illness or borderline personality disorder	Grounded theory, Structured interviews and focus group	9
Das et al. [24]	UK	Qualitative exploration of attitudes towards taking depot neuroleptics	11 6 M, 5 F 18–40 years (median 24 years) Early Intervention Services, any psychotic illness developed in the last 3 years	Grounded theory, semi-structured interviews	8
Dumas [34]	USA	Qualitative exploration of experience of taking neuroleptic medication and adherence	11 10 M, 1 F Age 28–81 (mean 45 years) Outpatient services schizophrenia	Phenomenology, open phenomenological interviews	9
Duxbury et al. [47]	UK	Qualitative exploration of experience of receiving and giving neuroleptic medication	57 (age and sex not specified) Acute inpatients, diagnosis not specified	Semi-structured interviews, thematic analysis	9
Gee et al. [40]	UK	Qualitative exploration of quality of life in schizophrenia	6 3 M, 3 F 20–55 years (33.3 years) Outpatient services, schizophrenia	Semi-structured interviews, grounded theory	10
Geyt et al. [30]	UK	Qualitative exploration of factors related to discontinuing neuroleptics	12 5 M, 7 F 21–60 years Looking to discontinue medication, psychosis	Semi-structured interviews, grounded theory	9
Gill [29]	UK	Qualitative exploration of the experience of taking atypical neuroleptics	19 13 M, 6 F 28–56 years (median 46 years) Outpatient services, schizophrenia	Diaries and semi-structured interviews phenomenology	10

Table 1 (continued)

Author (year)	Country	Aim	Sample size, characteristics, setting and diagnoses	Analytic approach	CASP score (maximum 10)
Gray and Deane [35]	UK	Qualitative exploration of the experience of taking neuroleptics	20 (sex not specified) Mean age 26 years Early intervention services, schizophrenia	Semi-structured interviews, thematic analysis	10
Hagen et al. [31]	Canada	Qualitative exploration of the experience of taking neuroleptics after recovery from psychosis	22 4 M, 18 F 27–64 years (mean 41 years) Self-identified recovered from psychosis	Semi-structured interviews, phenomenology	9
Harris et al. [71]	UK	Qualitative exploration of views and experiences of neuroleptic prescribing	9 service users (sex and age not specified) Outpatient services, diagnosis not specified	Focus groups and semi-structured interviews, framework analysis	9
Jenkins et al. [69]	USA	Qualitative exploration of improvement and recovery of persons taking neuroleptics	90 49 M, 41 F Mean age 47 years Outpatient services, schizophrenia or schizoaffective disorder	Ethnographic interviewing, observations and questionnaires, not specified	6
Lacasse et al. [49]	USA	Qualitative exploration of the experiences of taking neuroleptics for those in functional recovery	16 (sex and age not specified) Self-identified as having reached functional recovery, history of severe mental illness	Semi-structured interviews, thematic analysis	9
Meshach et al. [44]	Nigeria	Qualitative exploration of experiences of treatment among those with a diagnosis of schizophrenia in Nigeria	11 7 M, 4 F 22–49 years Outpatient services, schizophrenia	Semi-structured interviews, phenomenology	9
Mills et al. [26]	UK	Exploration of (non)adherence of neuroleptics in prisoners	44 36 M, 8 F 19–61 years (37 years) Prison Any ICD-10 psychiatric disorder	Semi-structured interviews, not specified	10
Moncrieff et al. [37]	UK	An analysis of the subjective effects of olanzapine, risperidone and older neuroleptics	439 comments 215 M, 224 F Mean age 32.6 years Online sample Mixed diagnoses (61% psychosis or bipolar disorder)	Internet comments, content analysis	9
Morant et al. [36]	UK	Qualitative exploration of experiences of taking neuroleptic medication and medication decision-making	20 13 M, 7 F 22–62 years (mean 40.3 years) Outpatient services, schizophrenia or schizoaffective disorder	Semi-structured interviews, thematic analysis	9
Morrison et al. [28]	Australia	Qualitative exploration of the impact of neuroleptic side effects in the community	10 (sex not specified) 28–69 years Outpatient services, 6 schizophrenia and 4 bipolar disorder	Semi-structured interview, phenomenology	8

Table 1 (continued)

Author (year)	Country	Aim	Sample size, characteristics, setting and diagnoses	Analytic approach	CASP score (maximum 10)
Murphy et al. [38]	Canada	Qualitative exploration of the experience of youth prescribed neuroleptics	18 10 M, 8 F 13–26 years Self-reported Various diagnoses	Semi-structured interviews, phenomenology	9
Novak and Svab [45]	Slovenia	Qualitative exploration of personal experiences of stigma	10 4 M, 8 F Inpatients due for discharge, schizophrenia	Focus groups, not specified	8
Read [72]	Ghana	Qualitative anthropological study of people diagnosed with mental illness and their families and their responses to treatment with neuroleptics	47 focus groups (sex and age not specified) 25 semi-structured interviews (sex and age not specified) Schizophrenia	Focus groups, semi-structured interviews, observations, ethnography	8
Rofail et al. [27]	UK	Analysis of experiences of patients with schizophrenia	80 45 M, 35 F 35–44 years Outpatient, inpatient and rehabilitation services, schizophrenia	Open-ended self-report questionnaires, not specified	9
Rogers and Pilgrim [41]	UK	Analysis of service users' views of psychiatric interventions	34 (sex and age not specified) At least one previous admission, diagnosis not specified	Open-ended self-report questionnaires, not specified	6
Rogers et al. [46]	UK	Qualitative exploration of experiences of taking neuroleptic medications	34 22 M, 12 F 18–56 years Inpatients and outpatients, schizophrenia or schizoaffective disorder	Semi-structured interviews, not specified	8
Salomon and Hamilton [43]	Australia	Analysis of the experience of discontinuing neuroleptic medication	98 50 M, 46 F, 1 transgender, 1 undisclosed Mean age 56 years Outpatient services Currently or previously taking neuroleptics, diagnosis not specified	Survey self completed by post or online, thematic analysis	10
Semar [74]	USA	Qualitative exploration of the experience of taking neuroleptics	7 4 M, 3 F 33–46 years Inpatient and outpatient services Diagnosis of schizophrenia	Open interviews, phenomenology	9
Stewart et al. [50]	UK	Qualitative exploration of patients' views and experiences of medication management	15 (male) 27–70 years Outpatient services, schizophrenia	Semi-structured interviews, grounded theory	10

Table 1 (continued)

Author (year)	Country	Aim	Sample size, characteristics, setting and diagnoses	Analytic approach	CASP score (maximum 10)
Teferra et al. [73]	Ethiopia	Qualitative exploration of the reasons for low adherence to medications	24 (sex and age not specified) Rural community, schizophrenia or bipolar disorder	Focus groups and semi-structured interviews, thematic analysis	9
Tooth et al. [25]	Australia	Qualitative exploration of recovery from schizophrenia	60 45 M, 15 F 21–60 years (mean age 36 years) Recruited through advertisements and mental health services Participants self-identified as in recovery, schizophrenia	Focus groups, thematic analysis	9
Tranulis et al. [52]	USA	Qualitative exploration of perspectives on discontinuing neuroleptic medication	20 17 M, 3 F Mean age 39 years Outpatient services, schizophrenia spectrum disorders	Semi-structured interviews, grounded theory	9
Usher [39]	Australia	Qualitative exploration of the experience of taking neuroleptic medications	10 (sex and age not specified) Recruited through targeted advertisements Diagnosis in last 5 years, schizophrenia	Semi-structured interviews, phenomenology	9
Vedana et al. [48]; Vedana and Miasso [51]	Brazil	Qualitative exploration of experience and meaning of taking atypical neuroleptic medication	36 (sex and age not specified) Outpatient services schizophrenia	Semi-structured interviews, grounded theory	9
Williams and Pinfold [32]	UK	Qualitative exploration of how service users manage the effects of neuroleptic medication	36 20 M, 16 F (age not specified) Community charity groups, schizophrenia, schizoaffective disorder and bipolar disorder	Focus groups, not specified	7
Yeisen et al. [70]	Norway	Qualitative exploration of subjective experiences of taking neuroleptic medication in the first 2 years following treatment for a first episode of psychosis	20 7 M, 13 F 15–65 years Early intervention services, psychosis	Semi-structured interviews, phenomenology	9

one focused on the experience of taking depot medication exclusively [24]. Others involved people who were taking a variety of agents (see Table 1). Quality scores are shown in Table 1.

Themes (Table 2)

In the following analysis, we begin with how alterations to normal conscious experience, emotions, cognition and behaviour are described, in line with our first research question. We then explore how the drugs impacted on symptoms of psychosis and other symptoms and problems. Overall, the first theme consists mainly of negative comments about neuroleptic-induced changes that were usually experienced as unpleasant. In comparison, descriptions of effects on symptoms are primarily positive. Themes 3 and 4 address our second research question and focus, respectively, on how neuroleptics affect people's sense of self in both positive and negative ways, and on impacts on agency and how people perceive their level of control over the use of these drugs.

1. Neuroleptic-induced mental and behavioural alterations

‘The majority of participants spoke of feeling stupefied, numb and slowed down, of being unable to interact in a normal fashion or undertake even modest activities, most wanting to sleep or lie down’ (pg S73) [25].

‘I remember taking my first depot... and it absolutely knocked me out... I couldn't even lift a dustpan and brush in that I didn't have any movement in my arms, in my legs... I didn't have any thoughts in my head. I couldn't do anything... I was like a zombie’ (pg 117) [26].

Across studies participants provided consistent descriptions of a distinctive state produced by neuroleptics This generally consisted of lethargy, cognitive difficulties, dampened emotions and reduced motivation, which was

associated with a variety of physical effects and could lead to impaired functioning. Participants in many studies complained of feeling sedated and fatigued [4, 7, 8, 18, 19, 22, 24–26] and highlighted the strength and unpleasantness of these effects using descriptions such as ‘dopey,’ [27] ‘zonked,’ [28] feeling like a ‘cabbage’ [29] or ‘being hit by a truck’ [30]. These effects were summarised in one study as ‘crippling lethargy’ [31]. Associated with this were complaints of impaired cognitive function [23, 29, 31–39], emotional blunting [31, 37, 38] and loss of motivation [23, 26, 29, 30, 32, 35–37, 40], which were again described as profound and debilitating. Across studies, participants referred to feeling they had reduced clarity of thinking, intelligence, concentration and memory and felt ‘slowed down’ [31]. They referred to feeling ‘numbed out,’ [31] ‘empty’ [38], ‘lazy’ [36], being ‘less enthusiastic about life’ [35] and lacking ‘motivation and energy’ [41]. In some studies, these effects were associated with incapacitating physical effects including muscle weakness, stiffness and tremor [23, 26, 28, 32, 33, 41]. Sexual dysfunction, particularly erectile dysfunction and loss of libido [23, 33, 34, 40], and weight gain [23, 27, 30, 31, 33, 35–37, 40–43] were also common.

The negative impacts of these effects on the ability to function were often considerable [23, 27, 28, 36, 39, 44–46]. They prevented people from having the motivation or physical capability to carry out simple tasks like brushing their teeth [39], using a dustpan and brush [26] or going shopping [34]. Participants in some studies mentioned how the effects of neuroleptics prevented them from working [27, 46]. In some studies it was noted that the experience of taking neuroleptics had made some people depressed, anxious or suicidal [27, 31, 32, 34, 36, 37]. Participants in ten studies explicitly compared the general state of physical, emotional and cognitive impairment that neuroleptics produced to being a ‘zombie’ [26, 28, 29, 31, 32, 34, 37, 38, 42, 46].

2. Impact on symptoms

Table 2 Themes

Themes	References	Total
1. Global effects of neuroleptics	[23, 25–52, 69–74]	35
2. Impact on symptoms	[23, 26, 27, 29, 33–35, 37, 39, 40, 46, 47, 71, 74]	14
3. Medication and the self	[23, 30–33, 35–39, 41, 43, 72]	12
(a) Depleting the self		
(b) Restoring the self	[23, 26, 27, 34, 39]	5
(c) Symbolic effects	[24, 28–30, 32–35, 38, 39, 44–46, 49, 51, 52]	16
4. Agency and medication	[23–26, 28, 30–36, 38–44, 46–52, 70, 71, 74]	29

‘I can see a change in my thinking, I used to have some...oh, you know, some funny thoughts... this medication helps me in a way that I can think...and see that it’s not right (thinking)...it has offered me hope again for a normal life’ (pg 148) [39].

‘Others described how the medication decreased the intensity, intrusiveness or emotional impact of psychotic symptoms or unwelcome thoughts’ (pg 6) [37].

Despite the nature of drug-induced alterations, many participants across studies felt that neuroleptics had helped to reduce symptoms and, as a consequence, improve their day to day life. Participants in numerous studies reported that the drugs decreased auditory hallucinations or ‘voices’ [23, 26, 27, 33–35, 37, 46, 47]. In addition, three studies described how some participants felt that the medication improved their clarity of thinking [27, 34, 37] which was attributed in one study to reduced feelings of mental confusion [34].

Data in some studies provided an insight into how symptom improvement might reflect the global effects induced by neuroleptics described above. In some studies, participants described how the cognitive and emotion blunting effects of neuroleptics interacted with symptoms in a beneficial way, acting as a ‘shield’ or a ‘glove’ to minimise the impact of psychotic experiences or beliefs [23, 35]. They described how the medication ‘slowed down’, ‘muffled’ or quietened voices [26, 34] or reduced symptoms or distress more generally [35, 40], as expressed in the idea that the medication ‘deadens things down’ [40]. A participant in one study described how the drugs helped by producing a ‘blockage of brain functions’ [23] and others expressed the idea that the medication acted as a protection against the intrusion of unwanted emotions or symptoms, acting as a ‘nice buffer between my anxiety/emotions and the outside world’ [37] and ‘giving my soul some protection’ [23].

Although there were more reports of sedative effects being unwelcome and unpleasant, participants in some studies reported that they valued the sedative effects of neuroleptics for their ability to increase sleep [23, 27, 33, 35, 37] and to produce feelings of calmness and relaxation [23, 26, 27, 34, 37, 46]. These effects were especially evident in the study of clozapine [23]. In a number of studies, participants reported that neuroleptic medication improved the stability of their mood and helped them to become more ‘level-headed’ [23, 27, 33, 35, 37].

Data from several studies suggested that the symptom reduction achieved by neuroleptics appeared to improve people’s ability to function or ‘cope’ [46] and enabled some to lead a ‘fairly normal life’ [23, 27, 29, 34, 39, 46]. The authors of one study concluded that neuroleptics worked ‘not by completely removing symptoms, but by calming the self and muffling the voices enough so that life was manageable and the person felt good.’ [34].

3. Medication and the self

(a) Depleting the self

‘A majority of these participants spoke specifically about the impairment to selfhood associated with psychotropic drug use, such as damaged psychic connections to others and other losses of a spiritual nature’ (pg 48) [31].

‘It makes me fat, depressed, lethargic. It strips my life and soul’ (pg 163) [43].

Across studies, some participants identified how the general alterations produced by neuroleptics affected their sense of self in a negative way, depriving them of valued aspects of their personality. The emotion-dampening effects of neuroleptics, their impact on motivation and initiative and the general dulling of cognitive capacities were particularly perceived as producing unwanted changes [36, 37]. ‘Your mind changes and you think differently’ was how a participant from one study put it [39]. This made people feel as if they had lost their real selves: ‘I felt like a zombie. I did not feel like myself’ [38]. In addition, some people mentioned the loss of creativity [32, 33, 35, 37], imagination [41], humour [37] or a sense of ‘spirituality and spiritual connection’ [31]. They described how this altered their sense of who they were in a negative way, leading to ‘an impairment of selfhood,’ [31] or a loss of one’s ‘soul’ [43] or ‘spiritual nature’ [31]. One study concluded that the effects of neuroleptic medication disrupted people’s ‘emotional and perceptual being-in-the-world,’ but also commented on how these effects could be difficult to separate from the individual’s ‘illness experience’ [34]. Drug-induced physical changes like weight gain [23, 30, 32, 35, 43] and sexual dysfunction [34, 40] were also discussed in terms of how they negatively affected people’s sense of themselves and how they understood that they would be perceived by others.

(b) Restoring the self

On medication ‘the person felt in better control of him/herself and recognised that she/he was functioning more and more like the old self’ (pg 135) [34].

‘When I started taking medication, I felt like a new man. I was taking [name of antipsychotic] and I was getting on with it, I felt really positive, I felt level-headed’ (Y06) (pg 114) [26].

In contrast, a few participants in some studies identified how improvements in their mental symptoms produced by medication enabled them to regain a sense of self that had been negatively affected by their condition [26, 27, 34, 39]. People described feeling more like their ‘old self’ [34], a

‘new man’ [26], having hope of a ‘normal’ life and feeling like an ‘ordinary’ person again [39]. They described how, by enabling them to return to activities they enjoyed that were consistent with their underlying desires and values, neuroleptic medication enhanced their self-esteem [26] and helped them to feel ‘worthwhile’ [39]. Participants in some studies were reported as feeling that treatment had restored them to ‘normal,’ [23, 34], although the authors of one paper commented on how it was ‘only a few’ participants that held this view [23]. However, it seems that for some people neuroleptics facilitated the repair of a previously disrupted sense of self.

(c) Symbolic effects

‘In this way, the act of continuously ingesting the medication makes the individual feel compelled to reaffirm and to acknowledge the schizophrenia. Therefore, due to being strongly linked, the medication can be as undesirable as the schizophrenia’ (pg 367) [48].

‘I felt it was eroding of my self-image and when I took the medication it was more or less saying that I wasn’t whole’ (pg 150) [39].

Apart from the direct, pharmacological effects, taking neuroleptic medication also had a symbolic impact on people’s sense of identity. For many people, the medication represented the fact that they were a patient with a disease. A few participants welcomed this view [30, 33, 34, 46, 49, 50]. Some others described how they had initially believed the medication represented a ‘cure’ for their disease, but later became disillusioned with this idea [30, 34, 35, 44], coming to see their previous beliefs in the possibility of a ‘miracle cure’ [34] as overly simplistic or ‘reductionist’ [30].

Participants from several studies expressed how they did not want to regard themselves as having ‘schizophrenia’ or a long-term condition and for these people, taking neuroleptic medication symbolised an unwanted and stigmatised identity as a chronic psychiatric patient [24, 29, 33, 38, 39, 44, 51, 52]. They felt that needing to take medication made them ‘lesser people’ [39] and confirmed to others that they were ‘weird’ [24], ‘mad’ [44] or ‘crazy’ [38], especially because the effects of neuroleptics were sometimes very visible and described as making people ‘look ill’ [32] or ‘like a patient’ [29]. Neurological effects [28, 32, 39, 42, 45, 46] and weight gain [23, 39, 45] particularly contributed to this. There was a sense expressed in some studies that being regarded as needing medication denied the participants’ own intrinsic value, as if without treatment they were simply seen as the manifestation of a disease process and not a fully fledged person [34, 52]. A participant from one study expressed it as follows:

“They would think that the pill itself is what’s helping me be a person. And I mean, that’s not the case. Whether I took it or not, I still have value” [52].

4. Agency and medication

‘Several of the interviewees felt that they had no control over, or ability to influence, their drug treatment. There are many examples in the interviews of situations where the choices of drugs and doses were made by the psychiatrist without prior discussion with the person about former experiences of the drugs or of his or her own preferences’ (pg 824) [33].

‘I always accepted the medication. It may have made me feel bad, but I accepted it. I accepted it without complaint’ (P33) [48].

Many participants across studies appeared to have a passive attitude towards their medication that was often related to a broader sense of loss of agency. In some studies, for example, participants were noted to endure serious and unpleasant adverse effects without complaint, as if this was the normal, expected outcome of treatment [28, 48]. In several studies participants explained that they took medication simply because doctors told them to, and many felt they had no choice over it, nor did they understand what the medication was for or how it was meant to work [30–32, 36, 39, 42, 47–49, 52]. The authors of one study commented that people who accepted neuroleptic medication were often unable to articulate exactly why they took it [31]. In various studies, participants described feelings of hopelessness, helplessness, fear, confusion or indifference concerning their neuroleptic medication [28, 31, 33, 36, 48–50, 52].

Data from included studies also record how participants perceived their autonomy over medication to be restricted by assumptions about the underlying disorder, often reporting medication taking as necessary to avoiding a further relapse or rehospitalisation [23, 26, 30, 31, 35, 36, 40, 43, 44, 51]. For some this involved having to ‘put up with side effects’ [42], but they concluded that taking the medication was ‘the lesser of two evils’ [38]. Others described broader social processes in which medication and reduced autonomy were related. Some were subject to formal legal controls, or felt that there was an informal threat of rehospitalisation if they did not accept medication [26, 31, 36, 42, 46, 49]. Some described pressure from mental health professionals, relatives or friends [26, 31, 36, 39, 46], and some voiced concern about losing access to care and services if they refused medication [30, 46]. Across studies, participants also described the impediments to taking an active role in decisions about their treatment due to not being given

information or opportunities to express their preferences [26, 30–33, 36, 38, 39, 42, 43, 46, 47, 49, 52].

These effects combined to produce what some studies termed a ‘resigned’ or ‘reluctant’ acceptance of medication [28, 36]. Some participants had ‘given up’ trying to exert an influence over their treatment and a state of passive endurance had become a ‘pervading way of life’ for many people [28]. However, passive acceptance was not ubiquitous: many studies also reported some participants who actively embraced taking neuroleptic medication, and described contributing to decisions about their treatment in the context of a positive and collaborative relationship with their clinicians [24, 26, 30, 33, 34, 36, 42, 43, 47–51]. Others actively resisted the expectations of professionals and asserted their autonomy over their medication either by discontinuing it altogether [26, 30, 31, 34, 42, 43, 46, 48, 51], or by modifying the regime to suit their needs [26, 28, 33, 36, 45, 46].

Discussion

The current paper synthesises data from the increasing number of studies of people’s experiences of neuroleptic medications. Users of neuroleptics consistently described a distinctive experience characterised by sedation, cognitive impairment, emotional blunting and reduced motivation, which was associated with a variety of physical effects, including neurological effects, weight gain and sexual dysfunction. These effects are also documented in non-clinical samples [53]. They have been referred to in the past as ‘neuroleptic-induced deficit’ syndrome [54], ‘neuroleptic dysphoria’ [55] and ‘deactivation syndrome’ [56], and they have been linked with negative effects on quality of life [55]. Harsher critics suggest neuroleptic effects represent a form of chemical modification of behaviour and personality [56, 57]. In the current study, the effects of neuroleptics were reported to interfere with people’s ability to carry out basic activities, but they were also associated with beneficial effects on the symptoms of psychosis and some other symptoms such as anxiety and insomnia. When medication reduced the intensity of intrusive psychotic experiences and other symptoms, it was able to improve people’s ability to function and restore a sense of normality. Others found the mental restriction and physical alterations hard to bear, and experienced a loss of important aspects of their sense of self and agency.

The data therefore provide some support for suggestions that dampening of emotional responses and slowing of cognitive processes may explain the ability of neuroleptic drugs to reduce psychotic symptoms [8, 9, 58]. Some authors have suggested that the therapeutic emotional effects of neuroleptics are mediated through the dopamine system [10], but the fact that neuroleptics have varying effects on many other

neurotransmitter systems that affect arousal, cognition and emotion (noradrenaline and serotonin, for example) [59, 60] suggests that the origins of these effects may be more complex.

Anything that changes our mental faculties is likely to impact on our sense of ourselves, and this is a common experience in relation to mood or experience-modifying agents [11]. In the studies we reviewed, some participants felt neuroleptic-induced effects deprived them of important aspects of their personality; their drives, imagination or humour, for example. Others felt that by reducing the symptoms of psychosis, the drugs were able to restore them to a state in which they felt ‘themselves’ again. Similarly, some people were content to view themselves as having a disease requiring ongoing treatment, while others felt that taking neuroleptic medication symbolised a tainted identity. Schizophrenia or psychosis can disrupt people’s sense of self [61, 62], and studies of personal recovery have described the importance of reconstructing a sense of self [63] in a way that is distinct from symptom improvement [64]. Therefore, although neuroleptics may effectively suppress symptoms, their effects can nevertheless be experienced as detrimental to sense of self and identity, with important implications for social functioning and achievement of life goals.

Several studies, including some of those included in this review, have commented on the loss of autonomy experienced by people with severe mental disorder, and their relative lack of involvement in decision-making compared to patients with other medical conditions [36, 46, 65]. In the current review, this was due to the ongoing or recurrent nature of the underlying condition, legal restrictions, informal pressures from family, friends or professionals, or lack of encouragement by clinicians to be involved in treatment decisions. The passivity and occasional indifference described in several studies may also reflect the effects of neuroleptics on energy and motivation, or might alternatively be a manifestation of the negative symptoms of schizophrenia in some cases. A previous systematic review also highlighted loss of autonomy in neuroleptic users, identifying this as occurring in relation to early treatment of the acute stages of the condition, and suggesting that people regain a sense of agency as their condition stabilises [13]. In contrast, the current review found that across studies, there appeared to be a group of people who had fallen into a long-term state of passivity and hopelessness in relation to their neuroleptic medication.

Limitations

The included studies were diverse in their settings and populations studied, but most were conducted in Western countries and studies not published in English were not included. Therefore, findings may not generalise to other parts of the

world. The quality of the papers was generally high, but studies employed diverse methods of data collection and analysis and the aims and focus of different studies also varied. Given the variety of populations and the consistency of results, the analysis suggests that the included studies provide a reasonably representative view of the typical experience of taking neuroleptic medication.

Qualitative methods of systematic reviewing are still relatively new [20], but thematic synthesis facilitates the analysis of a relatively large number of studies, and allows for a broad summary of the literature. The collaborative nature of the current analysis through the various iterations ensured that the themes were firmly grounded in the data.

Clinical implications

Clinicians have been found to underestimate the impact of the adverse effects of neuroleptics on patients' quality of life [66, 67], which may contribute to the difficulties of achieving a more collaborative approach to decision-making with people with severe mental disorders [65, 68]. A fuller understanding of how neuroleptic drugs impact on important aspects of people's experience and feelings about themselves, and how these effects are entwined with effects on symptoms will enable clinicians to better recognise and respond to patients' concerns. This can facilitate better collaboration and improve clinicians' ability to support patients to retain agency and make informed decisions about their drug treatment based on balancing the benefits of neuroleptic drugs against the unwanted changes they can produce.

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Compliance with ethical standards

Conflict of interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

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