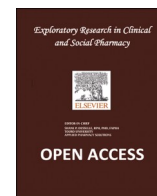


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Medication management issues perceived by pharmacists and disability caregivers while supporting people with disability

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ABSTRACT

Background: Australia has a notable gap in guidance for pharmacists, caregivers and disability service providers in: (i) supporting people with disabilities (PWD) within the medication management cycle, (ii) understanding their obligations for providing high quality care, and (iii) preventing medication-related harm.

Objective: The objective of this study was to identify medication management issues for PWD from the perspective of disability caregivers and pharmacists when supporting PWD with their medication.

Methods: A qualitative study design using semi-structured interviews of pharmacists and disability caregivers was undertaken across six different states or territories in Australia.

Results: Interviews were conducted with registered pharmacist participants (n=10), and disability workers (n=10). Seven themes emerged for both pharmacists and caregivers, with most sub-themes and codes concordant between the two cohorts. Clinical issues, particularly related to polypharmacy and psychotropic use; confidence in providing medicines and medication information accurately to PWD; practical and behavioural issues caregivers experienced when administering medication; challenges in providing individualised and person-centred care to PWD; inadequate communication and transfer of information between healthcare professionals, caregivers, and PWD; insufficient disability awareness training for pharmacists and medication training for caregivers; and challenges working with provider organisations within the current practice environment were described.

Conclusions: This study highlighted seven areas where issues were perceived to arise in medication management for PWD. By understanding the issues perceived by those directly providing care, it may be possible to improve medication management. Further research is needed to understand the perceived role of pharmacists in supporting medication management for PWD and their caregivers, and how enabling pharmacists scope might reduce medication-related risks and support QUM in this sector.

1. Introduction

There are currently 4 million Australians living with a disability, accounting for approximately 18 % of the population.¹ The World Health Organisation (WHO) regards disability broadly as a negative interaction between individuals with a health condition, and their personal and environmental context.² Many people with disability (PWD) require extensive, specialised health care needs due to their associated health conditions.³ Those with intellectual disability have 2.5 times the number of health problems compared with those without intellectual

disability,⁴ and high rates of epilepsy, hyperactivity disorders, schizophrenia, bipolar disorder, anxiety, depression, sleep and gastrointestinal disorders are found in this cohort.⁵⁻⁷ The most common therapeutic intervention is medication, however medicines have also increasingly become a global health concern due to a high prevalence of medication errors and unsafe practices.⁸ This is particularly pertinent to the Australian context for two reasons; (i) the introduction of the National Disability Insurance Scheme (NDIS), a mechanism to fund costs associated with disability, has resulted in a shift in living arrangements which sees a higher role for caregivers in managing medication, rather than

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nurses, and (ii) advocacy for the right to accessible, high quality healthcare for PWD and the scrutiny of medication has increased in the wake of the ongoing Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability (Disability Royal Commission).

Medication has become a growing concern in the disability sector with a gathering body of evidence demonstrating high rates of polypharmacy,^{9,10} commonly defined as the use of five or more medicines,¹¹ and the potential over-reliance on psychotropic medication.^{10,12–15} Inappropriate medicines are more commonly experienced in those with an intellectual or developmental disability, and those who are living in supported independent living or group home arrangements.¹¹ In addition to polypharmacy and inappropriate medication use within this population, the medication management burden experienced by PWD and their caregivers is further complicated by the changing environment within which PWD receive care. The introduction of the NDIS in 2013 has resulted in a shift from providing care in institutions such as residential aged care facilities (RACF), to providing care to PWD in their own home. The consequence has been a workforce shift from primarily nurse-led care to disability support workers providing care within organisations. This has led to disability caregivers navigating health matters and medication management without a requisite background in health or health literacy, and an increase in expectations for pharmacists and general practitioners (GPs) to understand the unique challenges of medication provision to PWD.¹⁶

Within health care systems across the world, medication errors and unsafe practices are a leading cause of avoidable harm, with most errors occurring during the administration process.⁸ This has been recognised by the 2017 launch of the Medication Without Harm Global Patient Safety Challenge by the WHO⁸ and the 2019 announcement by the Council of Australian Governments to make Medicine Safety the 10th National Health Priority Area.¹⁷ The Australian National Safety and Quality Health Service (NSQHS) Standards acknowledge the medication management cycle as a systematic and evidence-based approach to minimise risks and improve medication safety.¹⁸ The medication management cycle is a continuous system of nine activities and three system

processes to manage the safe and effective use of medication at each episode of care, as shown in Fig. 1. The activities include the decision to prescribe medication, record of medication order, review of medication order, issue of medication, provision of medication information, distribution and storage, administration of medication, monitoring for response, and transfer of verified information.¹⁸

Australia has a notable gap in guidance for pharmacists, caregivers, and disability service providers in supporting people with disabilities within the medication management cycle, and understanding their obligations for providing high quality care and preventing medication-related harm.¹⁶ The Disability Services Medication Management Framework developed by the Tasmanian Department of Health and Human Services in 2016 provide the only guidelines available that specifically address medication management in PWD and is not nationally recognised.²⁰ With the limited guidance provided in national and state-based legislation governing medication management, provider organisations are left responsible for determining the extent and content of training, policy, and guidelines with no standard to define best practice.¹⁶ The WHO notes that lack of therapeutic training, inadequate perception of risk, insufficient drug knowledge and experience, and complexity of clinical cases, such as those with multimorbidity, polypharmacy, and high-risk medications, influences medication errors.³ It is not clear how this limited guidance affects caregivers and pharmacists at the grass roots supporting PWD with their medication, or what challenges arise related to medication management.

Pharmacists promote patient safety and improve quality use of medicines (QUM) to PWD,²¹ and should ideally be embedded in the medication management cycle at every step.^{22–25} Previous Australian studies have explored community pharmacists' perceptions of their role in providing healthcare to people with intellectual disability,²⁶ and the efficacy of novel community pharmacy services to support caregivers in the community.²⁷ Earlier Australian studies have focused on the experience of GPs in providing healthcare to people with intellectual disabilities, and have identified communication difficulties, accuracy of medical histories, high workloads and lack of resources as problems when supporting this group.^{28,29} However, there are no Australian studies that have explored the day to day challenges of managing medications for PWD from the perspective of caregivers and pharmacists. The objective of this study was to use grounded theory to identify medication management issues for PWD from the perspective of disability caregivers and pharmacists when supporting PWD with their medication.

2. Methods

2.1. Study design

A qualitative study design using semi-structured interviews of pharmacists and disability caregivers was undertaken across six different states in Australia.

2.2. Recruitment

Recruitment of pharmacist and disability carer participants occurred through profession-specific social media channels, convenience, and snow-ball sampling, creating a mixture of non-probability sampling methods. Social media posts allowed for initial recruitment of pharmacist participants, and disability organisations within the Hunter New England Health District were approached to support recruitment of disability support workers by disseminating the participant information statement and consent forms through their communication channels. Participants who had provided consent were contacted to organise a mutually beneficial time for the interview and were offered a \$25 gift voucher as honorarium.

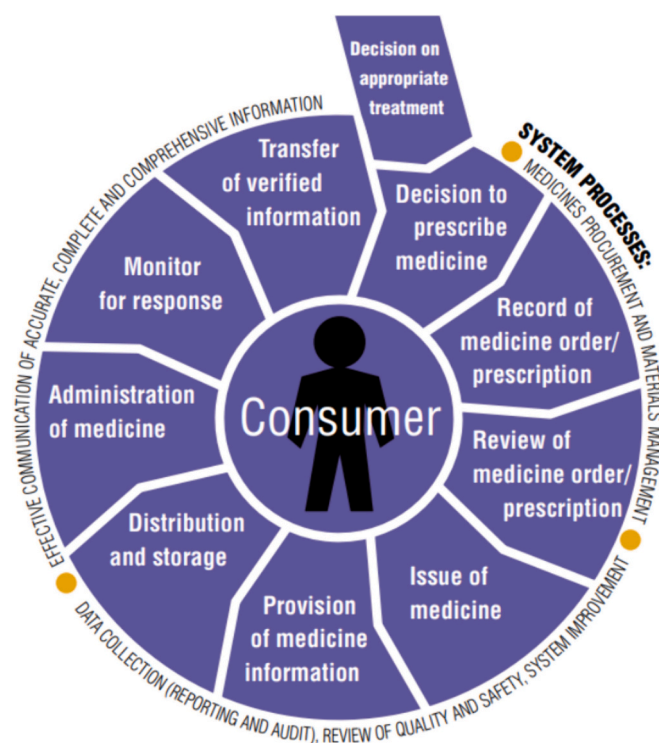


Fig. 1. Medication Management Cycle¹⁹.

2.3. Inclusion criteria

Any pharmacist currently registered with the Australian Health Practitioner Regulation Agency (AHPRA) who provided medication support to PWD in the community. Employed disability caregivers, as well as unpaid disability caregivers were invited to participate in the study if they cared for a PWD in the community and supported this person with their medication.

2.4. Data collection

Data were collected via one-to-one semi-structured interviews facilitated by interviewers CF and AR. Interviews began with collecting participant characteristics such as the number of hours the participant spends with PWD per week, and activities they perform as part of their role, followed by interview questions divided into two sections. Section one focused on the nature, extent, and source of medication-related issues for PWD from the perspective of pharmacists and disability caregivers. Section two explored the perceptions of participants about the role of the pharmacist in supporting medication use for PWD and their caregivers, and the barriers and enablers to fulfilling this role. The semi-structured interview guides were developed based on other comparable interviews found as part of the literature review by the research team, and suitability was determined by a pilot interview. Video and audio of the interviews were recorded with permission from participants via Zoom and an initial transcription obtained through Zoom software. Transcripts were reviewed and corrected to verbatim using the recordings by CF and AR.

2.5. Data analysis

Given the explorative nature of this study, inductive data coding was used across open, axial and selective coding processes guided by the Corbin and Strauss (1990) grounded theory analytical approach.³⁰ Excerpts were derived from the raw data by CF, with CF and AR linking key words or concepts with each excerpt. Key-words and concepts were reviewed independently by CF and AR to group excerpts together into codes, and then categorised into broad themes. The codes and initial themes were compared between researchers CF and AR, and differences in interpretation and analysis discussed. Axial coding using the raw data and interview notes was performed by CF to further validate the broad themes that emerged from the codes, which was reviewed independently by HC who had been present for 6 of the 20 interviews. Themes and sub-themes were subsequently refined following consensus from each researcher on the categorisation of the codes, and a description of each theme and sub-theme was provided along with data extracts to support each as evidence, strengthening the performed analysis. The selective coding stage helped the researchers to identify that the themes and their summaries strongly followed the medication management cycle and was subsequently mapped to this. Excerpts were coded according to whether the participant who quoted the excerpt was a pharmacist (P) or carer (C) with a number to indicate the participant interview. Data saturation was evident after six to seven interviews in the pharmacist participant group, and eight interviews within the carer group, with no new themes emerging from interviews after this point.

2.6. Ethics

The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines³¹ were used to guide the study. Ethics approval for this study was granted by the University of Newcastle Human Research Ethics Committee [H-2020-0098].

3. Results

3.1. Demographics

Ten interviews were conducted with registered pharmacist participants, and ten with disability workers. Interview times ranged from 30 to 50 min, and 25–40 min, respectively.

Pharmacist participants ranged from 30 years to 63 years of age, with equal numbers of participants working full time and part time. All participants conducted medication reviews as part of their roles, and nine participants had also worked in a community pharmacy within the last six months. Services performed included provision of dose administration aids, dispensing activities, reviewing medication charts, completing reviews for medications either at home as a specialised pharmacist or within a community pharmacy as the pharmacist on duty, and undertaking QUM services including providing education, over-seeing medication audits, and providing input into medication-related policies and procedures. Demographic data for pharmacists is shown in Table 1.

Disability caregiver participants ranged from 35 years to 82 years of age, with eight participants working full time hours in a paid care role and two participants working part time hours in an unpaid role. Roles among the paid caregivers ranged from disability support workers, house managers, and managing directors, while the unpaid caregivers were parents looking after adult children. All but two participants had more than 10 years of experience caring for PWD, and nine of the ten participants had completed a vocational education and training course through Technical and Further Education (TAFE) or a University degree. Demographic data for caregivers collected during the interviews is shown in Table 2.

3.2. Themes

Results from the thematic analysis are presented in Appendix 1. A total of seven themes were identified for both pharmacists and caregivers, with many overlapping sub-themes and codes between the two cohorts. These seven themes were Clinical Issues, Medication Supply, Medication Administration, Person-centred Care, Communication, Training and Education, and Contextual Issues.

Table 1
Demographic data for pharmacist participants.

Demographic		Number of Participants
Gender	Male	1
	Female	9
Location	NSW	2
	QLD	1
	SA	6
	Tas	1
Average hours per week spent in direct communication with PWD and/or carer	< 2 h	1
	2–4 h	5
	> 4 h	4
Roles*	Community Pharmacist	9
	Consultant (medication reviews)	10
	Clinical role**	8
	Hospital pharmacist	0

* Multiple roles could be selected, such as a pharmacist who worked part time as a community pharmacist, and part time as a consultant pharmacist.

** Clinical roles included pharmacists employed within a General Practice (GP) setting, or other primary health setting in which they undertook clinical duties outside of the dispensing role.

Table 2
Demographic data for disability carer participants.

Demographic		Number of Participants
Gender	Male	4
	Female	6
Location	NSW	8
	VIC	1
	WA	1
Type of care	Paid (employed carer)	8
	Unpaid (family carer)	2
Role of carer	Disability Support Worker	2
	House Manager	4
	Managing Director	2
	Family Member	2
Years of experience caring for a PWD	< 20 years	5
	20–40 years	2
	> 40 years	3
Level of education	High School	1
	TAFE*	5
	University	4

* TAFE or Technical and Further Education is education after high school that focuses on specific skill for a particular workplace, such as IT, design, childcare, disability care, business and more.

Table 3
Clinical issue sub-themes described by pharmacists and caregivers.

Theme	Sub-Theme	Code	Pharmacists	Caregivers
Clinical Issues	Psychotropic prescribing	Lack of regular psychotropic review	✓	
		Prevalence and volume of psychotropic prescribing	✓	✓
		Evidence base for psychotropic use in PWD	✓	✓
	Monitoring therapeutic/adverse effects	Observational monitoring	✓	✓
		Monitoring cardiometabolic adverse effects	✓	
	Polypharmacy	Prevalence and difficulties of polypharmacy	✓	✓

Table 4
Medication Supply sub-themes and codes described by pharmacists and caregivers.

Theme	Sub-Theme	Code	Pharmacists	Caregivers
Medication Supply	Medication supply	Packing/prescription errors	✓	✓
		Timeliness of changes	✓	✓
	Medication information	Accessibility of pharmacist		
Medication information provision		✓	✓	

4. Clinical issues

There were three sub-themes that emerged within clinical issues; psychotropic prescribing, monitoring therapeutic/adverse effects, and

inappropriate changes in formulation. Psychotropic prescribing was mentioned by most pharmacists and caregivers, particularly with respect to the prevalence of psychotropic medication, and multiple psychotropic agents being taken by a single person; “*it’s never just one [antipsychotic]. It’s around like two or three*” (P1). Pharmacists also noted that the lack of regular psychotropic review was a particular concern, with medications continuing for decades without an indication. The evidence base for prescribing psychotropics to PWD was identified as a clinical issue by both cohorts, particularly in relation to chemical restraint. Pharmacists were concerned that the lack of evidence made practicing in the area of intellectual disability particularly difficult, and that specialists would often prescribe outside the guidelines for mental health conditions, which made providing recommendations challenging. Identification and monitoring for therapeutic and adverse effects of medications was also noted by both caregivers and pharmacists. Some caregivers had a lack of confidence that adverse effects would be identified in non-verbal PWD, and that both PWD and caregivers “*likely don’t know that the adverse effects they are experiencing are not normal*” (C5). Pharmacists felt observational monitoring was vital particularly in the context of group homes where subjective measures of behaviour or adverse effects might vary between staff, and a lack of continuity of the same staff might lead to poor monitoring.

Pharmacists noted the requirement for monitoring cardiometabolic adverse effects and difficulty in determining appropriate risk vs benefit of antipsychotics created difficulties in providing recommendations.

5. Medication supply

Medication supply and medication information were the two sub-themes identified. Some caregivers commented that medications supplied by community pharmacy was adequate, while others described circumstances where medication supplied within dose administration aides were incorrectly packed by the supplying pharmacy. Prescription errors and the difficulty in being able to contact a doctor to confirm information was highlighted by pharmacists, particularly as it could also be difficult to confirm information from the PWD or carer. This then impacted the timeliness of changes, as the prescriber might often be unavailable and changes to dose administration aids would have to be held over for days. The accessibility of pharmacists was felt by caregivers to be a major factor in obtaining information about medication and could vary depending on the time of day and how busy the pharmacist was. Caregivers noted that some pharmacists seemed to understand the needs of disability organisations better than others; “*Word gets around between managers and organisations as to who’s good and who’s not so good*” (C10). Pharmacists noted difficulties in providing medication information to caregivers with varying health and English literacy, or making the assumption of speaking to the carer and not the PWD regardless of capacity.

6. Medication administration

Medication administration covered the practical and cognitive challenges of supporting PWD in the administration of their medication.

Dosage forms were noted as a practical area where administration issues occurred, particularly where individuals were prescribed devices such as inhalers that the individual had difficulty using. Caregivers felt polypharmacy was an issue due to the length of time and likelihood of errors in administration of the medication to the patient, with organisational procedures requiring caregivers to identify individual tablets, ensure all tablets are present, and send any tablets back to the pharmacy that were dropped on the floor. Multiple medications were hard to keep track of including remembering what medicines were being used for and what the adverse effects were likely to be for each one of them. Medication brand changes created confusion for caregivers when trying to identify tablets, and created additional problems when being administered to individuals who refused to take tablets they didn’t recognise.

Table 5
Medication Administration sub-themes described by pharmacists and caregivers.

Theme	Sub-Theme	Code	Pharmacists	Caregivers
Medication Administration	Practical issues	Identifying individuals	✓	
		Dosage forms/devices	✓	
		Illegible/paper-based charts	✓	✓
		Polypharmacy		✓
		Medication brand changes		✓
	Behavioural issues	Adherence/refusals	✓	✓
		Staff confidence and accountability		✓
		Person-centred administration of doses	✓	✓
	Both	PRN / short-term medication use	✓	✓

Table 6
Person-centred care sub-themes described by pharmacists and caregivers.

Theme	Sub-theme	Code	Pharmacists	Caregivers
Person-centred Care	Working with caregivers	Relationship between carer and individual	✓	
		Supporting caregivers and families	✓	
	Capacity and consent process for PWD	✓	✓	
	Supporting decision-making of PWD	Decision making by PWD	✓	✓
		Advocating for PWD	✓	✓
Individualised care	Individualised care	✓	✓	

Organisational policies often required houses to keep handwritten medication charts, however caregivers and pharmacists frequently reported discrepancies between charted medication and medications listed in pharmacy dispense records and GP practice notes and had

Table 8
Training and education sub-themes described by pharmacists and caregivers.

Theme	Sub-Theme	Codes	Pharmacists	Caregivers
Training and Education	Pharmacists	Disability awareness training	✓	✓
		Understanding best practice	✓	
	Doctors	Specialisation	✓	✓
		Carer medication training	✓	✓
	Caregivers	Carer health literacy	✓	✓

Table 7
Communication sub-themes described by pharmacists and caregivers.

Theme	Sub-Theme	Code	Pharmacists	Caregivers	
Communication	Communication and attitude	Family	✓	✓	
		Paid caregivers	✓	✓	
		HCPs	✓	✓	
	Transfer of information	Person-centred communication	Person-centred communication	✓	✓
		Transitions of care		✓	✓
		Paper charts		✓	✓

Table 9
Contextual issues sub-themes described by pharmacists and caregivers.

Theme	Sub-Theme	Codes	Pharmacists	Caregivers
Contextual Issues	Organisational environment	Concerns around costs for medication-related services	✓	✓
		Organisational ethos	✓	✓
		Policies and procedures	✓	✓
		Pressures on caregivers in organisation	✓	✓
		Continuity of care	✓	✓
	Practice environment	Organisational support		✓
		Limited pharmacist-led activities	✓	
		Best practice evidence and guidelines	✓	
		Government mandates	✓	✓

difficulty interpreting the charts.

Behavioural issues raised included caregivers' lack of confidence in administering medication and accountability for medication administration errors, with underreporting of errors being highlighted as a potential problem within organisations. Adherence to medications was largely felt to be well supported with dose administration aids, however refusal to take the medication was a frequently described theme raised by participants, particularly by paid caregivers.

Both pharmacists and caregivers agreed that individualising the way medication is administered for each patient, or person-centred administration of doses, was important and involved both practical and cognitive considerations. Examples included crushing tablets or placing tablets in custard, dispensing smaller strengths of a medication to provide a smaller tablet size, or assisting the removal of medication from a pack onto a plate for the PWD to then take. While caregivers highlighted some of the practical difficulties of individualised dosing, particularly for new or transient caregivers, pharmacists focused on their role in supporting individualised administration through identifying options such as changing the medication formulation or splitting doses. This also came with examples of inappropriate changes in formulation such as inappropriate tablet crushing and demonstrated the difficulties of ensuring individualised administration while maintaining the efficacy of the medication. Administration of medication "PRN", or "as needed", and short-term medications, such as a course of antibiotics, were raised as issues both from a practical and cognitive point of view. Both cohorts were concerned that caregivers might not have the clinical judgement or continuous observation of an individual to identify when a PRN medication might be necessary; "*We are asking carers to have clinical judgement to administer PRN medicines*" (P8). Pharmacists were also concerned that PRN and short-term medication use were a frequent source of error due to a lack of oversight and review, with medications often being continued for longer than intended. From a practical point of view, PRN and short-term medication could sometimes be missed, particularly if the medications were not co-located or if the carer was not familiar with the PWD.

7. Person-centred care

The theme of person-centred care consisted of three sub-themes,

including working with caregivers, supporting the decision-making of PWD, and individualised care. Pharmacists observed that the relationship between the PWD and the carer impacted the medication-related care the PWD would receive; a carer that was consistently engaged with the PWD would be more likely to advocate on their behalf. Pharmacists also found a distinct role in supporting families and caregivers to give voice to concerns through providing information regarding their medicines. Uncertainty around PWD's decision-making and consent capacity was often raised by pharmacists, and assumptions around a PWD's ability to understand or provide information had the pharmacist speaking more often to the carer than the PWD. Consent was raised by both cohorts as an ethical responsibility but a difficult process to undertake. Both cohorts agreed that where medications were concerned, consent was imperative, but not always sought in an inclusive manner. This was particularly linked with decision-making, where power imbalances between healthcare professionals, caregivers, and individuals, created an environment where "*their [PWD] healthcare is very much decided for them and they don't have an active part*" (P2). Individualised care was recognised as a complex issue in ensuring the needs of the PWD were addressed rather than the family or carer's belief of what was best for the person. However, it was acknowledged that often the person's quality of life was determined by those who cared for them, and how well they could advocate for the person. Advocacy to support the PWD was recognised as a role of pharmacists and caregivers, although the experience and confidence of pharmacists and caregivers consulting with GPs often determined the impact of the advocacy.

8. Communication

The communication theme showed a high level of concordance, with all three sub-themes and five codes emerging from both pharmacists and caregivers; person-centred communication, communication and attitude of caregivers, healthcare professionals, and family, and transitions of care. Person-centred communication highlighted the need to identify a better communication pathway for each individual, while recognising the difficulties in ensuring that information is provided at a level that the PWD can understand, without making assumptions. Pharmacists found many caregivers spoke English as a second language and caregivers working within organisations would undergo frequent change due to high staff turnover, creating communication challenges. Caregivers acknowledged that ensuring all healthcare professionals were informed of changes to medications could be problematic. Attitude appeared to impact the communication between the carer and pharmacist both negatively and positively, with some caregivers questioning the authority of pharmacists to review medications, and others requesting reviews and seeking further information and second opinions from pharmacists. Delays in communication between healthcare professionals, and the lack of open collaboration, appeared to equally concern caregivers and pharmacists. This was evident with respect to transitions of care, where difficulty reaching GPs could lead to delays in medication provision after a hospital admission, and movement in and out of care increased risk in medication errors. Finally, there was concordance by both pharmacists and caregivers that family involvement in a person's care would often lead to more medication prescribing and resisting the reduction of restrictive practices such as chemical restraint.

9. Training and education

This theme considered the training and education needs for caregivers, pharmacists, and prescribing doctors. The coding that was extracted from the data focused on disability awareness training, understanding what best practice is, specialisation, and carer education. Pharmacists felt their own lack of confidence and skills in ensuring the interactions they had with PWD and their caregivers were inclusive and responsive to the needs of the person. Caregivers noted that "*it's hard to*

find GPs with experience in disability in an area that's not too far to travel," (C8) and pharmacists felt there might be a lack of awareness about healthcare professional upskilling in disability, despite a growing momentum in this space by medical colleges. Medication training meant different things for paid and unpaid caregivers. Unpaid caregivers felt their knowledge was adequate and came from "years of doctors' appointments" (C2) with only the one person to look after. It was also felt by both pharmacists and caregivers that training undertaken by caregivers was inadequate in both length and content. There were concerns that the training did not cover different types of medications and adverse effects, and was unable to convey the importance of medication safety and adherence. In addition to education and training, the level of carer health literacy varied according to both cohorts, including examples of overconfidence where caregivers would conduct activities outside their skills set.

10. Contextual issues

The final theme that emerged from the data was contextual issues; the context within which pharmacists and caregivers worked while supporting medication use by PWD. The issues appeared to split into two sub-themes; issues that occurred within organisational settings, and issues that occurred in the practice setting. Pharmacists and caregivers both agreed that organisations did not want to shoulder the cost of medication-related services. Caregivers also felt that activities that were generated through pharmacies should be at no cost and were supportive of medication reviews as a free service to customers. Pharmacists perceived that while some organisations appear to provide more support and structure in the way they look after customers, other organisations provided more ad hoc support and lacked understanding of the critical and complex nature of medication management. Disability service providers are responsible for the health of the PWD they care for, however organisations were described overall to be "reactive, not proactive, in their policies and procedures and don't value the economics of investing in preventative health" (P8). Organisations have required policies and procedures to demonstrate they are meeting quality practice standards, however they were often described as difficult or impractical to follow, and pharmacists faced difficulties in trying to provide advice around these policies and procedures. Caregivers had similar concerns, describing the systems as very rigid and generalised, which reduced the ability to provide person-centred care. In addition to compliance pressures, both cohorts also felt that organisational pressures such as time constraints and an eclectic environment created pressures on caregivers while administering medication. The constantly changing workforce and complexity of co-ordinating healthcare services and handovers were areas of concern which impacted the continuity of care for individuals. Pharmacists perceived a high turnover and different caregivers looking after an individual meant information and education was not effective for supporting appropriate medication use. Caregivers also felt that communication during handover was not structured, leading to information being misinterpreted or missed entirely. Caregivers wanted to see more organisational and government support to help navigate the complex area of health within the context of group homes.

The practice environment focused on limited pharmacist-led activities and government mandates. Remunerated medication-related activities for people living at home are restricted to medication reviews in the home (HMR's). Pharmacists perceived that the reviews provided to PWD were inherently more difficult and time consuming, with some pharmacists indicating they avoided providing because of this. Limits in the funding for HMR's was also described that "does not account for the complexity of medications in this space and its embedded nature within homes" (P2) such as a lack of adequate remuneration for HMR's, and no government funding to provide education and training to caregivers, undertake auditing activities, and develop and review medication policies and procedures. While medication reviews had limitations for

meeting the medication-related needs for this sector, the lack of uptake of medication reviews further decreased the efficacy of pharmacists supporting this sector. Pharmacists and caregivers believed government changes could both facilitate and hinder medication management in this sector, with pharmacists having the potential to create safer medication practices if there was government recognition of their expertise and mandates to ensure safer medication practices. Pharmacists and caregivers both noted the divide between funding and legislation between the NDIS and healthcare system often meant that medication safety fell through the gaps for PWD.

11. Discussion

This is the first study to explore the challenges experienced by both caregivers and pharmacists who directly support medication management within the disability sector. The results have highlighted the potential reasons behind medication related problems, and opportunities to optimise medication management. The major findings identified from the data were captured in seven key themes; clinical issues, medication supply, medication administration, person-centred care, training and education, communication, and environmental issues, which could be mapped to the medication management process as captured in Appendix 2. The anecdotes conveyed in the interviews also showed that the seven themes were clearly inter-related, and there were strong similarities in the challenges perceived by both caregivers and pharmacists when supporting PWD. Importantly, this study demonstrated that PWD have a medication-related issue at all stages of the medication management process, as perceived by pharmacists and caregivers.

Erickson et al. explored caregiver perspectives on the medication management process for people with intellectual and developmental disabilities, and found that difficulties arose with prescribers' understanding of insurance and agency policies, a lack of care continuity and accuracy of medication and clinical records, poor communication, patient willingness to take medication, caregiver understanding and training in medication administration, and the health system being unprepared to work with people with intellectual disability.³² A 2006 Australian study by Di Blasi et al. investigated the role of the community pharmacist in the care of people with intellectual disabilities, and found communication, education and training, and interdisciplinary collaboration were issues in providing effective medication-related support to PWD.²⁶ Similar findings to the Erickson and Di Blasi studies were identified in this study, however the following issues not previously seen in the literature were also identified:

- Assumptions around capacity and the lack of active control held by the individual to make medication-related decisions.
- Perceived high prevalence of psychotropic prescribing and lack of monitoring and review of these high-risk medications.
- Siloing of regulation and funding between the disability sector and the health sector making implementation of practice change difficult.

Person-centred care was a strong theme throughout the interviews. Caregivers and healthcare professionals related difficulties in defining, advocating for, and providing person-centred care, but also recognised it to be at the heart of all medication-related activities. A 2019 UK study exploring the experiences of those with intellectual disability and family and paid caregivers, described a lack of involvement in joint decision-making about psychotropic medications with psychiatrists.³³ Similarly, caregivers in the present study described their role in advocating and supporting shared decision-making, the difficulty in finding prescribers with experience in disability, and the importance of pharmacists provision of knowledge to "arm" the caregiver with relevant medication information. This reflects similar findings from studies on the experiences of people with intellectual disability and their carers when interacting with prescribers, in which knowledge, validation and influence

were perceived as vital to be part of the decision-making process.^{27,33,34} Pharmacist participant insights supported the concept of collaboration and involvement in decision-making, identifying their role as to support caregivers and ensure residents have a voice with respect to medication use.

Clinical issues such as polypharmacy and psychotropic prescribing have previously been noted as high risk factors in descriptive studies examining medication errors in people with intellectual disability residing in institutions.^{35,36} The Australian Disability Royal Commission Hearing Six found that people with cognitive disability are overprescribed psychotropic medication, even when taking into account the higher prevalence of mental illness and absence of reliable statistical data.³⁷ The high rates of psychotropic prescribing has been associated with its use as chemical restraint, despite being potentially inappropriate or ineffective.³⁸ A recent Australian qualitative study exploring the views of 'guardian' decision makers found that there was concerning relationships with prescribers and disability sector staff, with prescribers sometimes diagnosing mental illness to avoid chemical restraint legislative requirements.¹² In addition, chemical restraint was perceived to be used in lieu of community supports and implementation of positive behaviour support plans.³⁹ The findings from the Disability Royal Commission supports the results of this study that the quantity of medications, the type of medications involved, and the lack of framework for monitoring this pose significant risk to the safety of PWD when using psychotropic medication.

Our study also adds to the literature by identifying the impact the organisational and practice environment has on pharmacists' ability to reduce these risk factors. Organisations are governed under the NDIS Quality and Safeguards Commission, however the practice standards for medication management covering accurate medication records, staff knowledge of the medication they administer, and storage and access of medication, are minimal and without clear quality indicators. Paper-based medication records, for example, was mentioned frequently as an issue and source of error for both pharmacists and caregivers. A review by Jiang et al., explored the impact of electronic health records on client safety in aged care facilities and found that electronic records can help provide guidelines for treatment and care, alert staff about test results and follow-ups, and reduce medication mistakes.⁴⁰ Electronic medication management charts are now considered standard practice in aged care facilities, and given the evidence for improved medication safety, the introduction of electronic medication management systems may create a simple solution that ensures communication of medication changes, review of medication orders, and transitions of care can occur safely. Pharmacists perceived difficulties in providing medication-related activities due to lack of funding, inadequate mandating of medication safeguard practices, and uncertainty on best practice due to a lack of robust psychotropic prescribing guidelines for PWD. Similar findings were identified in Hearing Six, which identified a high level of complexity and inconsistency between jurisdictions for the regulatory frameworks governing psychotropic medication as chemical restraint.³⁷ This lack of oversight, in combination with limited enforcement of safeguards, leaves PWD vulnerable to overprescribing of psychotropic medication with high risk of suboptimal quality of life.³⁷ Findings from a 2015 narrative review identified that pharmacists have the skills and capacity to support people with intellectual disabilities by promoting patient safety and improving the quality and appropriateness of medication use.²¹ However, awareness driven by organisations to embed pharmacists in primary healthcare teams, and funded services governed by quality frameworks to meet the needs of this sector is vital for translational impact.

A key strength of this study was the ability to compare the experiences of caregivers alongside the experiences of pharmacists to draw synergies and identify differences in their collective perspectives. The open-ended nature of the questions and prompts facilitated the exploration of participants' experiences, with many questions overlapping to add reliability to the data. The small sample size of 10 pharmacists and

10 caregivers prevents generalisation of this data to all pharmacists and caregivers, however data saturation was reached. While this study explored the views of both paid and unpaid care providers, the small sample of unpaid caregivers ($n = 2$) may have left data uncaptured for this cohort.

12. Conclusion

The findings from this study confirmed key issues that affect medication management for PWD including clinical issues, medication supply, administration issues, communication, and education and training that reflect what has been shown in existing literature. This study also adds to the literature by identifying new key issues that affect medication management for PWD such as person-centred care, and contextual issues found within the organisational and practice environment. Addressing these findings would likely create high impact medication safety improvements and enhance health outcomes for PWD and their caregivers. Further research is required to develop targeted strategies that overcome the issues outlined in this study and establish whether the strategies proposed are beneficial, feasible, and aimed at optimising the medication-related health and safety of this population.

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CRediT authorship contribution statement

Chelsea Felkai: Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **David Newby:** Supervision. **Joyce Cooper:** Supervision. **Suzanne Nielsen:** Supervision. **Angela Reeves:** Validation, Methodology, Formal analysis, Data curation. **Hayley Croft:** Validation, Supervision, Project administration, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.rcsop.2024.100489>.

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