

REVIEW

A narrative review of acute care nurses' experiences nursing patients with intellectual disability: underprepared, communication barriers and ambiguity about the role of caregivers

Peter Lewis, Ryan J Gaffney and Nathan J Wilson

Aims and objectives. To describe how nurses experience caring for people with intellectual disability in an acute care setting.

Background. Recent advances in the care of people with intellectual disability in hospital are primarily based upon the experiences of people with intellectual disability and their caregivers. Little is known about the experiences of registered nurses caring for people with intellectual disability, yet the experiences of nurses in delivering care largely determine the quality of care experienced by people with intellectual disability and their caregivers.

Methods. A narrative literature review using electronic database searches was conducted using variants of the terms disability, nursing and acute care.

Results. Through our reading of the recent literature describing the experiences of nurses caring for people with intellectual disability in an acute care setting, we have identified three themes: (1) nurses feel underprepared when caring for patients with intellectual disability, (2) nurses experience challenges when communicating with people with intellectual disability and (3) nurses have ambiguous expectations of paid and unpaid caregivers.

Conclusion. The enablers of and barriers to the delivery of nursing care in acute care settings need to be made explicit and researchers and nurses need to collaborate in the development, implementation and evaluation of care delivery strategies.

Relevance to clinical practice. Nurses need to be adequately prepared to care for people with intellectual disability. Preparation should include dealing with the complexities of communicating with people with intellectual disability and practical experience of doing so in clinical and educational environments that ensure the safety and dignity of nurses and people with intellectual disability. Nurses need supportive strategies for developing therapeutic relationships with a range of informal and formal caregivers.

Key words: acute care, experiences of care, intellectual disability, professional communication, registered nurse, therapeutic relationships

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What does this paper contribute to the wider global clinical community?

- This paper highlights the dearth of research into the experiences of registered nurses caring for people with ID in acute care settings.
- Registered nurses might feel underprepared to care for people with ID, challenged by difficult communicative interactions, and ambivalent about caregivers' roles in providing care.
- More needs to be known about the experiences of registered nurses caring for people with ID in acute care settings to develop strategies for delivering high-quality, sustainable care to this patient population.

Introduction

Since the 1980s when the deinstitutionalisation process increased its pace, people with intellectual disability (ID) have been supported and cared for in mainstream settings such as general hospitals. This policy shift has now evolved into goals to counter social exclusion and achieve widespread individualised support, community living and access to health services for all people with ID through initiatives such as the National Disability Insurance Scheme (NDIS) in Australia (Bigby 2013). Partly due to greater morbidity than people without ID, people with ID require more frequent and longer periods of hospitalisation for management of physical conditions than the general population (Ailey *et al.* 2015). In the UK, for example, people with ID are 1.6 times more likely to be hospitalised than the general population when ambulatory care should have been sufficient to prevent admission (Glover & Evison 2013). In Canada, this rate is greater at six times more likely (Friese & Ailey 2015) and the likelihood of hospitalisation increases further for people with comorbidities such as schizophrenia or epilepsy (Balogh *et al.* 2010). Complications during hospitalisation are also more common for people with ID. For example, people with ID hospitalised in the USA are twice as likely to experience complications, such as acquired infections, skin breakdown, falls and medication errors, compared to people without ID (Ailey *et al.* 2015). In addition, people with ID are nearly four times as likely to experience complications if they have multiple chronic health conditions (Ailey *et al.* 2015).

This suggests that nurses working in acute care settings are going to be responsible for the care of people with ID at some stage in their careers. Exploring the role of the nurse and nurses' experiences during these acute stays will enable a greater insight into how to minimise negative health and well-being outcomes for people with ID during hospitalisation. This is particularly vital in Western countries such as Australia where people with ID use mainstream health services and anyone with a sole qualification, and therefore expertise, in disability nursing cannot work in mainstream settings such as acute hospitals (Nursing and Midwifery Board of Australia, 2015). The delivery of care to this patient population is complex given the frequency with which they require hospitalisation and the complications that arise for them especially when they are diagnosed with multiple comorbidities.

People with ID are likely to experience suboptimal hospital care for two reasons. One occurs when the relationship between nurses and carers of people with ID is not adequately negotiated. This means that the various caring roles

are ill-defined, resulting in confusion, and caregivers might be excluded by hospital staff (Backer *et al.* 2009). The other occurs when hospital staff lack knowledge or skills in how to care for and communicate with people with ID (Backer *et al.* 2009). The physical safety of people with ID can be compromised by inadequate provision of specialised nursing care, misdiagnosis and delayed investigations and treatment due to lack of knowledge or inability of a nurse to communicate with the patient (Tuffrey-Wijne *et al.* 2014). These complications have an adverse effect on the health and well-being of people with ID and can lead to higher rates of preventable readmission to hospital than is experienced by the general population (Kelly *et al.* 2015).

In the UK, guidance is available for nurses who aim to deliver high-quality care to patients with ID within the acute care settings. For example, the National Patient Safety Agency has worked with people with ID to produce evidence-based guidelines for the appropriate care of people with ID in the acute care setting (National Patient Safety Agency, 2004). More recently, Friese and Ailey (2015) have published evidence-based standards of care covering nursing interventions to enhance communication, the provision of safe and accessible healthcare environments and collaboration with support of caregivers. In reality however, the presence of guidelines or standards in and of themselves does not guarantee the development of nursing knowledge and skills. This reality is recognised by researchers into the care of people with ID in hospital who recently identified that all healthcare workers have specific training needs in how to communicate with and provide care to people with ID (Hemm *et al.* 2015). Some of the latest Australian research has reviewed the barriers, as perceived by a range of stakeholders, towards delivering high-quality care to people with ID in hospital settings (Brown & Kalaitzidis 2013). The barriers they identified included poor nursing staff knowledge, communication and skills deficits, identifying special needs deficits, time and staffing shortfalls. Not surprisingly, exposure to people with ID had a supportive effect on the attitudes of nurses towards people with ID (Brown & Kalaitzidis 2013). Although it is important to know what the barriers are to the delivery of high-quality nursing care in any given context, a focus on deficit provides only a partial understanding of ways in which the quality of care can be improved. A focus on enablers of care might serve to enhance the opportunity for nurses to develop strategies for delivering high-quality care to people with ID.

The only countries who still offer a unique specialist qualification in ID nursing are the UK and Ireland (Doody *et al.* 2012). Nurses in Australia with sole disability

qualifications are not recognised by the registering authority as generalist nurses meaning they cannot work in acute care settings in Australia. However, the interests of nurses specialising in the care of people with ID in Australia, who typically work in disability-specific rather than mainstream settings, are represented by a professional association: the Professional Association of Nurses in Developmental Disability Australia Inc. (PANDDA) (Professional Association of Nurses in Developmental Disability Australia Inc., 2016). PANDDA has published a set of standards to guide nurses in caring for people with ID. The six domains of practice guide the development of therapeutic relationships between the nurse and patient. The domains include the establishment of partnerships between nurses and people with ID, the delivery of care consistent with the patients holistic needs, the promotion of health and well-being, the delivery of culturally sensitive care, a commitment to ongoing professional development and a commitment to practice within legal and ethical frameworks (Professional Association of Nurses in Developmental Disability Australia Inc., 2016).

The domains are clearly not a prescription for the delivery of high-quality care to people with ID but a set of guiding principles to which nurses in any context – acute care or home care – might refer. Although professional organisations such as PANDDA are likely to support the development and practice of nurses in a specialty area of practice, they do not necessarily suggest the availability of practical help for nurses to achieve sustainable, high-quality practice in *all* nursing contexts and settings. Moreover, the use or utility of such standards of care to acute care nurses is largely unknown as PANDDA's membership is primarily drawn from those remaining nurses working in the disability sector rather than acute care settings. Healthcare professionals working in Australian hospitals, like their colleagues in other countries, might require fundamental education and training to understand and support the needs of people with ID in their care.

We have commenced a programme of research with Australian nurses to answer research questions related specifically to nursing care delivered in mainstream acute care settings. Our broad areas of research interest are to explore (1) what personal challenges do nurses experience when delivering nursing care to people with ID; (2) what personal rewards do nurses experience as a result of caring for people with ID; (3) what are the contextual factors that nurses describe as barriers to the delivery of high-quality care to people with ID; and (4) what are the contextual factors that nurses describe as enabling the delivery of high-quality care to people with ID. The first step in commencing this programme of research is to

clarify what the literature can tell us about acute care nursing of people with ID.

Aims

The aim of this narrative review was to describe how nurses experience caring for people with ID in an acute care setting.

Methods

A narrative approach to this review was undertaken to summarise, explain and interpret evidence around the topic of nurse's experiences of caring for people with ID in an acute care setting (Mays *et al.* 2005). A thematic analysis of the literature was conducted to provide a synthesis of the findings across the included studies (Mays *et al.* 2005). A systematic search of the research literature was conducted using the following five data bases: Medline, CINAHL, Web of Science, PsycINFO and Cochrane Systematic Review. The search was conducted in December 2015.

Inclusion criteria

The review included research articles published in English between 2006–2015 where participants included nurses of any grade and findings from nursing participants were reported discretely, and empirical research into nurses' experiences of caring for people with ID in acute mainstream hospital settings.

Exclusion criteria

Articles excluded from this review were research studies in which findings from nurses were aggregated with those of other participants groups such as patients and families; studies that tested or evaluated healthcare interventions in people with ID; and nursing care delivered in community-based, segregated (i.e. disability-specific) or domestic settings.

Search strategy

The following search terms were used: mental* retard* OR intellectual disabil* OR learning disabil* OR developmental disabil* OR cognitive disabil* OR intellectual impairment OR mental deficiency OR mentally defective OR psychosocial retard* AND nurs* OR allied health AND car* AND hospital* OR care facility OR clinic* treat*. Once

duplicates were removed, the searches returned a total of 267 references. The abstracts of these references were reviewed, and once irrelevant references were removed, 14 full-text articles were included. We also checked the reference lists of the 14 included articles which yielded no additions to the review. Figure 1 provides an illustration of the search method.

Results

After individually reading each article, we collectively categorised the literature over many team meetings into three broad themes based on our agreed interpretation of the stated results of the research. The three themes identified are as follows: (1) nurses feel underprepared when caring for patients with ID, (2) nurses experience challenges when communicating with people with ID and (3) nurses have ambiguous expectations of paid and unpaid caregivers. Publications included in the review are listed and described in Table 1 which provides a descriptive snapshot of the methods, findings and participant groups.

Nurses feel underprepared when caring for patients with ID

Caring for people with ID requires that nurses access a range of personal and structural resources. Formal education or training as an ideal preparation for nurses delivering care to people with ID in hospital is a prominent discourse

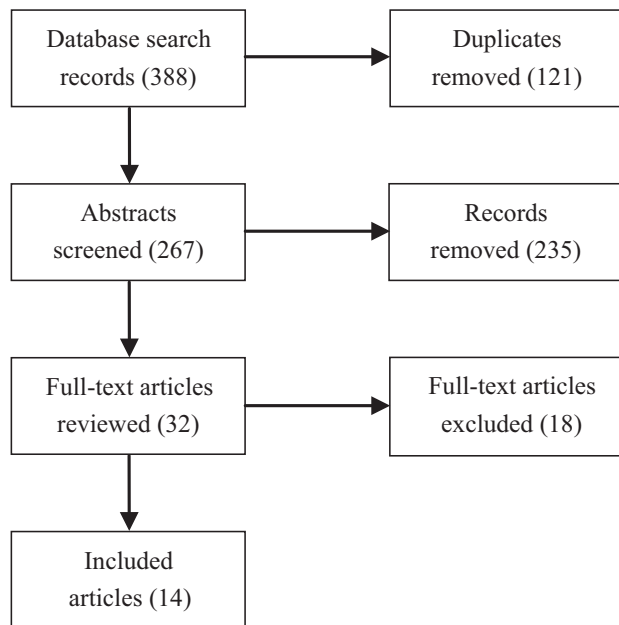


Figure 1 Literature review flow chart.

within the literature reviewed (e.g. Lewis & Stenfort-Kroese 2010, Merrifield 2011, Aston *et al.* 2014a,b, Cooper *et al.* 2014). Nurses who engage in disability awareness training have reportedly been able to improve the experience of patients with ID when attending hospital and to increase nurse's confidence in treating patients with ID (Buchanan 2011).

The types of training that nurses might require vary between different clinical contexts. For example, a lack of preregistration training and practice experience has reportedly adversely affected the quality of care provided to patients with ID in the accident and emergency (A&E) department (Sowney & Barr 2006). A lack of training has led nurses to feel ill-prepared to manage the presenting patient's challenging behaviours (Sowney & Barr 2006). Nurses in the A&E department have reported feeling undersupported as well as underprepared by a lack of knowledge about the kind of expert help available to them when caring for people with ID (Sowney & Barr 2006). This raises a question about the extent to which nurses are enabled to develop the skills required to care for patients with ID while actually practising rather than during the preregistration period.

Nurses providing end-of-life care to patients with ID have reportedly felt confident in identifying patients with end-of-life symptoms despite feeling inadequately trained in providing end-of-life care to them (Bekkema *et al.* 2014, Cooper *et al.* 2014). As a result of limited training, nurses also lack confidence in their abilities to provide psychosocial or spiritual care when informing patients and their caregivers that a person with ID requires end-of-life care (Cooper *et al.* 2014). Clearly in this instance, training in the delivery of palliative care to patients with ID is likely to be more highly valued by nurses than training in diagnosis of symptoms. This suggests that effective training needs to be targeted and tailored for nurses practising in specific contexts.

As a consequence of a lack of preparation for delivering care to people with ID in hospital, nurses reportedly experience a range of emotions. For example, Lewis and Stenfort-Kroese (2010) compared the emotional reactions of nurses' delivering care to patients with ID to those of patients with physical disability (PD). Nurses can feel hopeless and nervous when responsible for the care of people with ID. They also report feeling frustrated and awkward and are less likely to feel comfortable, confident, relaxed and optimistic when delivering care to a patient with ID compared to a patient with a PD (Lewis & Stenfort-Kroese 2010). Their feelings of fear and vulnerability can lead nurses to take a passive role in the delivery of patient care, instead relying

Table 1 Publications included in the review

Publication	Publication type	Methods	Findings	Participants
Aston <i>et al.</i> (2014a) Canada	Research Article	Qualitative design using a semi-structured interview schedule. Data analysed by discourse analysis and thematic coding	Explored the interactions between nurses, mothers and children with intellectual disability (ID) in hospital settings. Highlighted the need for nurses to challenge 2 broad stereotypes about children with ID: (1) unable to communicate and understand and (2) being difficult patients	Individual interviews with nurses ($n = 12$), mothers ($n = 17$) and children with ID ($n = 8$) able to speak and understand English
Aston <i>et al.</i> (2014b) Canada	Research Article	Qualitative design using a semi-structured interview schedule. Data analysed by discourse analysis and thematic coding	Positive nursing relationships with the child and parent as an important part of care although challenges in the development of these relationships remained. Positive relationships are necessary; connecting and communicating recognised as important to effective care. Time a factor affecting relationships and more training needed to provide better care	Individual interviews with nurses ($n = 12$), mothers ($n = 17$) and children with ID ($n = 8$) able to speak and understand English
Bekkema <i>et al.</i> (2014) the Netherlands	Research Article	Descriptive survey based on three domains: education, actual experience and attitudes regarding end-of-life care	Investigated the quality of end-of-life care for people with ID. Nurses were overall happy with the end-of-life care provision but felt they had not received adequate training in end-of-life care. It also identified the increased need of end-of-life care for people with an ID as more people living longer	Surveys from nurses ($n = 97$), Assistants in nursing ($n = 6$) and social workers ($n = 37$). There was a 71.8% response rate
Bradbury-Jones <i>et al.</i> (2013) N/A	Research Article	Structured literature review searching four databases (Medline; PsycINFO; BNI and archive; CINAHL)	Review was conducted to understand factors that influence the health, safety and welfare of patients with ID in an acute care setting. Issues of care provision for ADLs were highlighted, problems with facilities and medical treatment often not up to standards. Communication an issue due to busy environments, time restraints and the lack of documentation when the patient arrives at hospital. Staff attitudes are often discriminatory especially where there is a communication impairment	Review started with 3505 publications; the final number of papers included in the study was 7
Buchanan (2011) UK	Commentary	N/A	Discusses the need for more training for acute care nurses in caring for people with ID. Awareness training for nurses has reportedly improved hospital experiences of people with an ID and improved nurses' confidence. Recommends a link nurse for each ward	Targeted at nurses to provide better care to people with ID

Table 1 (continued)

Publication	Publication type	Methods	Findings	Participants
Cooper <i>et al.</i> (2014) UK	Research Article	Descriptive survey across three domains: demographics, patient care and end-of-life care	Investigates nurses' training and experiences and level of confidence providing palliative care. Nurses were generally confident managing symptoms. Nurses were less confident in providing psychosocial or spiritual care and believe there is a lack of formal assessment tools relevant to people with ID	Self-report questionnaires ($n = 111$) were sent to nurses, ward managers and matrons working at two general hospitals in the UK with a 30% response rate ($n = 33$)
Droz and Clinch (2015) UK	Research Article	Descriptive survey across nine domains. Quantitative data analysed using straightforward descriptive analysis; qualitative data analysed using interpretive thematic analysis	Explored the experiences of orthopaedic and trauma nurses caring for patients with ID using 'The 6Cs Framework': care, communication, courage, commitment, competence and compassion. Results suggest that care, communication and competence are worse when nursing a person with ID	A convenience sample of nurses ($n = 11$) and ward managers ($n = 2$) who were in attendance at a nursing conference in the UK. No response rate was stated
Hemsley <i>et al.</i> (2011a) Australia	Research Article	Qualitative design using a semi-structured interview scheduled. Data were analysed using narrative analysis	Explored the views of patients, paid carers and nurses about the communication needs of people with ID. A need for people with IDs to be able to communicate basic needs and wants to facilitate better care. Nurses perceive that people with ID will not understand which leads to a lack of direct communication about their health needs	Individual interviews with nurses ($n = 15$) from two metropolitan hospitals in Brisbane, paid carers ($n = 15$) and adults with a developmental disability ($n = 15$)
Hemsley <i>et al.</i> (2011b) Australia	Research Article	Qualitative design using a conversational style in-depth interview. Data were analysed using narrative analysis	Explored how paid carers, adults with ID and nurses view the role of paid carers' in supporting people with an ID in a hospital setting. Nurses perceived difficulties were that: (1) paid caregivers often disrupted the normal ward routine; (2) unpaid caregivers had more experience/expertise than paid caregivers; (3) nurses' expectations of support from paid carers often did not materialise; and (4) nurses felt that paid caregivers would be less active advocates, which was not the case	Individual interviews with nurses ($n = 15$) from two metropolitan hospitals, paid carers ($n = 15$) and adults with a developmental disability ($n = 15$)
Hemsley <i>et al.</i> (2012) Australia	Research Article	Qualitative design using a semi-structured interview scheduled. Data were analysed using narrative analysis	Examined if nurses' perspective of time as a barrier or facilitator of communication with people with ID. Time constraints due to workload a problem when communicating with people with ID. Nurses often rely on unpaid caregivers with direct communication in relation to a perception of poor comprehension in the person with ID. Poor perceptions of comprehension may be more of a barrier than a lack of time	Individual interviews with nurses ($n = 15$) from two metropolitan hospitals in Brisbane

Table 1 (continued)

Publication	Publication type	Methods	Findings	Participants
Lewis and Stenfort-Kroese (2010) UK	Research Article	Cross-sectional descriptive survey using a self-report questionnaire based on two vignettes (a patient with and without ID). Subscales were for attitudes and emotions	Nurses had significantly less positive attitudes, experienced fewer positive emotions and more negative emotions about caring for a person with ID when compared to a person with a physical disability. Less positive attitudes were: segregation, carrying out nursing tasks, communication, behaviour, time, training and skills. Nurses reported feeling hopeless, nervous, frustrated and awkward and less likely to feel comfortable, confident, relaxed, satisfied and optimistic	Self-report questionnaires ($n = 1350$) were sent to nurses working in 54 wards at six general hospitals in the UK. There was a 20% response rate ($n = 262$)
Merrifield (2011) UK	Commentary	N/A	Reviews the risks associated with and the needs of patients with ID in A&E. Focused on understanding communications needs, reliance on caregivers, nurses training/feeling underprepared and knowledge of the needs of people with ID	Targeted at nurses to provide better care to people with ID
Sowney and Barr (2006) UK	Research Article	Qualitative design using a semi-structured interview schedule. Data were analysed thematically	Examined the experiences of nurses working in A&E. Two key themes: (1) lack of knowledge and (2) dependence on caregivers. Nurses reported a lack of preregistration training, preregistration exposure increased self-competence, feelings of fear and vulnerability led to dependence on unpaid caregivers, and nurses tend to adopt more passive caring roles	Focus group interviews ($n = 5$) were conducted with nurses ($n = 27$) working in A&E >one year, from five hospitals in Northern Ireland
Sowney and Barr (2007) UK	Research Article	Qualitative design using a semi-structured interview schedule. Data were analysed thematically	The study explored the challenges experienced by nurses in A&E assessing and providing care. Gaining informed consent problematic, communication was often difficult leading to a poor understanding of needs, understanding nonverbal communication very difficult, perceived time constraints a factor effecting interactions and assessments, a lack of documentation from care homes hampered communication and a reliance on unpaid caregivers to provide proxy consent	Five focus group interviews ($n = 5$) were conducted with nurses ($n = 27$) working at five hospitals in Northern Ireland

on outside caregivers to provide the care that the patient needs (Sowney & Barr 2006, 2007).

Nurses experience challenges when communicating with people with ID

Effective communication between nurses and patients is challenging for both parties even under ideal circumstances. Nurses' frequency of interaction with hospitalised patients with ID is reportedly lower than that with a person without ID (Drozd & Clinch 2015). Nurses reported having difficulty interpreting nonverbal modes of communication from people with ID and are confused about terminology, for example by knowing how to refer to people with ID, which has inhibited their ability to communicate *about* people with ID (Bradbury-Jones *et al.* 2013).

This suggests that there are likely to be identifiable barriers to communication between nurses and their patients. First, nurses reportedly perceive the process of communication with people with ID as being time-consuming in ways that potentially compromise the quality of care deliverable (Sowney & Barr 2007, Hemsley *et al.* 2012, Bradbury-Jones *et al.* 2013, Aston *et al.* 2014a,b). However, having more time allocated for patient care might not actually improve communication between nurses and their patients (Hemsley *et al.* 2012). Therefore, although nurses might perceive time constraint as being a barrier to effective communication with people with ID, and this perception influences their behaviour, it is possible that time constraints are not the primary barriers to communication.

Second, nurses reportedly sometimes respond to people with ID in their care as stereotypes rather than as the individuals present before them. For example, according to Aston *et al.* (2014a,b), the two most common stereotypes associated with children with ID are that they are unable to communicate or understand and that they are difficult patients. One consequence of stereotyping might be that healthcare professionals are reluctant to engage with people with ID (Merrifield 2011), potentially reducing the length of time they are prepared to dedicate to communicating with people with ID. Nurses might be reluctant to engage in communication with people with ID if they perceive them as lacking the capacity to understand the interaction or they perceive them as difficult. Because the outcome of a given interaction is likely to be uncertain, nurses might prefer to avoid the discomfort that the uncertainty creates.

Third, people with ID often present to hospital with inadequate documentation or without any documentation at all (Sowney & Barr 2007, Bradbury-Jones *et al.* 2013).

This can hamper the process of diagnosis and the timely prescription of treatment especially when a person with ID is unable to communicate with nurses about their present acute illness (or to provide a medical history) and the person with ID is not accompanied by a carer who knows the person's medical history or history of present illness (Sowney & Barr 2007). Although this is about miscommunication between healthcare professionals specifically within the context of the A&E department, it has potentially adverse consequences for people with ID and the nurses caring for them in other acute care contexts.

Nurses' ambiguous expectations of paid and unpaid caregivers

Nurses have one prominent means of managing their feelings of underpreparedness and for overcoming the communication barriers that they experience when caring for people with ID. They reportedly rely on paid and/or unpaid caregivers to provide care to the person with ID while he or she is hospitalised. However, the presence of paid and/or unpaid carers in the hospital setting can present challenges to nurses as well. Nurses might expect paid carers to play an active role in providing direct support to their patient. However, this method is fallible because paid carers do not always fulfil this role (Hemsley *et al.* 2011b). For example, paid carers' attendance in the hospital ward sometimes interferes with hospital routines, making their presence unwelcome (Hemsley *et al.* 2011b). Some nurses give family members or unpaid carers higher status than paid carers because of their experience in caring for the patient.

Nurses' expectations of paid carers can be unclear. For example, nurses might expect paid carers to take an active role in the delivery of specialised nursing care – such as intimate and personal hygiene – which paid carers failed to deliver (Bradbury-Jones *et al.* 2013). Or they might expect paid carers to take a less active role in patient advocacy when that is precisely the role that the paid carers embrace (Hemsley *et al.* 2011b). The question of role clarity is of utmost importance to the delivery of high-quality collaborative health care to people with ID (Drozd & Clinch 2015). For example, nurses overrely on unpaid carers to provide information about the patient with ID to facilitate care. Although nurses rely on the information provided, they discussed experiencing ethical dilemmas about how accurate the information provided about the patient actually is (Sowney & Barr 2006). Nurses sometimes expect that the carer will stay with the patient to ensure appropriate care is delivered (Sowney & Barr 2007, Drozd & Clinch 2015), but nurses also sometimes misunderstand the role of unpaid

carers to provide proxy consent on behalf of the patient in A&E (Sowney & Barr 2007).

Discussion

This narrative review found that nurses feel underprepared to provide care for people with ID in acute care settings, that they experience barriers to communicating with people with ID and that they have ambiguous expectations of paid and/or unpaid caregivers in the delivery of care to people with ID in acute care settings. However, the extent of the problems associated with nursing people with ID in acute care settings identified in this review is difficult to determine even if the nature of those problems is not. As noted in the findings of this review, nurses might feel more confident when nursing a person with a PD than one with ID. This suggests that caring for people with different primary *disabilities* in acute care settings would not benefit from a uniform approach. Further, this review has not found evidence of a 'disablist nurse' phenomenon where the nursing professional claims control over the human needs of the patient (Illich 1992). Rather, this is an issue specific to the person's cognitive impairment as reflected in nurses' reported feelings of fear and uncertainty, challenges engaging in meaningful or therapeutic communication, and of the need to negotiate and partner with outside caregivers of people with ID.

Eight of the published research articles reviewed here came from the UK compared to three from Australia, two from Canada (albeit by the same authors and from the same study) and one from the Netherlands. This is not surprising given that the registering authority in the UK has retained disability nursing as a clinical speciality and there are over 21,000 learning disability nurses on the UK Nursing and Midwifery Council register (The Scottish Government, 2012). This is in comparison with approximately 6500 Australian nurses who work in the combined area of disability *and* rehabilitation which incorporates clinical areas such as brain injury and stroke (Australian Institute of Health and Welfare 2012). Like Australia, the USA and Canada have not retained a clinical speciality for disability nurses and following deinstitutionalisation people with ID use mainstream health services staffed by generalist nurses (Nehring 2010). That there was such a limited representation of published research from North America, European countries and other Western nations such as New Zealand illustrates the paucity of research in this area to help guide practice in acute care settings.

Given the complexities associated with caring for people with ID in acute care settings described in this review, it is

likely that more could be attempted to prepare, train and support generalist nurses, who have limited to no exposure to people with ID during their training, to provide high-quality care to people with ID in acute care settings. During preregistration nursing education, availability of clinical placement for students to experience caring for people with ID is necessarily limited due to widespread deinstitutionalisation. Despite this, it is apt to reflect on the reality that exposure to people with ID is positively associated with better attitudes towards people with ID (Brown & Kalaitzidis 2013). Instead of clinical placement experience, nursing schools with laboratory facilities could incorporate the care of people with ID more fully into this simulated learning environment. Case studies using actual video footage of people with ID could be embedded into learning material involving scenarios that feature people with ID. Alternatively, using people with ID as cofacilitators in tutorial groups should also be explored as another way to empower people with ID and help change stereotypically disabling perceptions. This would at least raise awareness of people with ID in acute care settings and start to instil confidence amongst preregistration nurses in delivering their care.

The three challenges of communication highlighted in our findings suggest the ongoing need for healthcare workers to understand the communication needs of people with ID in acute care settings. They suggest that healthcare professionals need to assess the patient's preferred mode of communication; for example, because some patients may be nonverbal, attempts at verbal communication may not work at all for that individual (Merrifield 2011). Rather, the use of nonverbal modes of communication or verbal communication augmented by symbols/pictures would potentially be far more effective. The onus is not necessarily on people with ID to be able to communicate their specific needs and wants to facilitate the provision of their own health care. Rather, it is for nurses to take the initiative to facilitate optimal communication (Hemsley *et al.* 2011a). This initiative might be more completely realised if a nurse feels well prepared and well supported in the care of people with ID regardless of the acute care context as suggested by recent studies of the training needs of nurses caring for people with ID (While & Clark 2014, Hemm *et al.* 2015).

It is clear that nurses need to build positive relationships with caregivers in order to provide high-quality health care to a person with ID in an acute care setting (Drozd & Clinch 2015). However, it is also clear that the processes required for achieving this are not easily followed – especially in critical care areas of a hospital where a busy environment produces time constraints that are difficult to resist. The findings of this review have highlighted an

ambiguous tension around the inclusion and exclusion of both paid and unpaid caregivers of people with ID in the acute care setting. On the one hand, nurses rely on the knowledge and skills that caregivers bring to the hospital because they potentially fill a gap in the knowledge and skills of hospital nursing staff. On the other hand, caregivers seeking to maintain their relationship with and routines of the person with ID might be perceived as a barrier to the delivery of care by nurses adhering to hospital routines when they conflict with those of the patient.

This ambiguity around performative roles in a range of areas seems critical to optimise health outcomes for the person with ID. For example, Bradbury-Jones *et al.* (2013) refer to an assumption that paid caregivers provide intimate hygiene support to the person with ID, yet a glance at the ID-specific literature shows that this is often a skill deficit for paid caregivers in disability-specific settings, let alone in acute care settings (Wilson *et al.* 2009). How nurses in acute care settings interpret the presence of caregivers at the patient's bedside (or their absence from the bedside) influences how they can form partnerships with caregivers to deliver high-quality care to patients in an acute care setting.

Future research

As a priority, effective, evidence-based strategies for preparing registered nurses to care for people with ID in acute care settings need to be identified and developed. One of these strategies should include targeted communication training to promote effective communication between registered nurses and people with ID. This will necessarily mean enabling registered nurses to participate in the development, implementation and evaluation of practical strategies that they value and adhere to. Research methodologies based in the critical social sciences, such as Action Research, would be ideal ways of facilitating such outcomes.

Facilitating therapeutic relationships between registered nurses and informal and formal caregivers of people with ID in hospital is likely to be more challenging because of the range of caregivers registered nurses encounter. People with ID might be admitted to acute care settings accompanied by no unpaid family caregivers, other unpaid informal caregivers, a succession of paid caregivers or any combination of these. We need to know more about how Australian registered nurses view 'caregivers' of people with ID generally before we can propose methods for facilitating partnerships in care with each caregiver variant. It is easy to imagine the added workload that

registered nurses might experience when engaging in the process of negotiating working partnerships with a wide variety of caregivers, but this is what needs to take place to enable registered nurses to provide high-quality care for people with ID in acute care settings.

Limitations of the review

We acknowledge that the narrative method that we have used to conduct this review has some limitations. First, the particular experiences, preferences and biases of the authors might have resulted in an unbalanced representation of the current healthcare situation. Some aspects of the themes we have identified might therefore be overstated, and we might have failed to capture other important aspects of nurses' experiences. This is an inevitable outcome of reviewing a body of literature that contains scarce examples of the phenomenon of interest. Also, because of the preponderance of studies of caring for people with ID generated in the UK, findings from this review might not be generalisable to the experiences of Australian nurses.

Conclusion

In general, nurses do not always feel confident and competent at providing optimal support for the health and well-being of patients with ID. Furthermore, we know little about the experiences of nurses providing care to this patient population, especially in acute care settings in Australia where specialist disability nursing education is no longer provided to undergraduate students. For strategies designed to improve the care of people with ID in acute care settings to be successful, the enablers of and barriers to the delivery of nursing care in these contexts need to be identified in detail and researchers and nurses need to work together in the development, implementation and evaluation of these strategies.

Relevance to practice

- Preparation for registered nurses, who are likely to be engaged in the care of people with ID during their professional practice, should commence during preregistration training and continue as a professional development activity after the nurse is registered.
- Preparation should include learning experiences designed to familiarise registered nurses with the complexities of communicating with people with ID and to give them practical experience of doing so in clinical and educational environments that ensure the safety and dignity of nurses and people with ID.

- Registered nurses need supportive strategies for developing therapeutic relationships with a range of informal and formal, paid and unpaid carers.

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Contributions

Study design: NJW, PL; data collection and analysis: RJG, PL, NJW; manuscript preparation: PL, RJG, NJW.

Conflict of interest

None.

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