

# ***Caring for People with Learning***

## ***Disabilities: Attitudes and Perceptions of***

### ***General nurses a literature review.***

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#### **Abstract**

**Background:** There is increasing evidence regarding people with learning disabilities (LD) having high unmet healthcare needs and poor care provided.

**Aim:** To explore the attitudes and perceptions of general nurses when caring for people with LD and how they affect the quality of care provided.

**Methods:** CINAHL and BND databases were examined for applicable literature published between 2006 and 2016. Resultant 4 papers were appraised (Polit and Beck 2012).

**Findings:** Two themes were identified: (1) attitudes and perceptions of general nurses and (2) lack of knowledge of general nurses caring for people with LD. These themes impacted on general nurses' competence and confidence to care and influenced the quality of care provided to people with LD.

**Conclusion:** This review of the literature indicated that in acute and general hospitals, often people with LD are cared for by general nurses who have less positive attitudes, lack of knowledge and appropriate training in LD awareness. Therefore, it is important to address general nurses' attitudes and perceptions by providing LD preregistration education and specific training on LD awareness, as these could improve the quality of care provided to people with LD.

## Keywords

Nurses, caring, learning disabilities, intellectual disabilities, attitudes, perceptions.

## Introduction

In the United Kingdom, people with learning disabilities (LD) have greater physical and mental healthcare needs than the general population (Public Health England (PHE) 2018) hence seek more support from general nurses (While and Clark 2014). The care provided to this client group within acute and general hospitals could be influenced by the attitudes and perceptions of general nurses (Rose et al 2012, Temple 2012). Heslop et al (2013) indicated that general nurses' lack of knowledge about learning disability, communication difficulties and low confidence in working with this client group, has led to this client group healthcare needs being misinterpreted or neglected. Furthermore, people with LD are usually faced with the additional burdens of stigma and discrimination (Dzirambe 2015). General nurses have a duty to provide compassionate, dignified and non-judgemental care (Nursing and Midwifery Council (NMC) 2015). General nurses work with diverse clients and certain clients require specific approaches to their care needs such as people with LD (Ndengeyingoma and Ruel 2016); it is the legal duty of all general nurses to ensure reasonable adjustments are undertaken to meet individual care needs (PHE 2018).

## Aim of the study

The aim of this literature review is to explore the attitudes and perceptions of general nurses when caring for people with LD and how they affect the quality of care provided. The research question was as follows; *How do the general nurses' attitudes and perceptions influence care provided to people with LD?* The answers for this research question will be able to help produce evidence-based care guidelines and hence improve standards of care provided to people with a learning disability.

## Methods

Cumulative Index of Nursing and Allied Health Literature (CINAHL) and British Nursing Database (BND) were used for searching the literature, these databases were selected as they provide a wide range of full text articles relating to nursing practice. Dates were limited to papers published between 2006 and 2016. From this review, articles excluded were research studies not published in English due to avoidance in translation errors (Higgins and Green, 2011). Research studies published before 2006 were omitted in order to focus on current research findings and research studies (Brechin and Siddell, 2000) articles which were not based on primary research were also excluded.

Table 1 below presents the results of the literature search conducted via the two databases.

Table 1 results of the literature search

Search	CINAHL	BND
(Learning disab* OR intellectual disab*)	23,876	34,563
(Learning disab* OR intellectual disab*) AND nurses	1,543	15,597
(Learning disab* OR intellectual disab*) AND nurses AND caring	101	5,710
(Learning disab* OR intellectual disab*) AND nurses AND caring AND (attitudes AND perceptions)	5	2,459
Filters: 2006-present	5	1,434
Filters: Peer-reviewed	5	775
Filters: Language (English)	5	565

The search yielded 570 papers, after removal of the duplicates 565 papers remained. Following a screening of the titles and abstracts by using the inclusion criteria (Table 2), 35 papers remained. Polit and Beck (2012) Critical Appraisal Tool was used to further refine the result, leaving 14 full-text papers. These were read in full and in-depth questions from the critical appraisal tool (Polit and Beck, 2012) was implemented to further refine the results, 4 papers (full-text articles) were identified for review.

Figure 1 below presents an explanation of the selection of included papers flow chart.

Figure 1: Selection of included studies flow chart

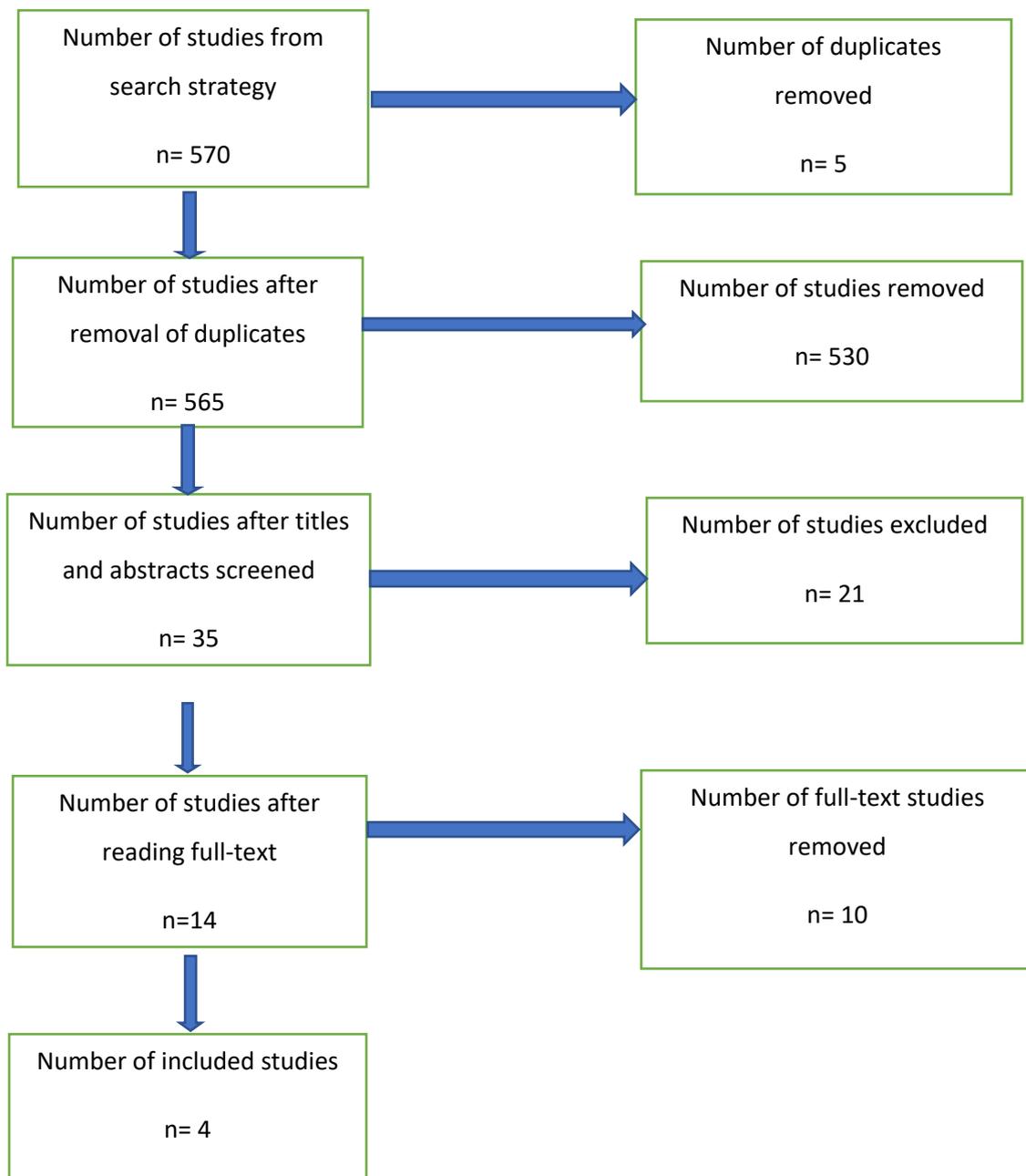


Table 2 Inclusion and exclusion criteria for the literature review

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"><li>• Participant general nurses of any grade/band caring for people with LD in acute and general hospitals</li><li>• Primary research articles (quantitative or qualitative methodologies)</li><li>• Published between 2006 to 2016</li></ul>	<ul style="list-style-type: none"><li>• Articles published not in English</li><li>• Research studies published before 2006</li><li>• Research studies which were not based on primary research</li></ul>

### Data extraction

Data were extracted based on the study (author, year and title); country of study; the aims of the research studies; methods used; study participants (sample), findings relevant to the study and recommendations.

**Error! Not a valid bookmark self-reference.**Table 3 Data extraction for the studies included in the literature review

Study (Author, Year and Title)	Country of Study	Study Aims and Objectives	Methods Used in the Study	Study Participant (Sample)	Study Findings	Recommendations
Cooper et al (2014) How confident are nurses that they can provide good care?	UK	To assess the registered nurses' levels of confidence when providing care for LD patients in an acute hospital setting, including patients with palliative care needs.	Descriptive survey was conducted in three areas; patient care, demographics and end-of-life care. A postal questionnaire with 'agree' or 'disagree' questions and a five-point Likert scales was applied.	111 questionnaires were distributed to nurses, ward managers and matrons working in two general hospitals with 30% response rate, n=33 (31 female and 2 male)	Few nurses were trained formally to care for people with LD yet, most of them indicated higher than expected levels of confidence in all areas of care. Although, when providing psychosocial and spiritual care nurses were less confident. Nurses highlighted	For nurses to attend relevant education sessions with hospital and community-based palliative care network nurses and community LD nurses.

					that there was a lack of awareness of relevant formal assessment tools for people with LD.	
Flynn et al (2015) Caring for cancer patients with an intellectual disability: Attitudes and care perceptions of UK oncology nurses	UK	To investigate the previously unexplored perceptions of oncology nurses with regards to the provision of cancer care for patients with LD and for patients without LD.	The vignette type (LD or non-LD) questionnaire was conducted with twelve care perceptions questions. Explanatory analysis using ANOVAs was used. The two open-ended questions responses were coded thematically	2309 members of UKONS were requested to participate. 138 nurses responded, with n= 83 nurses fully completing the questionnaire (81 female and 2 male)	Participant nurses felt less comfortable communicating with LD patients about their illness. They were less confident if the patients care needs would be identified and met. Participant nurses also indicated that caring for LD patients would induce more	Interventions to increase LD awareness and knowledge should be implemented to reduce anxiety and improve the perceptions and attitudes of oncology nurses when caring for this group of patients.

			and quantitatively analysed by using descriptive analysis.		stress, compared to caring for patients without LD.	
Lewis and Stenfert-Kroese (2010) An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general	UK	To investigate the attitudes and emotional reactions of nurses caring for patients with LD in general hospitals.	A self-report, questionnaire was used based on two vignettes (a patient with LD and a patient without LD). A cross-sectional descriptive survey was conducted. Data analysis was conducted using SPSS, Cronbach's alpha and Spearman's rho correlation co-	Self-report questionnaire (n=1350) were distributed to nurses working in 54 wards, at six general hospitals in the UK. There was 20% response rate, n=262 (240 female and 22 male)	Participant nurses reported fewer positive emotions, more negative emotions and less positive attitudes in response to caring for a patient with LD compared to a patient with a physical disability. Less positive attitudes were observed during communication and	Increased joint working between acute care services and community teams supporting people with LD.

hospital setting			efficient was used to investigate the internal test/re-test reliability.		when carrying out nursing tasks. Nurses reported feeling pessimistic, uncomfortable, hopeless, frustrated, nervous, awkward and lack confidence when caring for patients with LD.	
Sowney and Barr (2006) Caring for adults with intellectual disabilities: perceived challenges for nurses in	UK	To explore the experiences of nurses in accident and emergency units caring for people with LD.	Qualitative design using a semi-structured interview. A questionnaire was designed to collect relevant demographic data. Focus groups from	Focus group interviews (n=5) were conducted with nurses (n=27) working in accident and emergency unit in five hospitals. No specification of	Nurses adopted more passive roles when caring for patients with LD. The experience of fear and vulnerability was considered by nurses to be a consequence of their lack of	Nurses should participate in an awareness programme or a formal structured programme that addresses specific educational needs, including the nature of LD, conditions and associated health

accident and emergency units			<p>five hospitals were conducted, discussions were audiotape recorded. Data were thematically analysed.</p>	<p>male or female nurses was included in the research.</p>	<p>knowledge. The experience of negative emotions was a reason for nurses to depend on patients' informal carers. Participant nurses also reported a lack of preregistration training and indicated that exposure to preregistration training increased self-confidence and self-competence.</p>	<p>problems and communication, consent and management issues with people with LD. Involve community nurses in LD in supporting general hospital professionals to provide a more inclusive service by strengthening links and thereby sharing information to improve the quality of healthcare documentation.</p>
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### Strengths, limitations and usefulness of these studies

The study by Sowney and Barr (2006) used the focus group which was a beneficial method to inspire a number of opinions to be expressed and validated. However, there was no chance to pursue a great understanding of some important, emotive responses from participants. Moreover, the results cannot be generalised to all nurses working in emergency departments. In order to address the recognised knowledge deficits in other settings, the information gained from the data could be applicable. Lewis and Stenfert-Kroese (2010) study used a vignette style questionnaire of a patient with a disability in a detailed description, providing more information which allowed various responses from participants. However, the participating general nurses were required to describe their emotions and attitudes in a vignette of a hypothetical patient, hence caution must be taken when interpreting these findings as this might not reflect how they would actually behave. In order to enable general nurses more opportunity to reveal their attitudes, a qualitative approach would have been appropriate. Cooper et al (2014) study used postal questionnaires which had low response rates. This study finding created various initiatives such as education sessions and the distribution of staff-information leaflets to all members of staff required to care for people with LD. Flynn et al (2015) study had a low response rate due to using online survey research; however, the results may still be generalisable throughout UK as the sample was broadly representative.

## Findings

The literature search identified 4 studies that met the inclusion criteria. These articles were critically analysed using Polit and Beck (2012) Critical Appraisal Tool. Appraisal identified recurrent factors that influenced care that general nurses provided to people with LD in acute and general hospitals. Thus, the themes identified were; 'attitudes and perceptions of general nurses' and 'lack of knowledge of general nurses caring for people with LD'.

### Attitudes and perceptions of general nurses

This literature review identified studies that examined the attitudes and perceptions of general nurses when caring for patients with LD (Cooper et al 2014, Flynn et al 2015) and the perceived attitudes of general nurses themselves (Sowney and Barr 2006, Lewis and Stenfert-Kroese 2010). Lewis and Stenfert-Kroese (2010) argued that attitudes of general nurses when caring for people with LD are of paramount importance, as the quality of care provided could be affected by negative perceptions. Discrimination towards people with LD still exists by general nurses having negative attitudes and perceptions towards this client group (Sowney and Barr 2006, Lewis and Stenfert-Kroese 2010, Flynn et al 2015).

General nurses highlighted feeling awkward, nervous, hopeless, frightened and displeased (Lewis and Stenfert-Kroese 2010) and general nurses expressed that they would be overburdened by a patient with LD and felt less comfortable to communicate with LD patients about their illness (Flynn et al 2015). Flynn et al (2015) study applied explanatory analysis using ANOVAs with two open-ended questions responses which were coded thematically and quantitatively analysed by using descriptive analysis. The results indicated that general nurses felt less confident when communicating with patients with an LD about their illness ( $F(1,82) = 59.52, p < 0.001$ ), when identifying patient's needs they also had less confidence ( $F(1,82) = 42.03, p < 0.001$ ). Participants also highlighted that in comparison with patients without LD, caring for patients with LD would cause them more stress, ( $F(1,81) = 31.592, p < 0.001$ ). (Flynn et al 2015). The study by Lewis and Stenfert-Kroese (2010) applied two vignettes (a patient with and without LD) using a self-report questionnaire with subscales for attitudes and emotions and applied a cross-sectional descriptive survey. The Wilcoxon signed rank tests analysis resulted into the mean difference in score delivered from across the measures of the LD condition and the physical disability condition which revealed that scores obtained were significantly lower indicating attitudes that were less

positive ( $z = -10.66, P < 0.01$ ), experience emotions that were less positive ( $z = -7.42, P < 0.01$ ) and emotions that were more negative ( $z = -5.43, P < 0.01$ ) in response for patients with LD, in comparison with the patients with a physical disability (Lewis and Stenfert-Kroese 2010). These findings indicated that general nurses have significantly less positive attitudes and more negative emotions when caring for people with LD. Both Flynn et al (2015) and Lewis and Stenfert-Kroese (2010) studies, used vignettes when exploring attitudes and perceptions of ( $n=83$ ) and ( $n=262$ ) participant general nurses respectively, adding validity and reliability of the results which strengthened their findings due to plausible explanation (Polit and Beck 2012). Scior (2011) argued that the use of vignettes is a successful approach which enables researchers to monitor the beliefs and perceptions of participants regarding a specific situation with accuracy (Braun and Clarke 2013). However, it would have been important to determine the actual experiences of general nurses caring for LD patients by using a qualitative methodology (Flynn et al 2015) which would have allowed more freedom for general nurses to express their attitudes and perceptions (Lewis and Stenfert-Kroese 2010).

Sowney and Barr (2006) argued that general nurses in accident and emergency reported the experiences of fear and vulnerability when caring for adults with LD. Sowney and Barr (2006) study used qualitative design with ( $n=27$ ) participant general nurses and focus group interviews ( $n=5$ ), this methodology offered in-depth understanding of general nurses' attitudes and perceptions when caring for patients with LD (Polit and Beck 2012). The study examined the experiences of general nurses, the participants reported a lack of preregistration training and feeling less competent when caring for LD patients thus they adopted more passive caring roles. Consequently, this could have an impact on the quality of care provided (Sowney and Barr 2006). Contrary, 3 (9%) respondent general nurses in their capabilities to render end of life care in all aspects for patients with LD, reported that they were confident (Cooper et al 2014). The study of Cooper et al (2014) used three domains: demographics, patient care and end-of-life care by applying descriptive survey. General nurses, ward managers and matrons were sent self-report questionnaires ( $n=111$ ) with a response rate of 30% ( $n=33$ ). The results indicated that general nurses were confident managing symptoms of end of life care. However, most of the respondents were senior general nurses and ward managers who have got more experience and knowledge in

end of life care, hence reported high confidence in their abilities of caring for LD patients (Cooper et al 2014).

### **Lack of knowledge of general nurses caring for people with LD**

Negative attitudes and perceptions of general nurses such as fear, apprehension and discrimination are usually caused by lack of awareness and knowledge (Sowney and Barr 2006). A significant finding of this review was that when caring for people with LD, general nurses lacked the knowledge (Sowney and Barr 2006, Lewis and Stenfert-Kroese 2010, Cooper et al 2014, Flynn et al 2015).

General nurses' lack of knowledge about the nature of LD affected their recognition of the specific and complex needs relating to LD which in turn influenced the level of care provided for this client group; (n=83) general nurses reported possessing less relevant knowledge, experience and training for caring for people with LD (Flynn et al 2015). Remarkable interaction effects were discovered whereby general nurses with previous experience identified possessing most experience ( $F(1,81) = 6.992, p = 0.01$ ) and further relevant knowledge ( $F(1,81) = 7.670, p = 0.007$ ) when caring for LD patient compared to their counterparts who have no experience thus adding trustworthiness of these findings (Polit and Beck 2012). Similar results were reported in this review by Lewis and Stenfert-Kroese (2010) that general nurses lack of knowledge when caring for LD patients in hospital had led them to experience a range of emotions. Participant general nurses (n=262) felt less confident and pessimistic when caring for patients with LD compared to patients with physical disabilities; significant correlation of emotional and attitudinal variables indicated emotions that are negative being associated with unfavourable attitudes. This study used a non-parametric strategy to gain consistency across the analysis and inferential statistics were employed (Lewis and Stenfert-Kroese 2010). However, when inferring actual behaviour from attitudes expressed, caution needs to be taken. Moreover, the participant general nurses' attitudes and emotions responses were based on a hypothetical patient in a vignette (Lewis and Stenfert-Kroese 2010) which may not be a precise indication of how they would have felt in a real situation (Polit and Beck 2012). Nonetheless, most general nurses indicated lack of preregistration education and practice experience about LD while they were expected to know how to care for patients with LD who were acutely ill (Sowney and Barr 2006). In contrast, participant general nurses (n=31) caring for patients with LD in

palliative care, regardless of being insufficiently trained reported feeling confident in identifying end-of-life symptoms in these patients (Cooper et al 2014) this could be due to the fact that general nurses were more confident in their knowledge of end of life care regardless of whether the patient has LD or not. However, the response rates were low for these findings to be considered representative (Naoum 2004).

According to Lewis and Stenfert-Kroese (2010) general nurses reported having insufficient training and skills to accommodate the needs of patients with LD and they were not well equipped to care for LD patients' due to lack of knowledge. As a result of limited training or no LD training at all, general nurses lack the knowledge and confidence in abilities to provide psychosocial and spiritual care to people with LD (Cooper et al 2014). Flynn et al (2015) indicated that participant general nurses suggested on additional training needs in order to provide appropriate care to patients with LD. The topic of LD could be integrated into mandatory training or in-service and should be covered during general nurses' initial years of university. The need to improve and enhance knowledge on LD has been proposed by all the studies included in this review (Sowney and Barr 2006, Lewis and Stenfert-Kroese 2010, Cooper et al 2014, Flynn et al 2015). However, nurse training on its own is not sufficient to improve attitudes and perceptions of general nurses caring for people with LD (Lewis and Stenfert-Kroese 2010); therefore, more specific training and teaching on LD awareness such as the provision of effective communication by conducting more targeted communication training between general nurses and patients with LD is required.

## Discussion

People with LD are facing numerous hindrances in response to receiving appropriate care and have a high rise of unfulfilled healthcare needs (PHE 2018, Heslop et al 2013).

Nonetheless, the main priority of the Government has been to improve the health of people with LD (PHE 2015). Subsequently analysis of the general nurses' attitudes and perceptions when caring for people with LD through the identified themes in relation to the research question was explored. Whether the attitudes and perceptions of general nurses influence the quality of care provided for people with LD? The two themes presented in the findings indicated direct influence on the quality of care provided for people with LD. The presence of negative attitudes and perceptions among general nurses towards people with LD could lead to discrimination, exclusion and inequalities in providing care to this client group (Lewis and Stenfert-Kroese 2010).

The review of the studies found that general nurses felt underprepared and not well equipped to provide care for people with LD, moreover general nurses experienced barriers to communicate effectively with this client group (Sowney and Barr 2006, Lewis and Stenfert-Kroese 2010, Flynn et al 2015). As indicated in this review findings, general nurses would possess less confidence when providing care to a patient with LD compared to a patient with physical disability. This demonstrates that a uniform approach in acute and general hospitals when providing care for people with various primary disabilities would not be appropriate (Lewis et al, 2017) hence more targeted patient centred care approach is required in order to meet the needs of people with LD (Mencap 2018). Moreover, general nurses reported feelings of fear and uncertainty when caring for people with LD, which in turn could challenge these nurses in engaging in meaningful or effective communication with this client group. These negative attitudes and perceptions of general nurses influenced the quality of care provided to people with LD (Sowney and Barr 2006, Lewis and Stenfert-Kroese 2010, Flynn et al 2015). According to Glasby (2003) due to lengthen longevity, people with LD are highly inclined to acquire illnesses that are age-related such as cardiac conditions, respiratory or cancer and they may require palliative care ; reassuringly Cooper et al (2014) reported that general nurses revealed levels of confidence that were higher than expected and competence in providing end of life care for people with LD,

through clinical specialisation general nurses have developed more knowledge and confidence about end of life care.

General nurses lack of knowledge when caring for people with LD was highlighted by all the four studies included in this review (Sowney and Barr 2006, Lewis and Stenfert-Kroese 2010, Cooper et al 2014, Flynn et al 2015). This lack in knowledge could be one of the reasons for the negative attitudes and perceptions of general nurses when caring for people with LD in acute and general hospitals leading to negative feelings and discrimination (Lewis and Stenfert-Kroese 2010, Cooper et al 2014). The lack of relevant knowledge, training and experience among general nurses regarding the issue of LD and having no preregistration education in LD, simultaneously with fear and ignorance, these aspects causes negative attitudes in regard to people with LD (Michael 2008). To provide care for people with LD more efficiently, general nurses must conquer any prejudices and establish an awareness of LD.

Considering the ramifications affiliated with caring for people with LD in acute and general hospitals expounded in this review, it is significant to provide the right preparation, training and support to general nurses who have not being exposed to people with LD through their training and also in-service, to provide high quality care to this client group. As indicated by Sowney and Barr (2006) that most participant general nurses had not received preregistration education or practice experience about LD, yet they were expected to care for people with LD who were acutely ill. Therefore, students' accessibility for clinical placement to be involved in caring for people with LD during preregistration nursing education is necessary as better attitudes towards this client group is positively associated with the exposure of caring for people with LD (Brown and Kalaitzidis 2013). General nurses reported that their training and skills were not sufficient to accommodate the needs of people with LD (Lewis and Stenfert-Kroese 2010) indicating that training on its own is insufficient to improve general nurses' attitudes towards people with LD, therefore the provision of effective communication by conducting more targeted communication training between general nurses and patients with LD is required. Royal College of Speech and Language therapists (2013) designed the five good communication standards that could be used by healthcare professionals including general nurses when communicating with people with LD. Moreover, Treat Me Well campaign (Mencap 2018) has emphasised that all

hospital staff including general nurses to be trained in basic LD awareness. The LD awareness training for general nurses could significantly improve the attitudes and perceptions of these nurses.

## **Conclusion**

General nurses do not consistently feel competent and confident in caring for people with LD in acute and general hospitals. This review of the literature highlighted that people with LD are often cared for by general nurses who have less positive attitudes, lack the knowledge and appropriate training in LD awareness, yet not much is explored regarding the attitudes and perceptions of general nurses caring for this client group. These results have significant ramifications in providing care for people with LD particularly with the increase in number of LD patients gaining access to general healthcare services. For plan of actions created to enhance the care of people with LD to be successful, LD preregistration education, LD clinical placements and in-service LD awareness training may not only improve general nurses' attitudes and perceptions, but could reduce the associated negative emotions and uncertainty when caring for people with LD. It is argued that if general nurses have positive attitudes and perceptions when caring for people with LD, this would improve the quality of care provided. However, evidence-based plan of actions for educating general nurses to care for people with LD in acute and general hospitals need to be evolved and build on. Plan of actions should incorporate the provision of effective communication by conducting more targeted communication training between general nurses and patients with LD. This will enable general nurses to partake in developing, implementing and evaluating of practicable working procedures they could adhere to and consider valuable.

### Implications for practice (Box 1)

General nurses should commence LD awareness training during preregistration nursing education and continue their professional development training as a registered nurse;

Availability and provision of placements that are clinical for general nurse students to gain experience in caring for people with LD is crucial;

Mandatory education and LD awareness training sessions regarding the support and care needs for any LD patient should be provided for hospital staff including general nurses, alongside with development of a competency framework for general nurses which should appraise the incorporation of competencies for caring for people with LD in the near future;

Responsibility of existing registrants to continue developing LD awareness within their own Personal and Professional development;

The functions of the acute liaison LD nurse in acute and general hospitals should be apparent and recognised by general nurses, this could assist the application of reasonable adjustments that could be achievable in practice along with the provision of specialist assistance and guidance to general nurses.

Increase joint working between community LD services and liaison services focussing on improving attitudes and perceptions of general nurses through education and training on LD awareness;

Investigation into the Attitudes and Perceptions of General nurses caring for People with Learning Disabilities remains an important area for future research.

## Definitions:

General nurses: a nurse who has completed a three-year training course in all aspects of nursing care and has been registered with the NMC (Collins English Dictionary 2018).

Attitudes: a tendency to respond positively or negatively towards a certain idea, object, person or situation (Oxford Dictionary 2018).

Perceptions: The process by which people translate sensory impressions into a coherent and unified view of the world around them (Oxford Dictionary 2018).

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