BRIEF REPORT Staff Knowledge of the Side Effects of Anti-Psychotic Medication

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Background Anti-psychotic medications are widely prescribed to people with intellectual disabilities and have a range of negative side effects. The aim was to identify the level of knowledge of anti-psychotic medications and their side effects among key carers or home managers of adults with intellectual disabilities living in residential group homes who are prescribed such medication.

Method The sample was 25 of the 30 adults on the caseloads of community nurses in one community learning disability team who lived in residential services and who were prescribed anti-psychotic medication. Key carers (n = 22) or home managers (n = 3) were interviewed about their knowledge of these medications and their side effects, the source of their knowledge and their needs for training.

Results Knowledge of potential side effects was somewhat limited. Only two were identified by the majority of respondents. Most respondents felt insufficiently informed and in need of further training.

Conclusions There is a role for an informed professional, such as a community nurse, to ensure that carers receive good, verbal and written information about such medications and their side effects at the time of prescription.

Keywords: anti-psychotic medication, intellectual disability, staff knowledge

Introduction

Prescription of anti-psychotic medication to people with intellectual disabilities is common, with rates of 20-50% in hospital and community-based residential services (Clarke et al. 1990; Wressel et al. 1990; Branford 1994; Etherington et al. 1995; Fleming et al. 1996) and about 10% of people living with their natural or substitute families (Clarke et al. 1990; Branford 1994). A 48% rate of use was found in a combined hospital and community population of people with behavioural problems in the North West of England in 1988 (Kiernan et al. 1995). A follow-up study of a selected cohort of the 1988 population in 1995 found an increase in rate of prescription from 41% to 51% (Emerson et al. 1997). The same study found a 22% rate of use among a new total population sample of people with behavioural problems. A 21% rate of use was found in a primary health care sample (Molyneaux et al. 1999). Such rates are similar to those found in surveys overseas (Rinck 1998). About 8–15% of people with intellectual disabilities are thought to have serious psychiatric illness with psychotic illness clustering around 4–6% (Deb & Fraser 1994). Yet the commonest reason for the prescription of anti-psychotic medication is for the management of behavioural problems (Clarke *et al.* 1990; Wressel *et al.* 1990; Molyneaux *et al.* 1999). The case for such widespread use for behavioural management has not been demonstrated (Aman *et al.* 1995; Rinck 1998).

Anti-psychotic medications are complex in their actions and have a wide range of effects (Downie *et al.* 1995), including adverse cardiovascular, central and autonomic nervous system and endocrine function side effects (Baumeister *et al.* 1998). Common side effects include weight gain, drowsiness, apathy, agitation, insomnia, excitement, headache, dizziness, confusion and gastrointestinal problems. Davies (1986) reported that patients without an intellectual disability taking

psychotropic medication commonly complained about subjective unease with mental fatigue and general lethargy, which they had difficulty in explaining. Neuroleptics can produce a range of extrapyramidal side effects such as pseudo-Parkinsonism and other muscle or movement disorders and may infrequently cause neuroleptic malignant syndrome, a condition which can be fatal (Baumeister *et al.* 1998). Longer term, anti-psychotic medication may produce tardive dyskinesia. It can be irreversible and there is no effective treatment (Baumeister *et al.* 1998).

As care staff may under report or not recognize side effects (Fleming et al. 1996), Jenkins & Harris (1999) and Kroese et al. (2001) have recommended that care staff should be provided with information, training and support about anti-psychotic medications and their potential side effects. However, a literature search failed to identify research on staff knowledge of anti-psychotic medication and their associated side effects. The aim of this study was to conduct a pilot study in this area. Adults with intellectual disabilities on the caseloads of community nurses in one locality in South Wales who were prescribed anti-psychotic medication were identified. Staff knowledge of the prescribed anti-psychotic medications and their associated side effects, the sources of their information, and the extent and perceived adequacy of any specific training undertaken were ascertained.

Method

Participants: adults with intellectual disabilities

Community nurses within one Community Learning Disability Team in South Wales completed a simple questionnaire in order to identify all adults on their caseloads and their current medications. In total, 137 adults with intellectual disabilities were identified, of whom 60 (43.8%) were being prescribed anti-psychotic medication. A second inclusion criterion selecting only the adults living in staffed accommodation reduced the sample to 30. Twenty-five adults subsequently agreed to take part; two people refused, two moved into alternative residential accommodation out of the locality and one died.

The 25 adults (14 men, 11 women) lived in 14 staffed houses provided by five organizations. Their ages ranged from 25 to 72 years, with a mean age of 53 years. Total scores on part I of the Adaptive Behavior Scale (ABS) (Nihira *et al.* 1993) ranged from 44 to 256, with a mean of 162. Total scores on the Aberrant Behavior Checklist (ABC) (Aman & Singh 1986) ranged from 6 to 114, with a mean of 39. Seventeen (68%) had a mental illness indicated as a secondary diagnosis, eight (32%) bi-polar affective disorder and nine (36%) a non-specific mental illness. A further six (24%) were recorded as having epilepsy, autism or challenging behaviour, or a combination of these. Nineteen (76%) were prescribed a sole anti-psychotic. The remaining six (34%) were prescribed two anti-psychotic medications. In total, there were nine different anti-psychotic medications prescribed (see Table 1). DISCUS assessment (Sprague *et al.* 1989) showed that 16 adults (64%) did not display any signs or symptoms indicating dyskinesia, while the scores of the remaining nine indicated only 'minimal symptoms'.

Participants: staff respondents

One member of staff designated as a 'key carer' participated in the research for each of 22 of the 25 adults with intellectual disabilities who took part. Three adults did not have a designated key carer and the home manager was the respondent in each case. The length of time that the 22 key carers had been appointed as a key carer varied from 1 month to 10 years with a mean of 2 years and 5 months. Sixteen of the 25 staff respondents (64%) were female and nine (36%) were male. Their mean age was 40 years (range: 23-58 years). The majority, 22 (88%), worked full time (37 h and over per week) and three (12%) were part time (below 36 h per week). Length of employment in the homes varied from 10 months to 12 years, with a mean of 4 years and 5 months and 15 (60%) had been in lengthier employment with their employing organizations, working in other homes. Two (8%) had nursing qualifications, six (24%) had national vocational qualifications (NVQ), five (20%) had A levels or university degrees, eight (32%)

Table I Frequency of prescribed medications

Medication	Frequency of prescription $(n = 25)$		
Chlorpromazine	6		
Risperidone	6		
Olanzepine	4		
Clopixol	Injection 2		
	Tablet 2		
Fluphenazine injection	4		
Haloperidol	2 + 1 Pro Re Nata		
Amisulpuride	2		
Depixol tablets	1		
Quetiapine	1		

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had General Certificate of Secondary Education (GCSE) or O level qualifications and four (16%) had no qualifications at GCSE or O level or above.

Measurement

In addition to the ABS, ABC and DISCUS assessments and the obtaining of other participant characteristics, a questionnaire was developed to cover: (i) staff respondent characteristics (qualifications, length of time in current employment, hours worked, length of association with the participant, length of experiences as the participant's key carer); (ii) their knowledge of the participant's current medication and the possible side effects of prescribed anti-psychotic medication; (iii) the source of that knowledge; (iv) past training on the side effects of anti-psychotic medication; and (v) their perception about the adequacy of the information they possessed and their perceived requirements for further training.

Procedure

Ethical approval was gained from the Gwent Ethics Committee. Permission for the researcher (CF) to approach the homes identified was obtained from the service organizations. Consent forms and briefing information were developed for participants and staff respondents. The information for staff respondents explained the purpose of the research and that at least 2 h would be necessary to complete assessments. It was made clear that the information gained would remain confidential and that the questions regarding knowledge should not be regarded as a test but as an indication of how well staff had been informed. The information for participants was provided in clear, concise and simplified terms. Text was written in large, bold font. Adequate time was set aside to talk to participants to try to ensure that they understood the purpose of the research and that personal information on their medication and behaviour was being sought from their carers. It was made clear that refusal to participate would not affect the care that they were receiving or the care that they might receive in the future.

The researcher met staff respondents and participants in each home to discuss the proposed research and give out the briefing information. Although all staff respondents and some participants agreed to take part at the first meeting, time was given for reflection and for participants to discuss the research with their carers alone. A second visit was arranged so that the researcher could discuss the research requirements again. Consent forms were made available at this second appointment and signed at this visit providing the participant agreed to take part. Two witnesses within the home signed to vouchsafe that the information was understood and consent was being given. Staff respondents signed consent forms with respect to their own involvement after the participant had consented to take part. A proportion of participants could not give informed consent and assent was gained from their key carer and home manager. Copies of signed consent or assent forms were given to participants and staff respondents to be put in participants' personal files.

Once consent had been obtained, a further appointment was made to complete the questionnaire and assessments at a time when the participant was also available within the home so that the observations required to complete the DISCUS could be undertaken. All staff respondents were given dedicated time by home managers to take part in the research and it was not necessary to return to any home to complete an assessment.

Results

Staff respondent knowledge

Overall, staff respondents identified 18 different potential side effects (see Table 2). Apart from tremor and

Table 2 Potential side effects identified by staff respondents(n = 25)

Side effects associated with anti-psychotic medications	Number of staff respondents who identified side effect		
Tremor	13		
Drowsiness	13		
Slurred speech	12		
Dry mouth	11		
Dizziness	10		
Upset stomach	10		
Sleep disturbance	9		
Headache	9		
Dribbling	9		
Weight change	8		
Photosensitivity	8		
Jaundice	8		
Confusion	6		
Rash	2		
Tardive dyskinesia	1		
Sensory impairment	1		
Hypersensitivity	1		
Constipation	1		

	How	From whom	When
Information received			
Yes (<i>n</i> = 14)	Specifically written $(n = 2)$	Community nurse $(n = 3)$	Later date $(n = 2)$
	Leaflet $(n = 1)$	-	When prescribed $(n = 1)$
	Leaflet $(n = 9)$	Pharmacy $(n = 4)$	When prescribed $(n = 2)$
		-	Don't know $(n = 2)$
		Consultant ($n = 3$)	When prescribed $(n = 3)$
		Work colleague ($n = 2$)	Don't know $(n = 2)$
	Verbally $(n = 2)$	Consultant ($n = 2$)	When prescribed $(n = 2)$
No (<i>n</i> = 11)	Not applicable		

Table 3 Information on prescribed anti-psychotic medication received by staff respondents

drowsiness, each potential side effect was mentioned by a minority of respondents. The number of potential side effects identified by each staff respondent averaged 5.4 (range: 0-13). Five staff respondents (20%) were unable to identify any side-effects associated with the prescribed anti-psychotic medication. Seven (28%) identified 1-3 side effects. Six (24%) identified 4-9 side effects. Seven (28%) identified 10-13 side effects. Using Mann-Whitney U-tests, there were no significant differences in the number of potential side effects identified between staff with nursing or NVQ qualifications and staff with only academic or no qualifications (U = 58.5, P > 0.05), staff who had above and below average length of service with their employing organization (U = 72.0, P > 0.05), staff who had above and below average length of service within the current setting (U = 58.5, P > 0.05) and staff who had and had not received training on the side effects of anti-psychotic medication (U = 59.5, P > 0.05). However, staff who reported receiving specific information about the prescribed antipsychotic medications (see next section) identified significantly more potential side effects than staff who reported not receiving such information (U = 18.5, P < 0.001).

Source of information and training needs

Table 3 shows whether staff respondents had received information about the prescribed anti-psychotic medications and their side effects, the form of that information, when it was received and who gave it to them. Eleven staff respondents (44%) reported not having received information regarding the prescribed medication. The remaining 14 had received information, two through specifically written documentation, 10 through leaflets and two verbally. The consultant was the source of information for five key carers, the pharmacy for four, the community nurse for three and work colleagues for **Table 4** Perceptions about knowledge of medication and need for training

	Sufficiently informed		Perceived training need	
	Yes	No	Yes	No
Training				
Yes	5	4	6	3
No	5	11	16	0

two. Eight of the staff respondents had received the information when the medication was first prescribed, two reported being given it at a later date and four were unable to say when the information had been given. Only a minority of staff respondents felt that they had sufficient information and required no further training (see Table 4). Most thought that they did require training, including the majority of those who had already had some training.

Discussion

The study had a small sample drawn from the caseloads of community nurses in only one community learning disability team. Its focus was on key carers' or home managers' training in relation to anti-psychotic medication and their knowledge of potential related side effects. One must be cautious about generalizing too far on the basis of such evidence. The findings here may not be representative of other community team areas within the United Kingdom, as training of carers within community settings is not uniform and can be dependent on factors such as the resources and time dedicated to training, the qualifications and experience of carers and the approach and orientation of professionals such as psychiatrists and community nurses.

However, the findings of this study do give some cause for concern in that only a minority of a largely unqualified, albeit experienced, group of staff had received prior training on anti-psychotic medications and their side effects and, while slightly more than half had received relevant written or verbal information, most thought that the information they had was insufficient and that they would benefit from training. It is difficult to interpret the staff knowledge of potential side effects found precisely. There are no standards for what level of knowledge would be deemed sufficient and what balance should be achieved between awareness of the relatively high likelihood of such side effects as weight gain or diabetes associated with the use of certain atypical anti-psychotic medications such as, olanzapine, as against, for example, alertness to the possibility of extrapyramidal side effects. Nearly half showed awareness of a reasonable number of potential side effects, but the remaining slight majority identified three or fewer. Moreover, only two potential side effects were mentioned by a majority of respondents. This summary would seem to indicate a situation which could be improved.

Staff respondents felt that information regarding side effects to prescribed medication should be given: (i) at source; (ii) when first prescribed; and (iii) preferably in a written format. This would appear to be important as receiving such information was associated with identifying a greater number of potential side effects. In this study, all participants received their medication via a monitored dosage system (dosset box), meaning that all medication was sent from the pharmacy ready to give out on a daily basis. Information sheets were not automatically sent out with the medication even if it was new, the onus being on care staff to ask the pharmacy to supply them, which did not always happen. Active and automatic provision of information leaflets would constitute better practice.

Another possible explanation for the lack of staff knowledge is that they were not always present at the meetings at which medication changes were made. All of the participants received regular medication reviews, mainly via a consultant psychiatrist or a junior member of the medical team. Such reviews provide an opportunity for information exchange between informed professionals and carers. Ideally the key carer or home manager should attend review appointments. Moreover, it might be expected that the community nurse would attend appointments where a review of medication was undertaken. Community nurses have relatively frequent and consistent contact with participants receiving anti-psychotic medication and their carers. They are also knowledgeable about such medications and their side effects. Therefore, it would seem appropriate for community nurses to take on the responsibility for making sure that participants and their carers know about the nature of the medications being prescribed and their potential side effects. This would fit well with their role to monitor such medications and report any adverse effects to the prescribing doctor.

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