

Health of ageing people with intellectual disability and the role of the nurse in Ireland

Abstract

The number of people with intellectual disability living into old age continues to increase. As one ages, generally, functional ability decreases and health issues increase, with recognising and responding to the health needs of the person with intellectual disability of great importance and the responsibility of the intellectual disability nurse. The nurse must review and adjust the way they deliver care to ageing people with intellectual disability, not only in terms of responding to their health needs but also through collaborative working within teams and other services. As Ireland has specifically trained nurses in intellectual disability, it has a prime opportunity to address the health needs and concerns of people with intdisability and actively advocate for how services develop and responds to the changing health needs of ageing people with intellectual disability.

Keywords; ageing, health needs, intellectual disability, literature review, nursing

Introduction

As people age, they often confront issues of dependency and functioning impairment related to chronic conditions (Nobel, 2001). However, for people with intellectual disability, there may be a compounding of existing dependency and functional impairments and an increased risk for chronic disorders that typically accompany the ageing process (Fisher, 2004). Individuals with intellectual disability are more likely to suffer from health problems than persons in the general population (O'Hara et al., 2010). However, the identification of health problems in individuals with intellectual disability can present significant problems. Satisfactory medical care relies on an individual comprehending the need to seek medical advice, the ability to furnish essential information on which a diagnosis is made and understanding that he or she has to follow the advice obtained (Alborz et al., 2005). However, such capacities cannot be taken for granted in people with intellectual disability as inadequate communication and the fact that they cannot easily articulate their symptoms is one of the major factors contributing to insufficient health care (Cook and Lennox, 2000; Martin et al., 2004). In addition, people with intellectual disability often feel uncomfortable because of the unfamiliarity with physical examinations and various screening procedures, such as blood test and visual/auditory examination, consequently relying on others to understand and represent their needs as well as implement recommendations (Barr et al., 1999; Kerr et al., 2003). Therefore, the responsibility shifts onto trained nurses in intellectual disability (RNIDs) to recognise atypical symptoms such as challenging behaviour that could be indicative of an underlying health problem and support people with an intellectual disability and maintain their health. Since Jenkins (2000) identified that little attention had been paid to the nursing needs of this group and called for disability nurses to develop their skills and knowledge in this area and provide advice on potential areas of need, international literature and research publications within the area is growing. Opinion from articles such as Jenkins and Jones (2003) highlighted good nursing practice through their personal

reflections, Service and Hahn (2003) highlighted nurses positive impact in physical and mental health, ageing families, assessment, planning and interventions, Jenkins (2005a, 2005b) highlighted good nursing practice in improving access through case studies and Davies (2008) highlighted the role of nurses in meeting health needs. Research into the role of nurses in meeting the needs of older people with disabilities in the United States (Aronow and Hahn, 2005; Hahn and Aronow, 2005) explored advanced practice nurse initiatives to reduce health disparities and improve healthy ageing and demonstrated that positive results could be achieved by nurses in enhancing healthy ageing. Conversely, Sheerin (2004) identified that in the absence of nursing studies in Ireland, it is difficult to obtain points of reference on the health needs of older people with intellectual disability; therefore, there is an immediate necessity for defining the essence of intellectual disability nursing and ensure nurses meet the health and social care needs of an ageing people with intellectual disability (Tolson et al., 2005).

In Ireland, intellectual disability nursing has been a reality since the 1960s and the discipline has grown as one of the main divisions of Irish nursing (Doody et al., 2012). Since 1980s, intellectual disability public policy in Ireland has shown a clear trajectory towards community-based services (Department of Health, 1990, 1996; National Federation of Voluntary Bodies, 1996; Government of Ireland, 2004; Health Service Executive, 2011), resulting in the range of settings where nursing care is provided expanding with an emphasis on partnership with the service user and their family (Bruton, 2003). In addition, Sheerin (2004) identifies that 75% of people with intellectual disability are now residing at home or in community care settings. This service modernisation places great importance on the RNID to work effectively with people with intellectual disability, their families and mainstream services and refocus their roles in order to maximise the health and well-being of their service users. In order to meet the needs of the older population with intellectual disability, the nurses need to utilise their skills of health surveillance and health promotion, enablement and empowerment, enhancement of service quality, coordination of services, enhanced therapeutic skills, developing personal competence as well as management and leadership (Rose and Kay, 1995). RNIDs have the potential to become agents of inclusion because of their contribution to current health and social care reforms and the fact that they are working at the very heart of initiatives to develop services and facilitate health care within a person-centred approach (Beacock, 2001; Gates, 2006). The multifaceted role of the RNID, which includes direct care, management, administration, liaison work and educational activity (Alaszewski et al., 2001; Sheerin, 2004), is also underpinned by the promotion of autonomy, health promotion and evidence-based care (Barnsteiner and Prevost, 2002; Bollard, 2002; Moulster and Turnbull, 2004). Additionally, Gates (2006) identifies that people with intellectual disability view the RNID as a helper, enabler and as possessing specialist knowledge. Therefore, appropriate knowledge, skills and attitudes are vital in providing holistic and person-centred approaches to care delivery. Given that this discipline of nursing is unique to Ireland and the United Kingdom, there is a necessity for nurses within the discipline to create a sound accessible research base useable by nurses, which highlights the needs and effective care strategies (Griffiths et al., 2007). Therefore, the quintessence of intellectual disability nursing should be to endeavour to capture and illuminate the very heart and kernel of care to create an evidence-based quality service

worthy of underpinning care (Doody et al., 2012). In order to fulfil this, it is essential that RNIDs working with older people identify the growing complexities and challenges working with this population group and clinical nurse specialists (CNSs) in the area provide strong leadership in order to remain viable as a profession and continue to serve people with intellectual disabilities (Northway et al., 2006).

Health and ageing, the role of the RNID.

People with an intellectual disability are expected to survive into old age and experience the ageing process (Parrott et al., 2008; Strydom et al., 2005); however, people will only age if their lifestyle is healthy enough to reach this stage of life. It is commonly acknowledged that people with intellectual disability have a wide range of health problems (Cooper et al., 2004; Emerson et al., 2009). Compared with the general population, there is a higher prevalence rate of both psychological disorders (Deb et al., 2001; Taylor et al., 2004) and (untreated) physical disorders (Emerson and Baines, 2010; Leeder and Dominello, 2005). People with intellectual disability are often granted a 'permanent visa to the kingdom of the sick', as intellectual disability is often equated with ill health (Tighe, 2001, p. 511). Ageing for people with intellectual disability brings a normal process of decline such as deterioration in mobility (Strauss et al., 2004), increased musculoskeletal pain (Symons et al., 2008), vision and hearing reduction/problems (Merrick et al., 2004) and incontinence. However, while ageing is not a risk factor for constipation, associated factors such as cerebral palsy, specific medications and physical activity levels contribute to its prevalence (Morad et al., 2007). In addition, many factors influence the health of persons with intellectual disability such as smoking (McGillycuddy, 2006), nutrition (Draheim et al., 2007), obesity (Bhaumik et al., 2008) and physical activity levels (Stanish et al., 2006). Disease mortality is higher for persons with intellectual disability up to the age of 40 years but not in later years, with vascular disease, respiratory disease and cancer being the leading causes of death and disease of the digestive system been two and a half times more common than in the general population (Esbensen et al., 2007; Patja et al., 2001).

There is increasing evidence that psychiatric problems are seen more commonly in people with intellectual disability (Emerson, 2003). Generally, more symptoms of psychiatric disorders are found among people with mild-to-moderate intellectual disability than those with severe to profound (Myrbakk and von Tetzchner, 2008). Diagnosis is difficult within this population due to the higher rates of comorbidity and polypharmacy and a reduced tendency to voice psychological problems compared with physical complaints and further magnified by the presence of seizure disorders and their treatments that complicates the assessment of mental functioning (Thorpe et al., 2001). Other factors include communication barriers and baseline behavioural abnormalities overlapping with core mental illness symptomatology. Consequently, Salvador-Carulla et al. (2000) caution that mental health problems in people with intellectual disability may remain undetected and/or may be misinterpreted as behaviour disorders, as signs of physical discomfort such as head banging, may be misinterpreted as challenging behaviour instead of a sign of pain and a demand for help.

Health care services for people with an intellectual disability have been criticised both in relation to the direction and treatment of established conditions and to preventative care aiming to reduce risk factors (Turner and Moss, 1996). People with intellectual disability often receive less routine immunisations and blood pressure checks, with cervical and breast cancer screening programmes often overlooking women with an intellectual disability (Beange and Durvasula, 2001). Sullivan et al. (2003) highlight the need for improved access to and utilisation of primary health care services especially for women in residential facilities and as of which the RNID has a major role in promoting health screening and access to services for the clients within their care. For example, mammography screening rates reduce with the level of an intellectual disability and physical disability as physical disabilities are not easily accommodated by mammography scanners and often clients may have difficulty in understanding the procedure (Walsh et al., 2001). For these women, the RNID must engage in manual examination of the breast and advocate for an ultrasound as a more appropriate means of detection. Therefore, the most significant improvement in health can occur following the action in the fields well beyond what people can do to themselves. Leeder and Dominello (2005) identify that the social context and the structure of services available to people should be the central focus for health promotion for people with intellectual disability. These strategies include health promotion to reduce the risk of declining health and planning for the future, helping others to enhance the range of social resources that may be drawn upon in difficult times. In response to providing a guide to health promotion, the International Association for the Scientific Study of Intellectual Disabilities (IASSID; Leeder and Dominello, 2005) developed 15 health targets as highlighted in Table 1. These targets address conditions that are highly prevalent, easily detected and amenable to available treatments or preventive efforts; therefore, the RNIDs must actively engage in promoting health of the older people with intellectual disability by uphold these health targets as a step in the overall process.

Table 1. Health targets for people with an intellectual disability (In Beange et al. 1999)

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| <ul style="list-style-type: none"> • Assess hearing and vision regularly. • Assess nutritional status regularly and treat disorders such as underweight and obesity. • Prevent and treat chronic constipation. • Review epilepsy treatment. • Screen for thyroid problems. • Identify and treat mental health problems. • Identify and treat gastro-intestinal disease and helicobacter pylori infection. | <ul style="list-style-type: none"> • Identify and treat osteoporosis. • Review medication frequently. • Ensure full vaccination status. • Provide exercise opportunities. • Organise regular physical assessment. Review by a medical practitioner and refer to a genetic clinic and patient without a definitive aetiological diagnosis. • Arrange mammograms and pap smears as for the general population. • Assess dental health regularly. |
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Increased longevity for people with intellectual disability imposes important challenges for the RNID, which includes ensuring that the development of additional age-related disabilities can be prevented and maintaining general well-being and quality of life (Holland, 2000). As more people with intellectual disability attain old age, it is important to note that the excess functional impairment, morbidity and even mortality can result from the consequences of early age onset conditions through their long-term progression or their interaction with older age onset conditions (Evenhuis et al., 2001). An example of the potential consequences of the long-term progression is the high incidence of oesophageal reflux in children with cerebral palsy. If not identified and treated in childhood, it can lead to high rates of oesophageal stricture or cancer in adulthood (Bohmer et al., 1997a, b; Evenhuis et al., 2001). Hence, the RNID should adopt a life span approach that recognises the progression or consequences of specific diseases and therapeutic interventions for people with intellectual disability (DoH, 2001). It is acknowledged that preventative activities for successful ageing, in addition to reacting effectively to stressful changes, are important. Ouwehand et al. (2007) emphasises that successful ageing must be prepared for long in advance; a happy old age is the criterion and reward of a well-conducted life. At an individual level, the RNID should ensure that each person has a tailored health plan, describing their health status and their particular risks, with a health action plan based on their individual needs, which should be updated at regular intervals or transition points in their lives (DoH, 2001). For this to occur effectively, the RNID needs to actively engage the client and their family in designing the health plan and address aspects such as ageing in place (Bigby, 2010; Forbat, 2006). Ageing in place requires the RNID to actively engage with the client and their family and consider future plans for care provision and support; this is essential as older people with intellectual disability remain vulnerable to premature and often inappropriate admission to residential aged facilities (Bigby, 2010). Within this area, the RNID has to operate within a person- and family-centred approach and ensure that they advocate for the needs and desires of the individual along with empowering the client and family within the decision-making process. An option currently available in services in Ireland includes supported shared care between the family and the service provider. However, while this is welcomed and of support to the family, the RNID must still ensure that a plan is in place and this plan should commence at mid-life rather than at old age and should be updated and reviewed with the family and extended family and take into account the changing circumstances.

The main problem reported in relation to the diagnosis and classification of medical disorders in individuals with an intellectual disability is that very often they are unwilling or unable to communicate the symptoms, which are presented in the study by Doyle (2006) and Ziviani et al. (2004). As a result, detection at the asymptomatic stage of disease progression is compromised and there is low usage of health screening (Barr et al., 1999; Sutherland et al., 2002). The RNID has an important role in the detection of health problems in the early stages when clinical signs are least obvious, but intervention are more effective and least expensive. Therefore, the RNID has to actively identify and differentiate subtle physical changes indicative of a more significant medical disorder but this can only occur through knowledge of normal age-related changes and specific aspects related to ageing and intellectual disability. In addition an adult with an

intellectual disability may experience older age onset medical conditions at an earlier age and there is a wide range of health needs and reduced ability to seek appropriate assistance, the RNID should have a high index of suspicion (Evenhuis et al., 2001). This demands careful reassessment by the RNID regarding the medical needs of the clients at regular intervals throughout their life. However, this knowledge alone is not sufficient to ensure action, so the RNID needs to articulate a clear care strategy that identifies the functional baselines of the individuals along with health promotion and screening plans.

Health professionals have suggested ways to assess the health of older adults with intellectual disability based on a traditional medical model (Prasher and Janicki, 2002; Martin, 2003). Conversely, Fender et al. (2007) identified that these assessments were initially designed to detect threats to health but many assessments of older adults with intellectual disability contain many items that have poor validity, are considered too invasive and fail to address the health concerns of the older adult with intellectual disability themselves. Although the assessment procedure is much the same irrespective of the underlying level of disability, there are important and highly significant differences when applied to people with intellectual disability. Therefore, RNIDs are continually faced with the challenge of using valid, reliable assessment tools, which can diagnose conditions that present with similar overt symptomatology (Turner and Moss, 1996). Approaches to define health indicators for people with intellectual disability include those of the Pomona Project in Europe (Walsh, 2008) and the National Core Indicators project in the United States (Bradley and Moseley, 2007). As the implementation of health checks has been recommended internationally as one component of health policy responses to the poorer health of people with intellectual disability, RNIDs need to ensure health checks are conducted with this vulnerable group. While health checks from the general population have been used or adapted such as the Comprehensive Gerontological Assessment and others have been devised for adults with intellectual disability such as the Cardiff checklist (Baxter et al., 2006) and the Comprehensive Health Assessment Program (CHAP; Lennox et al., 2004), the RNID has to consider these in relation to their applicability to the range of disability and cognitive function of the individual been assessed. Others such as Ruddick and Oliver (2005) developed a self-reporting health status measure for people with intellectual disability and Fender et al. (2007) developed a health assessment based on the CHAP to include self-defined health and consider functional age but again the RNID needs to be aware that these tools need further evaluation before assertions of general applicability can be made.

The future mission of the RNID relates to the development of a workforce capable of meeting the needs of an increasingly diverse population in an ever-changing health care environment; intellectual disability nursing will always need to redefine and redesign itself to ensure that its practice is meeting the changing needs of individuals and their carers (DoHC, 2002). Gates (2006) suggested that this may be achieved through person-centredness that focuses on what is important for the person now and for the future and acting upon this in collaboration with the person's family and friends. While intellectual disability nursing has been stereotyped as a less developed area of nursing, many of the changes viewed in wider nursing such as 'named nurse,' 'person-centred planning' and 'inclusion' were well established in intellectual disability nursing before they became

popular in other areas of nursing (Barr, 2007). Nevertheless, Bostrom et al. (2006) emphasised that society and clients will demand high-quality care based on evidence, requiring an urgent development of various strategies for the implementation of evidence-based practice (EBP) in this sector implying challenges for several key groups including the RNID who have an important task to develop organisational strategies to realise EBP. As nurses, the RNID need to enhance health status, longevity, functional ability and quality of life of ageing adults with intellectual disability. This can only be achieved by increasing information resources and staff reading habits and despite the noted phenomenon of the ageing population, old age has only recently been conceptualised as a separate and distinct life stage for people with intellectual disability. Thereby, the RNID is often limited to evidence regarding physical health issues based primarily on generalisations from clinical and research findings on the general population and adults and children with intellectual disability (Prasher and Janicki, 2002). Nevertheless, Gates and Atherton (2001) and Mitchell (2004) have argued that intellectual disability nurses can utilise evidence from a range of other academic disciplines but the benefits of having a defined body of knowledge in nursing the older person with intellectual disability includes better client care, enhanced professional status for nurses and guidance for research and education (Newell and Burnard, 2006).

Currently, Ireland has CNS posts and four relate to intellectual disability and ageing and with the increasing profile of people with intellectual disability, the role of the CNS in the older person needs to be prioritised. The CNS has specific knowledge relating to specific health problems associated with this population group, the barriers they encounter in accessing care, their specific communication needs and liaison between specialist and generic services (Caples et al., 2010). However, given the current economic climate, the nonreplacement of staff and staff embargos, there may be little advancement in the provision of CNS posts. Nonetheless, it is vital that we remain focused on the support we provide and the impact this has on our clients and their families, thereby the RNID has a vital role in developing and supporting the older person and publishing their efforts. In addition, there has been a review of disability services under the value for money and policy review initiative 2008–2011 in Ireland, and given the current economic downturn, one may be concerned that such improved outcomes may not be valued against financial savings (Doody, 2012). However, it is clear that ‘one size fits all’ approach to health and personal care services will not produce the desired results (National Disability Authority, 2010). Thereby, it will be necessary to develop an approach that takes into account the differences between groups such as age, type or degree of disability when planning and delivering community living systems and practice (National Disability Authority, 2010), thus reinforcing the RNID and CNS role in care provision for the older person.

Conclusion

Evidence suggests that too often general assumptions are made that physical decline or poor health in people with intellectual disability is due to the impact of ‘ageing.’ As a consequence, medical conditions, particularly those that are chronic, may remain unacknowledged, uninvestigated and untreated in older people with intellectual disability (Bigby et al., 2001). RNIDs must be knowledgeable of probable age-related change in order to mobilise action to slow its occurrence or minimise its impact through appropriate

individual or environmental adaptation and compensation. The RNIDs knowledge helps differentiate normal from pathological changes and identify unexpected or disease-related changes that require medical diagnosis and treatment. Good health and health care are distinct needs, which should be recognised and met (Cooper et al., 2004), and for this to happen, further research and studies are required to understand the unique needs of the older person with intellectual disability. Such studies may provide a framework to guide education (Fisher, 2004) and awareness by RNIDs of this challenge may improve both quality and access to care for this vulnerable population. Thereby, the RNID can actively engage and contributing to this knowledge by identifying their knowledge and experience in caring for older persons with intellectual disability. The specialist knowledge and skills of the RNID in a number of key areas such as assessment of health need, health promotion, specialist advice, behavioural assessment and intervention, development of packages of care and provision of residential support/services (Jenkins and Jones, 2003) indicate that their skills are too valuable to be diluted by being used in non-health-focused roles. Within their role as health promoter, the RNID assumes the responsibility for the care of the individual and accesses mainstream services providing specialist support and advice to team. With a growing population of older persons with intellectual disability in Ireland, there is a need to expand the number of CNS posts in this area and services need to recognise and incorporate the CNS role in service planning. Thereby expertise from the disability and aged care sectors can unify their knowledge and skill to ensure that the services are appropriate, accessible and sensitive to the needs of this group (DoHC, 2001). A unified approach is essential as the current primary care system cannot be reasonably expected to undertake the comprehensive, individual health screening necessary to fully recognise the health needs of people with intellectual disability. For this to happen, there must be cooperation and collaborative working of specialised intellectual disability, aged and primary health care workers. This multiprofessional team working is a crucial element in identifying and meeting individual needs and providing a seamless service for the client with the RNID/CNS adopting a leading role in collaboration and planning of care (Jenkins et al., 2006).

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