

The role of nurses in meeting the health care needs of older people with intellectual disabilities: A review of the published literature

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Abstract

People with intellectual disabilities are now living longer and as a consequence are likely to have greater physical and mental health needs compared to the general population. Nurses may have a crucial role to play in meeting such needs, although it is unclear whether nurses are prepared for this role. This review of the available literature found little evidence of nurses undertaking effective interventions in meeting the health needs of older people with intellectual disabilities in the UK and Ireland. Nurses have been alerted to the increase in numbers of older people with intellectual disabilities and offered some direction on their future role in this area. Most of the available literature is based mainly on informed opinion rather than research findings.

Keywords

health, intellectual disabilities, literature review, nursing, older people

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Introduction

There is little doubt that people are living longer due to such things as improvements in medicine, science, public health, technology and education. These factors have also contributed to some extent to increasing the life expectancy of people with intellectual disabilities (World Health Organization, 2001; Bigby, 2010). It is thought that older people with intellectual disabilities

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generally succumb to the same physical deterioration as they age as do the general population (Holland, 2000; Janicki et al., 1999; 2002). However, Holland (2000) states that although there is a levelling out in terms of health and social care needs between the general population and people with intellectual disabilities in later life, there are still differences in physical health needs. Physical ill-health is relatively common amongst older people with intellectual disabilities (Cooper and Holland, 2007). It has also been identified that specific populations of people with intellectual disabilities have particular health risks. Examples include individuals with a specific syndrome (Down syndrome, fragile X) or a central nervous system condition such as cerebral palsy or epilepsy (World Health Organization, 2001; Evenhuis et al., 2001).

Haveman et al. (2010) reviewed the literature published since 1999 regarding the major health risks in older people with intellectual disabilities. They identified some of the health risks as being cardiovascular disease, hypertension, gastrointestinal conditions (helicobacter pylori, gastro-esophageal reflux disease, and constipation), osteoporosis, oral health conditions (caries, gingivitis, periodontal disease) and obesity. The paper also discussed lifestyle risk factors such as poor diet and lack of exercise, and called for improvements in these areas.

Psychiatric disorders are also common amongst older people with intellectual disabilities due to additional vulnerability risk factors such as neurological changes, sensory impairments, pain, loss of confidence, bereavement and loss, deteriorating physical health and diminishing social networks and activities (Luty and Cooper 2006). It was reported by Hubert and Hollins (2000) that the higher rates of psychiatric disorders include dementia, anxiety, depression, and affective and delusional states. Holland (2000) posits that the increase in psychiatric disorders in this client group can be attributed to the ageing process and associated social changes. Strydom et al. (2010), in a review of the literature between 1997 and 2008, report that levels of dementia amongst people with intellectual disabilities (excluding Down syndrome) are similar or higher than the general population. However, they state that due to the use of different methodologies, diagnostic criteria and populations, prevalence rates of dementia are varied. It is well recognized that there is an association between Down syndrome and Alzheimer's disease (Hutchinson, 1999; Strydom et al., 2010), with McCarron (1999) stating that virtually all individuals with Down syndrome aged over 35 years have neuropathological changes characteristic of Alzheimer's disease. It must be remembered that many symptoms of illness may pass undetected in people with intellectual disabilities, so the levels of physical and mental health need may be much higher (Kerr et al., 2003).

In view of this evidence of the additional health needs of older people with intellectual disabilities, it is therefore likely that nurses would have some involvement in addressing such health needs. Jenkins (2005b) believes that

Nurses are often in unique and privileged positions in which to help people with learning disabilities live long and fruitful lives . . . for some individuals there will be particular health needs that require the intervention of specialist nurses or healthcare professionals . . . Therefore there needs to be a greater awareness by the nursing profession of the particular challenges that this client group presents.

It is therefore important to determine the extent to which this nursing role is reflected within current research and literature.

Literature review

Two important factors were taken into consideration before undertaking this literature review.¹ First, research into ageing matters regarding people with intellectual disabilities is a relatively new

undertaking (Bigby and Balandin, 2004). Second, Parahoo et al. (2000) found that intellectual disability nurses carried out less research than the other three branches of nursing. It was therefore not surprising that Northway (2003) called for more intellectual disability nurses to publish their work as she felt that many examples of good practice were not widely disseminated. Interestingly, Northway et al.'s (2006a) study of intellectual disability nursing research between 1995 and 2003 found that although the research which had been undertaken was limited, it was nevertheless expanding. There was more or less an even spread of both qualitative and quantitative types of research. They highlighted that problems occurred with accessing intellectual disability research through standard electronic databases due to the use of different key words and because of the lack of a single database which indexed all the intellectual disability journals publishing contributions within this branch of nursing. Griffiths et al. (2007), building on this review, were less optimistic in that they stated that what little research had been undertaken appeared not to be fit for purpose. Both of these studies found little in the literature examining the outcome of nursing interventions.

The lack of published research does not mean that intellectual disability nurses are undertaking work which is not worthwhile or is unworthy of research. There is an abundance of anecdotal evidence that this is the case, but little research as to why intellectual disability nurses tend not to get their work published. For instance, the Department of Health (2007) issued a good practice guide in which a number of good practice initiatives were developed in England by intellectual disability nurses. However, most of these initiatives have not been turned into publications or research. Part of the reason for very little research having been undertaken by intellectual disability nurses is a lack of research funding for this area of nursing (Griffiths et al., 2007). The UK intellectual disability consultant nurse network document *Shaping the Future: A Vision for Learning Disability Nursing* (Northway et al., 2006b) acknowledged this problem and made undertaking and utilizing research a key recommendation. It also recommended that intellectual disability nurses should disseminate and publish their work more widely, thus increasing the amount of literature from this branch of nursing.

Method

A search was carried out using major electronic databases which it was felt would contain nursing literature, such as CINAHL, EMBASE and MEDLINE, between the years 1982 and 2011. Further searches were also carried out using other databases such as PsycINFO and ASSIA which it was felt might also contain relevant literature. A hand search was made of some key intellectual disability, nursing and disability journals to identify papers which were not identified in the previous searches. Finally, the reference lists of papers identified were examined in order to discover any further potential papers using a snowball technique.

A number of key search terms which are used in the UK and Ireland were used such as 'learning disabilities', 'learning difficulties' and 'intellectual disabilities'. Older terms such as 'mental handicap' and terms familiar to the USA such as 'developmental disabilities' and 'mental retardation' were also used as key search terms. These were then combined with other relevant terms such as 'nursing', 'older people', 'elderly', 'ageing' and 'health'. An initial analysis of the literature revealed few articles concerning older people with intellectual disabilities prior to 1990. This may be due to the issue of ageing in people with intellectual disabilities not gaining much prominence amongst academics and practitioners. The literature review was thus adjusted to identifying articles between the years 1990 and 2011.

Results

Terms such as 'learning disabilities', 'learning difficulties', 'intellectual disabilities', 'developmental disabilities', 'mental handicap' and 'mental retardation' yielded a large number of citations. When these were then combined with terms such as 'older people', 'elderly', 'nursing', 'health' and 'ageing', a smaller number of articles were identified. There was a great deal of duplication between databases, especially MEDLINE, CINAHL and EMBASE. Once the duplication was eliminated, a number of papers were identified which specifically related to older people with intellectual disabilities. Some of these papers were excluded as their focus was not exclusively on the nursing needs of older people with intellectual disabilities. For example, papers focusing primarily on dementia and palliative care needs were excluded, as whilst they included reference to older people their focus was not specifically on older people. The inclusion criteria were determined as:

- Published in the English language.
- Published between the years 1990 and 2011.
- Having a specific focus on the role of nurses, particularly intellectual disability nurses, in meeting the needs of older people with intellectual disabilities in the United Kingdom and Ireland. These two countries have a long established specialist pre-registration programme of study for intellectual disability nursing. This is not reflected in other countries around the world.

Once the literature had been examined, only 10 journal articles and one book chapter were found to have some specific focus on the role of nurses in meeting the needs of older people with intellectual disabilities in the United Kingdom (UK) and Ireland between the years 1990 and 2011 (see Table 1). The literature was then analysed in order to assess the relative merits of the contributions in relation to the topic under investigation. For example, they were categorized as being opinion papers, reports or research studies or a combination of two or all three types. Finally, a critical appraisal was undertaken of each paper in order to determine the merits of the work undertaken in relation to the role of nurses.

Discussion on the published papers

It can be seen from the literature search that very little research had been specifically undertaken which investigated the role of nurses in meeting the needs of older people with intellectual disabilities. Most of the papers which had been published in this area tended to be opinion papers, although there was some research which did have an element of a nursing focus. Smith's (1994) news article alerted readers that people with intellectual disabilities were living longer and posed the question as to whether nurses would be involved in their care. This was the first alert for nurses to start considering the needs of this growing population. Jenkins's (2000) paper again highlighted that little attention had been paid to the nursing needs of older people with intellectual disabilities. He called for intellectual disability nurses to develop their skills and knowledge in this area and provided some advice on potential areas of need. Little reference or advice was provided on how other groups of nurses might be able to support this client group. McCarron and Griffiths (2003) addressed this in some respect when they discussed the nurse's role in supporting older people with intellectual disabilities with additional mental health needs. They identified areas and practices which may have improved the diagnosis of mental health problems with this client group.

Table 1. Identified literature in the UK related to the role of nurses in caring for older people with intellectual disabilities 1990–2011

Authors	General focus	Nursing focus	Journal and type of paper
Smith (1994)	News article highlighting that people with intellectual disabilities are living longer	Poses the question as to whether nurses will be involved in their care	<i>Nursing Times</i> (UK) Informed opinion
Jenkins (2000)	Discusses that little attention has been paid to the nursing needs of older people with intellectual disabilities	Argues that intellectual disability nurses should develop their skills and knowledge in this area	<i>British Journal of Nursing</i> (UK) Informed opinion
McCarron and Griffiths (2003)	Discusses the nurse's role in supporting older people with intellectual disabilities with additional mental health needs	Identifies areas and practices which may improve diagnosis and care of older people with intellectual disabilities with additional mental health needs	Book chapter (UK) Informed opinion
Jenkins and Jones (2003)	Personal reflections on introducing clinical governance into a residential home for older people with intellectual disabilities	Highlights some good nursing practice of intellectual disability nurses in the care of older people with intellectual disabilities	<i>Learning Disability Practice</i> (UK) Research and perceptions
Bland et al. (2003)	Discusses research findings on the health needs and services of older people with intellectual disabilities. Questionnaire study of carers of ($n = 94$) older people with intellectual disabilities living in a variety of community settings in Yorkshire, UK	Highlights support, access, monitoring roles, satisfaction of community, district and practice nurses for older people with intellectual disabilities	<i>Journal of Learning Disabilities</i> (UK) Research
Jenkins (2005a)	Part 1 discusses the ageing process and health needs of older people with intellectual disabilities	See part 2 for nursing focus	<i>Nursing Older People</i> (UK) Continuing professional development (CPD) based on informed opinion
Jenkins (2005b)	Part 2 discusses the problems of accessing health care and the implications for nursing practice	Highlights some good nursing practice in improving access. Provides examples of how primary care, intellectual disability, mental health and palliative care nurses can meet the needs of an older person with intellectual disabilities	<i>Nursing Older People</i> (UK) Continuing professional development (CPD) based on informed opinion

(continued)

Table 1. (continued)

Authors	General focus	Nursing focus	Journal and type of paper
Davies (2008)	Highlights growing number of older people with intellectual disabilities and associated health problems	Specifically refers to a nurse's role in caring for older people with intellectual disabilities	<i>Nursing Standard</i> (UK) Continuing professional development (CPD) based on informed opinion
Jenkins (2009a)	Personal reflections on introducing clinical governance into a residential home for older people with intellectual disabilities	Highlights some good nursing practice of intellectual disability nurses in the care of older people with intellectual disabilities; updates Jenkins and Jones's (2003) study highlighted earlier	Book chapter (UK) Research findings and perceptions
Jenkins (2009b)	Explores the role of nurses in meeting the health needs of older people with intellectual disabilities	Explores the views of a number of nurses regarding the health needs of older people with intellectual disabilities. This was stage 3 of a PhD research study	<i>Learning Disability Practice</i> (UK) Research findings
Caples et al. (2010)	Calls for a dedicated gerontological clinical nurse specialist role for older people with intellectual disabilities in Ireland	This paper provides arguments for the development of a gerontological clinical nurse specialist for older people with intellectual disabilities in order to develop specialist services or liaison with generic services	<i>Learning Disability Practice</i> (UK) Informed opinion

However, the account was more focused on nurses in general rather than a particular specialty and was based on informed opinion rather than research.

Jenkins and Jones's (2003) personal reflections on working in a residential care home for older people with intellectual disabilities highlighted some good nursing practice by intellectual disability nurses in the care of older people with intellectual disabilities. This action research study was mainly concerned with introducing clinical governance rather than focusing on nursing roles. The article was limited as it lacked sufficient detail and rigour on the actual process of the action research and focused more on personal reflections. A follow up account by Jenkins (2009a) indicated that some of the positives changes introduced and as a consequence of the initial study had remained some years later.

Bland et al.'s (2003) study highlighted satisfaction levels of carers ($n = 94$) regarding the support, access and monitoring roles of community/district/practice nurses for older people with intellectual disabilities. This study's main focus was on the health needs and services of older people with intellectual disabilities. However, it did highlight that community/district nurses provided the second highest levels of health care support after general practitioners (GPs). Jenkins's (2005a; 2005b) opinion papers discussed the ageing process and health needs of people with intellectual disabilities and the difficulties they experienced in accessing appropriate health services. He highlighted some good nursing practice in improving access and utilized a case study to illustrate how primary care, intellectual disability, mental health and palliative care nurses may be able to meet the needs of an older person with intellectual disabilities. Again these were personal opinions and built on his earlier article (Jenkins, 2000).

Although this was a review of literature in the UK and Ireland, interestingly outside the UK, in North America, there has been some research undertaken into the role of nurses in meeting the needs of older people with intellectual disabilities (see Table 2). Pilot studies undertaken by Hahn and Aronow (2005) and Aronow and Hahn (2005) explored advanced practice nurse initiatives to reduce health disparities and improve healthy ageing among older adults with intellectual disabilities. These studies ($n = 70$, $n = 100$ and $n = 101$) were concerned with in-home intervention packages of care provided by practice nurses in the USA. These proactive interventions demonstrated that positive results could be achieved by nurses in enhancing healthy ageing amongst older people with intellectual disabilities. However, it is difficult to generalize from these studies as the North American health care system is different from the UK and also nurses have different roles, training and culture.

Returning to UK and Ireland papers, Davies's (2008) informed opinion paper highlighted the role of nurses in meeting the health needs of older people with intellectual disabilities. There was a distinct weakness with this paper as it discussed health issues generally amongst people with intellectual disabilities and the nurse's role was implicitly discussed rather than being made explicit. It was also unclear whether the nurse's role related to people with intellectual disabilities generally or specifically to older people with intellectual disabilities. Jenkins's (2009b) research paper reported findings from his PhD study specifically exploring the role of nurses in meeting the health care needs of older people with intellectual disabilities. However, this particular article explored nurses' views ($n = 18$) in relation to current patterns of service delivery for people with intellectual disabilities. In spite of this, some of the implications for nursing practice were highlighted as the increase in complex needs, nurses needing to update their skills, accessing generic dementia care, and developing flexible services. Finally, Caples et al.'s (2010) paper presented an argument for the development of a gerontological clinical nurse specialist role for older people with intellectual disabilities in Ireland. However, as they highlighted that there were already

Table 2. Identified literature outside the UK related to the role of nurses in caring for older people with intellectual disabilities.

Authors	General focus	Nursing focus	Type
Roth and Morse (1994)	A nursing care textbook which discusses the care needs of people with intellectual disabilities	Identifies some of the nursing needs of older people with intellectual disabilities	Textbook (North America) Informed opinion
Service and Hahn (2003)	Discusses the role of the nurse in the care of older people with intellectual disabilities	Highlights a number of areas (physical and mental health, ageing families, assessment, planning and interventions) in which nurses may make a positive impact	<i>The Nursing Clinics of North America</i> (North America) Informed opinion
Fisher (2004)	Discusses nursing care of special populations: older people with intellectual disabilities	Argues for more education for nurses and appropriate community-based services in order to meet the needs of older people with intellectual disabilities	<i>Nursing Forum</i> (North America) Informed opinion
Hahn and Aronow (2005)	Discusses a pilot study of an in-home intervention package to improve health ageing of older people with intellectual disabilities ($n = 70$) in Los Angeles	Provides an account of advanced nursing practice in order to reduce health disparities and improve healthy ageing	<i>Journal of Applied Research in Intellectual Disabilities</i> (UK) Research findings
Aronow and Hahn (2005)	Discusses findings from two pilot group studies (health risk appraisal group, $n = 100$; or advanced practice nurse in-home intervention package, $n = 101$) in California. Age range from 32+	Similar to above study	<i>Journal of Applied Research in Intellectual Disabilities</i> (UK) Research findings

clinical nurse specialist roles in place in Ireland for older people with intellectual disabilities, it was unclear what the additional 'gerontological' nurse role would add.

It would appear from the above papers that nurses have been alerted and therefore made aware that there will be increasing numbers of older people with intellectual disabilities. There is also readily available literature regarding the physical and mental health needs of this client group. However, what is lacking is evidence on the actual roles that nurses will be undertaking in meeting the health needs of older people with intellectual disabilities. This is very apparent in the UK and Ireland, particularly with regards to the effectiveness of nursing interventions. In North America, some research has been undertaken in this area with some promising results. In spite of the limited amount of published work by intellectual disability nurses generally, most of the available literature in this review was authored by nurses with an intellectual disability nursing qualification.

Conclusion

It is evident there will be increasing numbers of older people with intellectual disabilities who are likely to require the services of nurses in meeting health needs. The lack of research into the role of nurses in this area, highlighted in this literature review, is concerning, as nursing practice should be based on the best available evidence. The historical lack of published research by intellectual disability nurses needs to be overcome in order to improve the body of nursing research for this specialism. Evidence is beginning to emerge, but much of what has been published to date has been based on informed opinion rather than the use of sound research methods. Therefore, researching the role of nurses in meeting the health needs of older people needs to be made a priority area.

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Note

1. This literature review formed part one of a three-stage PhD study which explored the role of nurses in meeting the health needs of older people with learning disabilities (Jenkins, 2011).

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