Learning disability liaison nurses: the provision of compassionate, person-centred care for people with learning disabilities accessing acute hospital care

by Michael Brown (FRCN 2015)

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The publication that underpins this article (Brown et al 2016) arose from research on equality of access to acute hospitals for people with learning disabilities. It presents findings from a large study involving four Scottish NHS boards and 11 acute hospitals.

The study had 100 participants, comprising families, carers and health professionals with direct experience of the contributions made by learning disability liaison nurses. We identified the outcomes achieved by the nurses and their contribution to the provision of person-centred and compassionate care in the acute hospital setting.

The work to improve acute hospital care for people with learning disabilities has continued for around 20 years, during which time there have been many developments. The work started in 1997 and was a collaboration with Dr Juliet MacArthur, who is now chief nurse for research and development with NHS Lothian.

At the time, I was a practice development nurse in Lothian Primary Care NHS Trust, and Juliet was in a similar role in the then Western General Hospitals NHS Trust. We established the first learning disability liaison nurse role in 1999 in the Western General Hospital Acute NHS Trust, Edinburgh. The role was an innovative response to the often complex health needs and the frequency of access to acute hospitals of people with learning disabilities.

The focus of the role was to provide people with learning disabilities and their families access to additional support and education, before and during hospital attendance and admission and at discharge.

The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person-centred care

Abstract
People with learning disabilities have a high number of comorbidities, requiring multidisciplinary care, and are at high risk of morbidity and preventable mortality. The effective provision of compassionate, person-centred care is essential to prevent complications and avoidable deaths. The aim and objectives of the study were to investigate the experiences of patients with learning disabilities, their family, carers and health professionals regarding the role of learning disability liaison nurses and the delivery of compassionate, person-centred care and from this, to propose a model of person-centred care embedded in these experiences.

A qualitative design was adopted with interpretative phenomenological analysis for data analysis. Semi-structured interviews and focus groups were conducted, Data were analysed with a focus on compassionate, person-centred care elements and components. Themes were modelled to develop a clinically meaningful model for practice.

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The themes identified were vulnerability, presence and the human interface; information balance; critical points and broken trust; roles and responsibilities; managing multiple transitions; 'flagging up' and communication. The findings provide the first 'anatomy' of compassionate, person-centred care and provide a model for operationalising this approach in practice. The applicability of the model will have to be evaluated further with this and other vulnerable groups.

Citation

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Introduction and background

The care and support of people with learning disabilities have seen significant policy changes in many developed countries across the world. Internationally, the term used is 'intellectual and developmental disabilities', and in the UK, 'learning disability'. Long-stay institutions across the UK have closed during the past 30 years, brought about by a policy shift towards care and support in the community, seeking to maximise autonomy, independence and social inclusion of people with learning disabilities (Scottish Government 2000). It is important to appreciate, however, that most people with learning disabilities have always lived at home with their families. Some lived in congregated institutional settings.

Alongside these developments, life expectancy has increased significantly over the past 100 years and today many people with learning disabilities live into older age (Dolan et al 2019). The number of children with intellectual disabilities has also increased due to a range of factors, including improved survival rates due to developments in neonatal and child healthcare (Heuvelman et al 2018). These children and young people are surviving into adulthood, however life expectancy for many may be 20-30 years shorter than the general population, particularly for those with the most complex of care needs (Scottish Government 2013). Many children, adults and older people with learning disabilities experience a range of complex, co-existing physical and mental health conditions and behaviours that can be challenging (Hughes-McCormack et al 2018). Physical health conditions are common and include, for example, respiratory disorders, gastric conditions and neurological disorders (Emerson et al 2016). Mental ill-health is also common by way of for example, depression and anxiety disorders (Hughes-McCormack et al 2017). Many have communication disorders that can have a negative impact on health-seeking behaviours (Chinn and Rudall 2019). As a result of their complex health conditions, people with learning disabilities are frequent consumers of all aspects of care services, including health (Kalseth and Halvorsen 2020).

Our collaboration began following a complaint and investigation regarding the care of a patient with learning disabilities admitted for treatment and care. The outcome of the investigation was a request from the two nurse directors in acute and primary care for a review and update of the local policy, Care of the Mentally Handicapped Patient, the existence of which was largely unknown by staff in the trust. Following the review of the policy, it became apparent that significant work was required to address the needs of people with learning disabilities and make service improvements.

We audited and identified patient care journeys into, within and out of acute hospital care. We reviewed national policies, reports and research evidence and it became apparent that people with learning disabilities accessed all clinical areas of acute care. Many accessed specific clinical areas such as respiratory, gastroenterology, neurology and dental services in greater numbers due to the extent of their health needs. Many were identified in emergency care and unscheduled care services, out-patients and day surgery and investigation units as well as in-patient units.

Influence and impact

The idea of developing the learning disability liaison nursing role was to ensure that people with learning disabilities and their families, carers and health professionals in acute care had access to a learning disability nurse with the knowledge, skills and expertise of

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the needs of the population. This was in the wider context of the distinct and complex health conditions experienced by many people with learning disabilities and their need to access assessment, treatment and investigations in acute hospitals (Glover et al 2019). Additionally, all public bodies had, and have, a legal duty to make 'reasonable adjustments' for all people with disabilities by complying with legislation to enable access to public services. The role was seen as a way to help achieve compliance (Heslop et al 2019). Following a review of the limited available research evidence, it became evident that the health needs of the population of people with learning disabilities were high, often unidentified and unmet and, yet access to additional support was limited (Burke and Heller 2017). Families gave accounts of being left to provide all but technical healthcare. Professionals in acute care described limited previous education on the specific needs of people with learning disabilities, with many lacking in the confidence and skills necessary to respond (Hemm et al 2015).

The first large long-stay institution for people with learning disabilities to close in Scotland was Gogarburn Hospital, on the outskirts of Edinburgh. As part of the closure programme, a service development fund was available, and Juliet MacArthur and I developed a funding proposal for the first learning disability liaison nursing role to be based at the Western General Hospital. Funding was secured for a two-year post, with the first postholder, Maria Rigg, appointed in 1999.

Implementing a new role in a large and busy acute hospital environment was challenging. However strategic support from Mrs Alex Harvey, nurse director at the Western General NHS Trust, was important. Dr Linda Pollock, nurse director in primary care, helped to facilitate the establishment of the role. The focus of the role was on the provision of additional support before, during and at the point of discharge for people with learning disabilities and their family, and education and support for health professionals in acute care.

A range of other initiatives were also tried, which met with varying success. These included a face-to-face education programme on the needs of people with learning disabilities for acute care professionals, and establishing a network of link-nurses in key clinical areas in the trust. These met with limited success due to the inability of the trust to release colleagues from their day-to-day role to attend education sessions, and the turnover and internal movement of the link-nurses in the organisation. We envisaged that the role would work with agencies, such as primary care, specialist learning disability and social care services, to undertake pre-attendance planning and communication with the relevant part of acute care to plan and coordinate the attendance or admission. The focus on attendance was important because of the move towards day investigations and procedures and admission, where clinically indicated. During attendance and admission, the focus of the role was on information sharing, communication and care coordination, and facilitating the identification and implementation of reasonable adjustment, necessary throughout the care episode (Redley et al 2019). The liaison nurse also provided short education sessions on specific support and care needs of individual patients with learning disabilities.

The findings from the study showed that, from the stakeholder perspectives, liaison nurses were able to provide additional support at a time when people with learning disabilities and their families were at their most vulnerable. Families highlighted the importance of the presence of the liaison nurse in providing the 'human interface', helping to make care more compassionate and person-centred. Families described previous care episodes in acute care where their trust and confidence in 'the system' had been broken, and they were overwhelmed by decision making and the volume of information provided. Liaison nurses' knowledge of the needs of people with learning disabilities, and of the acute care organisation and systems, led to enhanced communication and information. They had the opportunity to flag up specific care needs and issues. An important finding was that the liaison nurse followed and tracked people with learning disabilities throughout the care journey, which was seen as critical by families when they were transferred within departments and units in the acute hospital. This further promoted person-centred care.

Current and future relevance

The study was the first to research the outcomes achieved by learning disability liaison nursing in the acute care setting and the contributions the role made to compassionate, person-centred care and support. The findings enabled the development of a definition of compassionate, person-centred care in

the acute care context and enabled the development of a new model to support the application in clinical practice. Further posts were established in Lothian, including at Royal Infirmary of Edinburgh, The Royal Hospital for Sick Children and St John's Hospital.

Since the establishment of the first post in Edinburgh, similar roles have been introduced across Scotland, the rest of the UK and Ireland.

The research findings have attracted national and international attention. From a policy perspective, the role has been identified within a range of policy initiatives as necessary to support and facilitate access to acute hospital care for people with learning disabilities. The work of the leading charity Mencap has been influential in campaigning to improve the care and support of people with learning disabilities in the acute hospital setting (Mencap 2007, 2012).

The concerns highlighted by Mencap led the Department of Health in England to hold a review that led to the report, Healthcare for All?, which recommended the establishment of learning disability liaison nursing roles in all acute hospitals (Department of Health 2008). The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CiPOLD) also recommended the need for additional support to be put in place (Heslop et al 2014). The role has prompted other researchers to investigate acute hospital care and liaison nursing roles (Hall et al 2014, Tuffrey-Wijne et al 2014, Northway et al 2017). The model has been recommended by the World Health Organization (WHO) as an example of best practice (WHO 2010).

With the ageing population of people with learning disabilities and the increasing number of children living into adulthood with complex health needs, our follow-on research has focused on health transitions. The main focus of the transition study was on young people with complex physical learning disabilities. Those with complex neurodevelopmental disabilities, mental ill-health and behaviours that challenge are also populations that require specific research attention. A Scotland-wide study was completed at the end of 2019 on the transition from child to adult health services for young people with complex learning disabilities (Brown et al 2019). The role of the learning disability liaison nurse was cited by some participants as central to facilitating the smooth and effective transition between services (Brown et al 2020).

Since 1997, we have undertaken three research studies, published numerous papers and reports and have presented on the subject at conferences, workshops and seminars (Brown et al 2012, MacArthur et al 2015). The learning has also been integrated in education programmes for pre-registration nursing students in Scotland.

Given the range of issues affecting people with learning disabilities in acute hospital care, the development of the role should be seen as only part of the solution, not the whole solution. Improvements are also required in areas such as the education of health professionals of the distinct needs of people with learning disabilities, pre-admission planning, care pathways and admission and discharge policies, to highlight a few. Internationally, most nurses are educated and prepared with core competencies and skills which should, in theory, prepare them to meet the essential needs of all patients, including those with learning disabilities.

Irrespective of how nurses are educated and prepared, the need to improve care and support cannot be dependent on the existence of a learning disability specific pre-registration pathway. All nurses need to focus on reducing the health inequalities experienced by people with learning disabilities, promoting equality of healthcare access and health outcomes, in the context of social justice and protecting human rights.

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