Disability support workers’ knowledge and education needs about psychotropic medication

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accessible summary

- The staff who are paid to support people with an intellectual disability in Australia are called disability support workers.
- As part of their job, disability support workers give out medications when the doctor says to. Some of these medications are used to help people with disability to calm down when they are angry. Often, these medications are not for treating any illness. These medications can sometimes make people feel very ill. In the past, the staff who used to give out these medications were nurses, but nurses do not do this job anymore.
- This study asked disability support workers what they think they need to know about the medications they give out.
- Most of the disability support workers said they needed to know more about these medications if they were to keep people safe, and it would also help them to talk to the doctors about what these medications are for when they go to appointments with people with a disability.

Summary

Disability support workers are the predominant workforce employed to support people with an intellectual disability in Australia. Many support workers are required to assist people they support to take psychotropic medications in the form of chemical restraint. Support workers in Australia receive limited education and training in this area and as a result may miss important information about effects of medication on the people they support. In this study, we asked support workers about their education and training needs around chemical restraint. Our results showed that while the majority of support workers feel they are provided with good support from their co-workers and supervisors, they feel they need more specific information regarding the side effects of psychotropic medication and its alternatives. Finding ways to support the support workers is crucial if we are to minimise the use of chemical restraint and provide best support possible to people with disabilities.

Keywords challenging behaviour, disability, disability support workers, education, psychotropic medication
Introduction

In Victoria, Australia, the use of psychotropic medication for people with a disability in receipt of a service to control behaviours is considered by law to be a chemical restraint (Disability Act, 2006).

In Victoria, chemical restraint is defined as:

'the use, for the primary purpose of the behavioural control of a person with a disability, of a chemical substance to control or subdue the person but does not include the use of a drug prescribed by a registered medical practitioner for the treatment, or to enable the treatment, of a mental illness or a physical illness or physical condition' (Disability Act, 2006, p 2).

In Victoria, all government-funded disability support providers must report the use of restrictive interventions, such as chemical restraint, to the Senior Practitioner, who monitors the use of restrictive interventions in the State of Victoria. Our research has shown that chemical restraint is one of the most commonly used restraints in Victoria with 97% of approximately 2000 people reported to be subjected to chemical restraint every year (Webber et al. 2010a).

The workforce employed to support people with a disability in Victoria has dramatically changed over the past 15 years. Prior to 1993 in Australia, mental retardation nurses were, for the most part, trained in institutions that cared for people with an intellectual disability (Goodwin & Happell 2007; Happell 2007). At that time, it would have been common for nurses to oversee the health care and medical needs of people with intellectual disability. One of the outcomes of the de-institutionalisation process is a workforce of disability support workers who may not necessarily be trained in health care and psychotropic medication, but who are required to provide such interventions to people with an intellectual disability. Without critical information about the effects of medications, people with a disability may be suffering side effects of medication such as akathisia, nausea, headaches and stiffness in the joints, but go unnoticed by staff and family members. This is clearly a problem for people with disabilities, especially for those who may be unable to voice their distress.

While many argue that support workers should be made aware of information about psychotropic medications to manage challenging behaviours, such as the adverse effects of these medications (Brylewski & Duggan 2007), the majority of courses in intellectual disability support in Australia do not cover this information in any detail. Even when staff have been involved in training, there is evidence that they rarely pass their knowledge on to other staff (Institute of Medicine, 2004; Sienset al. 2007).

Recent best practice in behaviour support suggests that all people who present with severe challenging behaviour or behaviours of concern (harm to self and or others) should have a careful assessment of history, including a functional behaviour assessment (Carr et al. 2002). However, evidence suggests that often prescribing doctors rely solely on standard medical guidelines (Oliver-Africano et al. 2009; Tsioris 2010). In addition, disability support workers do not always complete functional behaviour assessments (Webber et al. 2011). Clearly, ethical concerns may arise when medication is used to solely control behaviour that is caused by environmental factors rather than biological factors (Lennox et al. 2005).

In the absence of education about chemical restraint in tertiary qualifications, continuing education and collaborative learning environments become critical to ensure the provision of good support to people with a disability (Ayers et al. 2008; Billet 2004; Clifford & Thorpe 2007; McDonnell et al. 2008; Robertson & Terrill 2005).

In this study, we set out to explore: (a) the perceptions of disability support workers' knowledge of chemical restraint, (b) support workers' perceptions of the support provided by other professionals and family of the person with a disability and (c) support workers' training needs in relation to the administration of chemical restraint. Based on previous studies and the current content of training provided to support workers, it was expected that support workers' knowledge of chemical restraint would be judged by support workers to be poor.

Method

There were two parts to this study. First, a survey was designed to examine support workers' perceptions about the support provided to them and their knowledge of chemical restraint. The survey consisted of two main sections: (a) demographic information and (b) a self-perception rating scale regarding the use of chemical restraint. Demographic information sought included age, gender, employer (government or community organisation) and whether or not the respondent had administered chemical restraint. The self-perception rating scale consisted of 15 questions about orientation to the role of support worker, support from other support workers, management and family for the role, knowledge about chemical restraint and ability to influence other workers. For each of these questions, the respondent was instructed to select a response from 1 to 5, where 1 = 'very poor' ability, skill, level of support, 2 = 'poor', 3 = 'average', 4 = 'good' and 5 = 'very good'. The survey also asked respondents whether they would participate in a follow-up interview. The first six volunteers who approached the researcher and consented were interviewed. Data were collected through semi-structured individual interviews. The interviews were audio-taped and lasted between 40 min and 1 h. An interview schedule was used to provide structure to the interview. Areas that were explored included the interviewee's training in relation to

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psychotropic medications and administration of psychotropic medications. The researcher also asked participants why they believed psychotropic medications are so widely used for people with a intellectual disability and in what circumstances they would consider giving a PRN (as needed) psychotropic medication. Finally, participants were asked to describe what other approaches they had seen used to calm people down and what training they would like to see offered to support workers regarding behaviours of concern. Each interview was transcribed in full, and emerging themes were identified. Ethics approval for the study was obtained from Deakin University Human Ethics Advisory Group.

Participants
The survey was e-mailed to 250 disability support workers in Victoria, Australia. One hundred and seventeen surveys were returned (46.8% response rate). Six respondents volunteered to participate in the semi-structured face to face interview.

Survey respondents
The majority of the survey respondents were from non-government disability services (n = 95). There were 14 surveys received from respondents in government services, and 8 respondents did not specify their employer. The mean age of the respondents was 41 years with an age range of 21–65 years.

Interview respondents
All interview participants were employed as support workers, but their workplace roles varied from direct support to supervisory roles; and settings varied and included accommodation, day and respite services.

Statistical analysis of the survey responses were completed using spss Version 16 (Chicago, IL, USA). The interviews were audio-taped with consent and transcribed by a research assistant, and to ensure reliability of data coding, a sample of what was checked by a research advisor. Data of the face to face interviews were analysed for themes.

Results
Knowledge about positive interventions
On average, participants rated their understanding of the term, positive intervention, as ‘good’ (M = 3.9). This was significantly and positively correlated with their ratings of other knowledge and abilities such as: (a) the understanding of the term chemical restraint (r = 0.58, P < 0.01); (b) knowledge of medications used for chemical restraint (r = 0.36, P < 0.01); (c) knowledge of side effects of medications used for chemical restraint (r = 0.31, P < 0.01); (d) knowledge of alternatives to chemical restraint (r = 0.54, P < 0.01); (e) their ability to manage behaviours of concern (r = 0.51, P < 0.01) and (f) ability to positively influence the practice of your co-workers (r = 0.31, P < 0.01). This pattern of results suggests that support workers who believe they have knowledge about positive interventions also feel that they have knowledge about other interventions and how to manage behaviours of concern and influence other co-workers.

Ability to communicate with people with an intellectual disability
On average, participants rated their ability to communicate with residents of the community residential unit (CRU) they are working in as ‘good’ (M = 4.4). Their perceived ability to communicate with the residents was significantly and positively correlated to: (a) their ability to manage behaviours of concern (r = 0.35, P < 0.01); (b) their understanding of the term positive intervention (r = 0.37, P < 0.01); (c) their perceived level of support given to them by their disability supervisor (r = 0.41, P < 0.01) and of support given by their co-workers (r = 0.39, P < 0.01). These results suggest that support workers who believe they can communicate well with the people they support also feel they understand how to use positive interventions and are supported themselves by other workers.

Ability to manage behaviours of concern
On average, participants rated their ability to manage behaviours of concern as ‘good’ (M = 4.1). This perception was significantly and positively correlated with (a) their understanding of the term chemical restraint (r = 0.54, P < 0.01); (b) knowledge of medications used for chemical restraint (r = 0.42, P < 0.01); (c) knowledge of side effects of medications used for chemical restraint (r = 0.40, P < 0.01); (d) knowledge of alternatives to chemical restraint (r = 0.40, P < 0.01) and (e) their ability to positively influence the practice of your DSW co-workers (r = 0.30, P < 0.01). These results suggest that support workers, who feel they can manage behaviours of concern shown by the people they support are likely to feel they have a good understanding of how to use chemical restraint, are aware of alternatives to chemical restraint and have the ability to positively influence other workers.

Perception of support provided by co-workers, family and allied health workers
The level of perceived support given by disability supervisor was rated as ‘good’ (M = 4.3). This was significantly and positively correlated to: (a) the level of support given to by
co-workers (r = 0.35, P < 0.01); the level of support given to by the Behavioural Intervention Support Team (r = 0.30, P < 0.01); as well as (c) participants understanding of the term chemical restraint (r = 0.30, P < 0.01). Similarly, the level of support given to them by co-workers was also rated as good (M = 4.2), and this perception was significantly and positively correlated to (a) the level of support given by the resident’s family (r = 0.29, P < 0.01) and (b) the level of support given by the behavioural intervention support team (r = 0.30, P < 0.01). The level of support given by the resident’s family was rated as ‘average’ (M = 3.6), and this perception was significantly and positively correlated to (a) the level of support given by the resident’s general practitioner (r = 0.53, P < 0.01); (b) the level of support given by the behavioural intervention support team (r = 0.46, P < 0.01); and (c) the participants’ ability to positively influence the practice of co-workers (r = 0.31, P < 0.01). The level of support given by the resident’s general practitioner was rated as ‘average’ (M = 3.5), and this was significantly and positively correlated with: (a) the level of support given by the behavioural intervention support team (r = 0.46, P < 0.01); and (b) the participants’ ability to access training/education sessions about chemical restraint (r = 0.34, P < 0.01).

The level of support from behavioural intervention support teams was rated as ‘average’ (M = 3.0). This was significantly and positively correlated with (a) understanding of the term positive intervention (r = 0.36, P < 0.01); (b) ability to manage behaviours of concern (r = 0.38, P < 0.01); as well as knowledge of medications used for chemical restraint (r = 0.32, P < 0.01); knowledge of side effects of medications used for chemical restraint (r = 0.41, P < 0.01); (d) knowledge of alternatives to chemical restraint (r = 0.39, P < 0.01) and (e) the participants’ ability to access training/education sessions about chemical restraint (r = 0.38, P < 0.01).

In summary, support workers who felt well supported to do their work by their colleagues tended to feel supported by other allied health professionals as well as family members. But, the majority of support workers only felt they received average levels of support from behaviour intervention specialists and medical doctors.

Disability workers’ perception of their knowledge about psychotropic medication

On average, participants rated their knowledge of medications, side effects of medications used for chemical restraint and alternatives to chemical restraint as ‘average’ (knowledge M = 3.3; side effects M = 3.0 and alternatives M = 3.4). Knowledge of medications used for chemical restraint was significantly and positively correlated with respondents’ perceptions of their knowledge of: (a) the term chemical restraint (r = 0.41, P < 0.01); (b) side effects of medications used for chemical restraint (r = 0.75, P < 0.01); (c) alternatives to chemical restraint (r = 0.47, P < 0.01) and (d) ability to access training/education sessions about chemical restraint (r = 0.31, P < 0.01).

Ability to access training about chemical restraint

In the survey, support workers felt they needed further training in the area of chemical restraint and its alternatives, rating their knowledge of medications used for chemical restraint as low (M = 3.0). There was a tendency for people who judged themselves to have greater confidence in knowledge of chemical restraint (r = 0.32, P < 0.01), associated side effects and alternatives to chemical restraint (r = 0.41, P < 0.01), when the behavioural intervention support team is involved. On average, participants’ ability to access training/education sessions about chemical restraint was rated as ‘average’ (M = 3.1). This was significantly and positively correlated with the ability to positively influence the practice of their DSW co-workers (r = 0.48, P < 0.01). On average, participants rated that their orientation to the role they are employed in rated as ‘good’ (M = 3.9). As expected, those who felt they had a good orientation to their role of support worker was found to be significantly positively correlated with: (a) the ability to communicate with residents who lived in the shared supported accommodation (SSA) they were working in (r = 0.43, P < 0.01); (b) an understanding of the term ‘positive intervention’ (r = 0.35, P < 0.01); (c) the level of support given to them by their disability supervisor (r = 0.38, P < 0.01); (d) the level of support given to them by the behavioural intervention support team (r = 0.32, P < 0.01) and (e) the ability to access training/education sessions about chemical restraint (r = 0.35, P < 0.01).

In summary, support workers rated their knowledge of chemical restraint as low and their knowledge of side effects and alternatives to chemical restraint as average, while rating their knowledge of other aspects of support as good to high. This suggests that the majority of support workers feel they need more information and skills in the area of chemical restraint. The interview results below add to this picture and have some implications for training in this area.

Interview results

The results of the interviews suggested that many staff regarded medication as the best and only solution to manage challenging behaviours. For example, four of the six participants stated that psychotropic medications were therapeutic and given as treatment, 'I mean I think that it's to improve their quality of life' (2B). However, the majority of interviewees claimed that an effective alternative to chemical restraint was talking to the client (1A, 1B, 1C, 2A, 2B). Other alternative approaches included the use of
humour (1A, 2A) and massage or aromatherapy (3A). Suggesting that support workers were aware of alternative approaches to the use of chemical restraint, e.g. 'I think that you can avoid medication, with 90% of people if the people who are working in that environment understand and provide a consistent approach' (1A).

The majority of interviewees said they would only use PRN medication, when a person was either posing harm to self or harm to others (1A, 1B, 2B), and one participant had only given PRN medication in the case of self-injurious behaviour (1C). One participant stated they would follow management guidelines (2A), and one said they would use their judgement based on past experience and patterns of escalation for the person (3A).

I think that there are so many people who might be on a drug, when they're really, just need someone to be able to try and understand what they're going through.... That's why they are so widely used is because, I mean it takes a while, but once the drugs are in the system, then they might stop exhibiting the behaviour. So then it's considered it's cured, when really it hasn't been addressed. (2A)

Although on average, support workers' survey responses rated their ability to communicate with residents good to very good, two interviewees felt that communication can be an issue (1C, 2A) and may lead to the prescribing of chemical restraint. However, no participants acknowledged the part support workers play in the ongoing prescribing of these medications. The prescribing of medications used as chemical restraint is greatly influenced by the information given to both psychiatrist and general practitioner by those who are employed as support workers, whose competency-based training may vary considerably (Grey & McClean 2007). Communication is a major issue with unqualified and untrained support workers expected to interpret and communicate the complex needs of those people they are employed to support.

There was a certain helplessness expressed by participants:

'I work in respite, so we don’t have that control of um taking the clients to the doctor’s, it’s all done by parents. So it’s really not our call to be saying whether or not they should be on it, or they should be not. We can advise that, they’re not displaying those sorts of behaviours here, that doesn’t mean to say that they’re not doing it at home'. (2B)

In this situation, roles need clarification regarding the use of restrictive interventions. The Disability Act (2006) legislates that all behavioural management plans are signed by an independent person under section 143, and this provides a transparency to planning that has previously not been open to question. Unfortunately, multiple plans continue to be submitted to the Office of the Senior Practitioner from different agencies providing support for the same person. Collaboration is a concept that continues to be too big a cultural shift for some service providers.

In terms of training, some interviewees felt their original orientation to the role of support worker was not very comprehensive, and training regarding psychotropic medications had only been experienced by two participants (1B, 2B). One participant (1B) claimed they had covered in general medication information and the other (2B) had attended a course provided by the government disability services. No training had been experienced by three participants (1A, 1C, 3A). The interviewees identified several areas for training in 'challenging behaviours' (1B, 3A); medications used as chemical restraint (3A), communication techniques (2A), mental health (2B) and restraining techniques (3A).

Only one participant queried the benefit of administering PRN chemical restraint:

They want medication um to bring down the behaviour when in fact it may not be doing that, but because they’re frightened and their anxiety levels are up, they really want the medication, but in fact for a PRN medication, it may be 40 min before that PRN medication kicks in, and by then the behaviour's probably already happened. (3A)

Conclusion

The results of this study suggest that the majority of disability support workers in Victoria, Australia, feel they have the skills and support from their co-workers to support people with a disability who show severe challenging behaviour, but also feel they do not have the information they need about chemical restraint and the side effects and alternatives. They also tend to feel not well supported by General Practitioners and behaviour intervention specialists (people who may be able to help them understand chemical restraint). One outcome from this finding is that support staff may be unable to interpret side effects and find alternatives to the use of chemical restraint and may continue the use of chemical restraint, because they do not know how better to support the person. A clear practice implication is that all disability support workers should be offered training in chemical restraint as part of their orientation to the role of disability support worker, and this should be performed in conjunction with positive behaviour support, so that connections can be made between good assessments of function and alternative skills and supports needed to improve quality of life.

For disability support workers already working in the field, perhaps, this may be best carried out through communities of practice, where support workers meet regularly to share and increase knowledge, especially with allied health workers such as behaviour intervention specialists (Wenger et al. 2002).

Although perhaps well intentioned, we know that much of the support given to people with a disability, who
demonstrate behaviours of concern, is primarily focused on reactive strategies, rather than understanding behaviours of concern and finding alternative support (Webber et al. 2010a,b). Unless the underlying problem causing the behaviour of concern is understood and addressed, it is likely that the behaviours of concern will continue once the effect of the chemical restraint is over (Webber et al. 2010b). Therefore, for systems change an important component of training will be positive behaviour support (Reid et al. 2003).

There were three main limitations that should be taken into account when interpreting these findings. First, the questions used in the survey sought perceptions rather than actual knowledge and skills, and perceptions may be different from actual abilities, as people have a tendency to overestimate some abilities and underestimate other abilities. A second limitation is the low numbers of people interviewed; such numbers are not representative of the population of disability support workers in Victoria. Finally, it appears there is a connection between perceived knowledge of positive interventions and chemical restraint, but the data collected here can not inform us about what disability support workers understood as ‘positive interventions’. Other research should examine this in greater detail uncovering what disability support workers understand to be included in positive interventions.

Despite the aforementioned limitations, the results of the study are interesting and suggest that disability support workers need information about both chemical restraint and alternatives. Such knowledge should be added to current positive behaviour training rather than separate, so that connections can be made between good assessments of function and alternative skills and supports needed to improve quality of life.

Conflict of interest

This study was part of a requirement of a Master in Professional Education and Training undertaken at Deakin University by the first author. This study was supported by the Office of the Senior Practitioner, and there is no restriction placed on the publication of this data, and there is no conflict of interest or financial gain for any of the authors listed.

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