Understanding the contribution of intellectual disabilities nurses: Paper 3 of 4- evaluation

Abstract The overall objective of this research was to identify intellectual disability nursing interventions and their impact on the health and healthcare of people with intellectual disability. This is part 3 of a 4-part series. In this paper we report the findings from quantitative questions from an online survey of intellectual disability nurses. The objective of this part of the study was to evaluate intellectual disability nurses' confidence in their understanding of the interventions they undertook. Quanitative data was collected using an online survey questionnaire from a voluntary response and snowball sample of 230 participants from 7 countries. Thematic, descriptive statistical, and inferential statistical analyses were undertaken. The evaluation data suggest and demonstrate a lack of clarity among intellectual disability nurses of the interventions they can effectively undertake. There appears to be correlations between lack of role clarity and the types of employer organisations and countries. Further work needs to be undertaken by nurse leaders to ascertain and address this lack of clarity.

Keywords intellectual disability, effectuating nursing procedures, enhancing impact, enhancing quality of life, nursing procedures

Introduction and Background

This is part 3 of a 4-part series. The overall aim of the research was to identify nursing led interventions that are in place to address the challenging and changing needs of people with intellectual disability. Paper 1 reports the findings from the scoping literature review that was undertaken between 1 February 2020 and 31 May 2020. Paper 2 reports the findings from an online cross-sectional survey of intellectual disability nurses that identified 5 major themes of nursing interventions; effectuating nursing procedures, enhancing impact of intellectuality disability services, enhancing impact of mainstream services, enhancing quality of life, and enhancing intellectual disability nursing practice. In this paper we report the findings from evaluation questions of an online survey of intellectual disability and other nurses working with people with intellectual disabilities understood these interventions. The objective of this part of the study was to evaluate intellectual disability nurses' confidence in their understanding of the interventions they undertook. We also sought to understand the factors that influenced interventions undertaken by these nurses within diverse settings across the lifespan.

The Nursing and Midwifery Council of the United Kingdom and the Nursing and Midwifery Board of Ireland offer pre-registration intellectual disability nursing programmes and in the Netherlands students can choose to specialise in intellectual disability in the 4th year of a generic programme

(Robinson & Griffiths, 2007). In other countries such as Australia, New Zealand and United States of America (USA) pre-registration nursing programmes have intellectual disability (Trollor et al., 2016). In countries like the USA and Canada, there are post-registration courses for nurses working with people with intellectual disability. Internationally, the role of intellectual disability nursing varies significantly but it is evident that the specialist knowledge and skills are essential in enhancing the delivery of person-centred care that improve health outcomes for people with intellectual disability (Brown et al., 2016).

The provision of health and healthcare services to people with intellectual disability is opportunistic. This is despite evidence that point to a need for specific and targeted interventions to achieve better outcomes (Chauhan et al., 2010; McIlfatrick et al., 2011; Robertson et. al., 2014), despite evidence demonstrating that preventative nursing interventions are effective in identifying the health needs of people with intellectual disability (Emerson et al., 2011; Robertson et. al., 2014). These nurses need to deliver effective nursing care to people with intellectual disability in challenging circumstances (Thomas & Kerr, 2011). This is also contrary to the the United Nations Convention on the Rights of Persons with Disability (United Nations, 2006), which stipulates that people with intellectual disability have the right to the highest attainable standard of health.

The avoidable disparities resulting from poor access to health services that are experienced by people with intellectual disability (Hatton and Emerson, 2015; Kavanagh et al., 2017; Kerr, 2004; LeDer, 2020; Straetmans, et al., 2007). These could be improved through appropriate nursing interventions (Campbell & Martin, 2009). It is unclear how intellectual disability nurses who work with people with intellectual disability perceive their preparedness and effectiveness of the interventions they undertake.

People with intellectual disability are known to have much greater health needs than those of comparable age groups who do not have intellectual disability (Backer et al., 2009), and experience preventable higher mortality rates (LeDeR, 2020). They are more likely to be dependent on others for their health and healthcare outcomes (Campbell & Martin, 2009). Their healthcare outcomes could be improved through appropriate nursing interventions (Ouellette-Kuntz, 2005). It could therefore be argued that nurses working with this population need to have clarity and confidence in the interventions they can undertake to improve outcomes for people with intellectual disability. McCarron et al. (2018) identified liaison in maternity services, providing psychosocial support, and health promotion as some of the interventions that could be undertaken by intellectual disability nurses when working with pregnant women with intellectual disability. Northway et al. (2017) suggested that intellectual disability nurses could be involved in pre-natal screening and provide support in relation to diagnosis.

Interventions undertaken by intellectual disability nurses in their work with children include pain assessment, objective clinical assessments, and parent consultation in school environments (Quinn & Smolinski, 2018), promoting health and wellbeing settings (Delahunty, 2017; Marshall et al., 2003; Northway et al., 2017), and, identifying children with potential intellectual disability, linking between schools and other services, facilitating transition from nursery into school or transition into adult services, identifying children who should be prioritised for further intellectual disability assessment, and monitoring children's development (Delahunty, 2017).

Existing literatures have identified a number of interventions undertaken by intellectual disability nurses when working with adults with intellectual disability (Barr et al., 1999; Brown et al., 2016; Brown et al., 2012; Campbell, 2011; Dalgarno & Riordan, 2014; Drozd & Clinch, 2016; Lee & Kiemle, 2014; Llewellyn, 2005; Lloyd & Coulson, 2014; Llewellyn & Northway, 2007; Lovell & Bailey, 2016; Lovell et al., 2014; MacArthur et al., 2015; McKeon, 2009; Marsham, 2012; Mason & Phipps, 2010; Pennington et al., 2019; Ring et al., 2018; Slevin & Sines, 2005; Taggart et al., 2011). These interventions include managing epilepsy and complex epilepsy (Auberry & Cullen, 2016; Pennington et al., 2019; Ring et al., 2018), preventing crisis (Lovell & Bailey, 2016), and undertaking psychological interventions (Campbell, 2011; Dalgarno and Riordan, 2014; Lee and Kiemle, 2014; Lovell et al., 2015; Mason & Phipps, 2010; McKeon, 2009). These interventions suggest that the intellectual disability nurses are highly skilled and have a very wide range of behaviours, skills, attitudes, and beliefs (Dalgarno & Riordan, 2014; Lovell et al., 2014). What is also clear from current studies is that intellectual disability nurses practice in a complex and non-condition-specific clinical environments. Studies identifying and describing intellectual disability nursing interventions with older adults is very limited. This is perhaps because in the UK there are likely to be very few or very limited specialist services for older adults with intellectual disability. Intellectual disability nurses have reported their involvement with pain management, behavioural support, problem solving when uncertainty around care exists, providing education for peers to develop an understanding of the changes caused by dementia, and providing environmental supports and staff training in the principles of person-centred dementia (Auberry & Cullen, 2016; Cleary & Doody, 2017; Cleary & Doody, 2017; Doody et al., 2013; Jenkins, 2012; Nelson & Carey, 2016).

Another area with a paucity of evidence regarding the interventions undertaken by intellectual disability nurses is end of life or palliative care. Some of the intellectual disability nursing interventions identified and described in current studies include shaping the nature of end-of-life care, influencing end-of-life decisions, detecting deterioration, and supporting relatives and helping medical staff to make more appropriate decisions, finding resources for end of life (Arrey, 2014; Bailey et al., 2014; McCarron et al., 2018; Ng, 2011; Wagemans et al., 2015).

What is clear in current literatures is that intellectual disability nurses do not only work directly with people with intellectual disability, but more importantly play significant roles in Mafuba et al. 3 the delivery of effective interventions by supporting other health and social care professionals who work directly with people with intellectual disability. Research is therefore needed, not only to identify, describe, and explain the interventions undertaken by intellectual disability nurses, but to evaluate how intellectual disability nurses experience their involvement with these interventions.

Methods

The Survey Method

We use the term 'survey' to describe our method, our data collection method, and our data collection tool (Creswell and Cresswell, 2018). An online survey was attractive for the study because it offered an opportunity to collect quantitative data that was essential for us to achieve the objective of the study. Another reason for using the survey method was that it was possible for us to reach a large number of participants (n = 230) very quickly (Kelly et al., 2003), economically (Kelly et al., 2003), and easily (Creswell and Cresswell, 2018). We collected evaluation data on participants' understanding of intellectual disability nursing roles and interventions.

Sampling and Participant Recruitment

We set out to recruit intellectual disability nurses registered by the Nursing and Midwifery Council of the UK. However, we received responses from other intellectual disability nurses registered with the Nursing and Midwifery Board of Ireland, as well as other registered nurses who exclusively worked with people with intellectual disability. Participants were therefore registered nurses and worked exclusively with people with intellectual disability. Ethics approval was obtained through the organisation of the lead researcher. Participants were recruited through professional networks. We used a combination of voluntary response sampling (McCombes, 2020) and snowball sampling (Creswell & Planko Clark, 2017). Blending voluntary response sampling with snowball sampling/chain-referral sampling provided an opportunity for participants to distribute the survey to their colleagues in their professional networks. Consent was obtained through the online survey form. We used the G*Power sample size calculator (Heinrich State University, 2020), and the appropriate sample size suitable for Pearson correlations and Pearson Chi-square tests was estimated at n = 225.

Data Collection

We used JISC Online Surveys platform (https://www.onlinesurveys.ac.uk/) to collect data.

Quantitative Data Analysis

We undertook descriptive and inferential statistical analysis of quantitative data (survey questions 1-8, 16-20) using SPSS 27.0 (IBM, 2020). We analysed the data for Pearson correlations (onetailed). This was important for us to observe any relationships between participant characteristic variables, and

response variables related to the interventions intellectual disability nurses undertook. For interpreting the Pearson correlation statistics, we followed the guidance provided by) (1988). We undertook Pearson Chi-square tests on the data to test how likely it is that what we observed distribution was due to chance.

Findings and Discussion

We asked participants how confident they felt about their understanding of what intellectual disability nurses do (How confident do you feel in your understanding of what all learning (intellectual) disabilities nurses do?). Figure 1 show that a significant proportion of the participants were not confident at all (1.3%) or had little confidence (12.6%) in their understanding of what the role intellectual disability nurses entail. This lack of clarity has been previously reported (Mafuba, 2013). It is concerning that such a significant proportion of participants lack confidence in what nurses working with people with intellectual disabilities do. It is however important to point out that 86.1 % of respondents were very confident of their understanding of what intellectual disability nurses do.

We asked participants how confident they felt about their understanding of the nursing procedures intellectual disability nurses undertake (see Figure 2) (How confident do you feel in your understanding of all the nursing procedures learning (intellectual) disabilities nurses are expected to perform in roles?). A significant proportion of the participants were not confident at all (2.2%) or had little confidence (32.6%) in their understanding of the nursing procedures undertaken by intellectual disability nurses. This may mean that intellectual disability nurses may have to depend on other professionals to undertake nursing procedures within their own sphere of practice. More worryingly, this may contribute to people with intellectual disability having unmet needs.

We asked participants how confident they felt in their understanding of interventions all intellectual disability nurses undertake to improve how other services or healthcare professionals deliver effective care to people with intellectual disability (see Figure 3) (How confident do you feel in your understanding of all activities learning (intellectual) disabilities nurses undertake in order to improve how other services or professionals deliver effective care to people with learning (intellectual) disabilities?). A significant proportion of the participants were not confident at all (1.3%) or had little confidence (25.5%) in their understanding of what interventions undertaken by intellectual disability nurses to enhance the impact of other services entail. It is concerning that such a significant proportion of participants lack confidence in what they can do to support other professionals and services to work more effectively with people with intellectual disability. The consequence of this may be that people with intellectual disability fail to access the appropriate services they may require.

We asked participants how confident they felt in their understanding of all activities intellectual disability nurses undertake to improve the quality of life of people with intellectual disability (see Figure 4) (How confident do you feel in your understanding of all activities learning (intellectual) disabilities nurses undertake in improving the quality of life of people with learning (intellectual) disabilities?). 76.1% of respondents were very confident, 0.4% were not confident at all, and 23.5% had little confidence in their understanding of what interventions undertaken by intellectual disability nurses to enhance the quality of life of people with intellectual disability entail. This may imply that people with intellectual disability may continue to experience health inequalities and inequities that should otherwise be addressed by intellectual disability nurses.

We asked participants their perception of the utility of a compendium that describe what intellectual disability nurses do as a guide for their own practice (see Figure 5). Mafuba et al. 5 Figure 1. Participants' confidence in understanding the intellectual disability nurse's role. Figure 2. Participants' confidence in understanding intellectual disability nursing procedures. Mafuba et al. 7 Figure 3. Participants' confidence in understanding intellectual disability nurse's role in enhancing impact of services. Figure 4. Participants' confidence in understanding intellectual disability nurse role in enhancing quality of life. Mafuba et al. 9 (A compendium describing what learning (intellectual) disabilities nurses do would be a useful resource for my practice). The compendium of intellectual disability nursing interventions is a catalogue of interventions undertaken by intellectual disability nurses as described in paper 2 of this four-part series. These findings indicate that 82.6% consider a compendium of intellectual disability nursing interventions a useful resource.

Considering the lack of role clarity discussed above and, in an effort, to obtain a better understanding of intellectual disability nurses' understanding of interventions they undertake and their attributes, we analysed the data to ascertain any relationships between variables that may contribute to this lack of clarity.

We interpreted the Pearson correlations using Cohen (1988)'s interpretation guide; Small ($r = +-.10$ to $+-.29$), Medium ($r = +-.30$ to $+-.49$), Large ($r = +-.50$ to $+-1.0$). Table 1 highlights variables with significant relations. The medium and large correlations in Table 1 mean that there is a strong or very strong correlation between the two variables. These findings clearly demonstrate that significant relationships exist between some of the variables. We observed significant correlations between intellectual disability nurses' broader understanding of their role and their understanding of intellectual disability nurse roles in effectuating nursing procedures, $r = .44$, $p < 0.01$ (Sig. = .000, $n = 230$, $p < 0.05$) Large Age and Qualifications $.17$ $p < 0.01$ (Sig. = .005, $n =$ The interpretation of this is that intellectual disability nurses need to keep their skills up to date to be more effective in the work they do with people with intellectual disability. We also observed a very strong correlation between

intellectual disability nurses' broader understanding of their role and their understanding of intellectual disability nurse roles in enhancing the impact of services, r = .45 p<0.01 (Sig. = .000, n = 230, p<0.05). This is important because intellectual disability nurses support other health and social care services to deliver care to people with intellectual disabilities. Therefore, having clarity of what that role entails is important. We also observed a large correlation between intellectual disability nurses' broader understanding of their role and their understanding of intellectual disability nurse roles in enhancing quality of life, r = .39, p<0.01 (Sig. = .000, n = 230, p<0.05). This is an important finding because intellectual disability nurses play an important role in promoting the health of people with intellectual disability.

The chi-square test determined a significant association between participants' age and their qualifications, (X^2) (value = 69.39, df = 24, N = 230, Sig. = .000, p =.05) (see Table 2).

The chi-square test determined a significant association between participants' age and their length of experience, (X^2) (value = 200.06, df = 16, N = 230, Sig. = .000, p =.05) (see Table 3).

The chi-square test highlighted a significant association between the participants' country of practice and their understanding of intellectual disability nursing roles (X^2) (value = 24.57, df = 8, N = 230, Sig. = .002, p =.05). Of particular significance in these results are the proportions of the distributions of participants who have little confidence in their understanding of intellectual disability nurse roles. Participants from Northern Ireland constituted 9.1% of participants, and those from Scotland constituted 16.1%. There is a disproportionate number of participants from Northern Ireland (24.1%) and Scotland (20.7%) who reported that they had little confidence in their understanding of the intellectual disability nurse role.

The chi-square test identified a significant association between participants' country of practice and their understanding of intellectual disability nursing roles in enhancing the quality of life of people with intellectual disability, (X^2) (value = 15.96, df = 8, N = 230, Sig. = .043, p =.05). What is important to note in these findings is the overall proportion of participants who had little confidence in their understanding of the intellectual disability nurse role in enhancing the quality of life of people with intellectual disability (23.5%). The distribution by country of these participants is also disproportionate, England (48.1%), Scotland (24.1%), Northern Ireland (11.1%), Other countries (11.1%), and Wales (5.6%).

The chi-square test determined a borderline association between the type of organisation participants worked in and their understanding of intellectual disability nursing roles in enhancing the quality of life of people with intellectual disability, (X^2) (value = 23.24, df = 14, N = 230, Sig. = .056, p =.05). Overall, 13.5% of participants had no, or had little confidence in their understanding of intellectual disability nursing roles in enhancing the quality of life of people with intellectual

disability. Also, it is important to note the disproportionate distribution participants who had little confidence in their understanding of intellectual disability nurse roles in enhancing the quality of life of people with intellectual disability between types of employer; NHS (intellectual disability inpatient) (6.9%), NHS (intellectual disability community) (58.6%), private/voluntary sector organisations (6.9%), schools / children services (6.9%), and other employer organisations (13.8%). The chi-square test highlighted a significant association between the participants' country of practice and their understanding of intellectual disability nursing roles (X 2) (value = 24.57, df = 8, N = 230, Sig. = .002, p =.05). Of particular significance in these results are the proportions of the distributions of participants who have little confidence in their understanding of intellectual disability nurse roles. Participants from Northern Ireland constituted 9.1% of participants, and those from Scotland constituted 16.1%. There is disproportionate number of participants from Northern Ireland (24.1%) and Scotland (20.7%) who reported that they had little confidence in their understanding of the intellectual disability nurse role. The chi-square test identified a significant association between participants' country of practice and their understanding of intellectual disability nursing roles in enhancing the quality of life of people with intellectual disability, (X2) (value = 15.96, df = 8, N = 230, Sig. = .043, p =.05). What is important to note in these findings is the overall proportion of participants who had little confidence in their understanding of the intellectual disability nurse role in enhancing the quality of life of people with intellectual disability (23.5%). The distribution by country of these participants is also disproportionate, England (48.1%), Scotland (24.1%), Northern Ireland (11.1%), Other countries (11.1%), and Wales (5.6%).

The chi-square test determined a borderline association between the type of organisation participants worked in and their understanding of intellectual disability nursing roles in enhancing the quality of life of people with intellectual disability, (X2) (value = 23.24, df = 14, N = 230, Sig. = .056, p =.05). Overall, 13.5% of participants had no, or had little confidence in their understanding of intellectual disability nursing roles in enhancing the quality of life of people with intellectual disability. Also, it is important to note the disproportionate distribution participants who had little confidence in their understanding of intellectual disability nurse roles in enhancing the quality of life of people with intellectual disability between types of employer; NHS (intellectual disability inpatient) (6.9%), NHS (intellectual disability community) (58.6%), private / voluntary sector organisations (6.9%), schools / children services (6.9%), and other employer organisations (13.8%). The lack of role clarity of the professionals working with people with intellectual disabilities has been consistently identified as one of the most common barriers to accessing appropriate services (Melville et al., 2006; Mafuba, 2009; NHS Health Scotland, 2004; Powrie, 2003; Phillips et al., 2004; Thornton, 1996). More recently, in the UK, Mafuba (2013), Mafuba and Gates (2015), and Mafuba et.

al. (2015) highlighted the lack of role clarity among intellectual disability nurses themselves. This scoping survey included a significant proportion of participants from outside of the UK. This suggests that this lack of clarity may very well similar in other countries where intellectual disability nurses practice.

Findings from this study demonstrate that a significant proportion of participants from the UK and elsewhere were not very confident in understanding what the role of an intellectual disability nurse's entails. In addition, a significant proportion of the participants were also not very confident in their understanding of what nursing procedures were undertaken by intellectual disability nurses, or in their understanding of interventions undertaken by intellectual disability nurses to improve the impact of services in meeting the needs of people with intellectual disabilities. What is also clear from these findings is that there appear to be correlations between lack of role clarity and the types of employer organisations and countries of the participants. Despite a significant proportion of participants being unclear about intellectual disability nurse roles and interventions which impact the lives of people with intellectual disability, it is surprising that; 4.8% of participants strongly disagreed, 2.6% of participants disagreed, and 10% with the idea of a compendium of intellectual disability nursing interventions that could be used as a guide for their own practice. Without clarity of what the expectations are for their own role it is no surprise other healthcare professionals will have varying interpretations resulting in further ambiguities. This lack of clarity of the interventions they can effectively undertake is likely to have a negative impact on health and healthcare outcomes for people with intellectual disability.

Conclusions

What is evident from this research is the wide range of interventions that intellectual disability nurses undertake in a complex sphere of practice. It is clear from the extent of these interventions that intellectual disability nurses need to constantly adapt and engage in a wide range of roles, whilst constantly assimilate emergent roles (Northway et al., 2017). The complexities and changing needs of people with intellectual disability, the changing environments in which intellectual disability nurses are practising, and the increasing expectation for intellectual disability nurses to meet health, healthcare, and social needs of people with intellectual disability across the lifespan was also clear within the research findings. Given the well documented complexity of health needs, poorer health, higher rates of co-morbidity, inequalities in health, poor access to health services and higher rates of premature mortality experienced by people with intellectual disabilities, further research is needed on intellectual disability nurses' repertoire of interventions, more specifically in relation to maternity, frailty, and end of life care.

The evaluation data from this survey suggest and demonstrate a lack of clarity among intellectual disability nurses of the interventions they can effectively undertake. What is also clear from our

findings is that there appears to be correlations between lack of role clarity and types of employer organisations and countries. This is likely to have negative impacts on the health and healthcare outcomes for people with intellectual disability. Further work should be undertaken by nurse leaders across countries to ascertain and address the reasons for the lack of clarity. Perhaps an internationally agreed definition of intellectual disability nursing may improve our understanding of their roles and interventions they undertake.

Limitations

The sample was not random and consequently it can be argued that it is unrepresentative. Therefore, although our findings are not generalisable and need to be understood from the context of participants who took part in the survey, they provide an important starting point for future work. Covid-19 restrictions impacted on the process of data collection.

Declaration of conflicting interests

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Consent statement

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