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The perspectives of stakeholders of intellectual disability liaison nurses: A Model of Compassionate, Person-Centred Care

Professor Michael Brown,
PhD, MSc, PGCE, BSc (Hons), RGN, RNLD, FHEA, FRCN
Professor of Health and Social Care Research,
Edinburgh Napier University and Nurse Consultant, Learning Disability Service, NHS
Lothian, Edinburgh
m.brown@napier.ac.uk

Dr Zoë Chouliara,
BSc, PsyDip., MSc, PhD, PGDip. Counselling CPsychol (Health), FHEA, AFBPsS
Reader in Person-Centred Care,
Edinburgh Napier University

Dr Juliet MacArthur,
PhD, MSc, PGCE, BSc, RGN,
Chief Nurse, Research and Development,
NHS Lothian, Edinburgh

Dr Andrew McKechnie,
MB CHB, MRCPsych,
Research Fellow, University of Edinburgh and Honorary Consultant Psychiatrist, Learning
Disability Service, NHS Lothian, Edinburgh

Dr Siobhan Mack,
PhD, BSc
Speech and Language Therapist, Queen Margaret University, Musselburgh, East Lothian,
Scotland, UK and Learning Disability Service, NHS Lothian, Edinburgh

Matt Hayes,
BN, RNLD
Learning Disability Liaison Nurse, NHS Lothian and Research Assistant, University of
Edinburgh

Joan Fletcher, MA
Clinical Governance Facilitator, NHS Lothian, Edinburgh

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and NHS Forth Valley

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ABSTRACT

Aim and objectives: To investigate the experiences of patients with intellectual disabilities, family and paid carers regarding the role of liaison nurses and the delivery of compassionate, person-centred care. From this to propose a model of person-centred care embedded in these experiences

Background: People with intellectual disabilities have a high number of co-morbidities, requiring multidisciplinary care, and are at high risk of morbidity and preventable mortality. Provision of compassionate, person-centred care is essential to prevent complications and avoid death.

Design: A qualitative design was adopted with IPA for data analysis.

Methods: 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.

Results: Themes identified: Vulnerability, Presence and the Human Interface; Information Balance; Critical Points and Broken Trust; Roles and Responsibilities; Managing Multiple Transitions; 'Flagging up' and Communication.

Conclusions: 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.

Relevance to clinical practice: This is the first study to provide a definition of compassionate, person-centred care and proposes a model to support its application into clinical practice for this and other vulnerable groups.

Key words: Intellectual Disability, Liaison Nurses, Compassionate care, Person Centred Care, Models of Care

What this paper adds to the global clinical community

- People with intellectual disabilities are high users of general hospitals yet their needs, views and experiences are not well represented in the research literature
- Due to their multi-morbidities and complex care needs people with intellectual disabilities require additional support when attending general hospitals, with intellectual disability liaison nursing roles recommended to promote and facilitate person centred care.
- A new model of compassionate, person centred care from the perspective of patients with intellectual disabilities and their carers has been developed to enable safe and effective care in acute hospital settings.

INTRODUCTION

Individuals with intellectual disabilities are high users of universal health services, including general hospitals due to their range of health needs. There have been a series of investigations and reports in the United Kingdom (UK) highlighting service failures and poor care that have resulted in deaths that are premature and avoidable. The term person-centred care is one that is increasingly appearing in policy and best practice reports, however, there is a need to better understand the concepts from the perspective of individuals with intellectual disabilities and their carers. Across the UK intellectual disability liaison nursing roles have been established with registered nurses with knowledge and clinical expertise of the care needs of people with intellectual disabilities being located within acute hospitals to offer access to additional support and expertise. This paper aims to examine the impact of liaison nurses based within general hospitals and their impact on influencing nursing care, and the development of a model of person centred care.

BACKGROUND

An intellectual disability is the international term used to describe people with learning and developmental disabilities and requires three elements to be present:

- A global intellectual impairment, with an IQ < 70
- Adaptive behaviour that is impaired
- Early childhood onset

People with intellectual disabilities are consumers of universal health services and evidence sets out concerns about access to healthcare, institutional discrimination, poor care and treatment and avoidable deaths (Department of Health 2008, Heslop et al. 2013). The evidence highlights that many health care professionals have limited confidence and experience of the needs of this population and when linked to poor communication and information sharing, results in a lack of both compassionate and person-centred care that can result in avoidable deaths. (NHS Quality Improvement Scotland 2009, Brown et al. 2012, Heslop et al. 2013).

The leading UK charity Mencap published two reports: “*Death by Indifference*” and “*Death by Indifference: 74 Lives and Counting*” (Mencap 2007 and 2012), setting out the issues that lead to premature and in some cases deaths that could have been avoided with appropriate assessments, interventions and treatment. The English Department of Health responded by

undertaking a review of the concerns and in 2008 published *Healthcare for All*, setting out actions to address the issues (Department of Health 2008).

People with intellectual disabilities have increased life expectancy and many have a range of health needs that can necessitate access to general hospitals for conditions such as epilepsy, respiratory disease, gastric-oesophageal disorders and cancers (McCarron et al. 2013). To respond to the care needs, intellectual disability liaison nursing services have been developed in many areas of the UK to contribute to meeting needs by providing access to support and nursing expertise when acute hospital care is required (Brown et al. 2012, World Health Organisation 2010). Backer et al. (2009) reviewed the literature on people with intellectual disabilities when accessing general healthcare and made a number of recommendations: the development of liaison nursing models; developing and enhancing systems within health services to provide person; developing education that improves practitioner knowledge and confidence about the needs of people with intellectual disabilities; improving systems to share information; and communication and providing support for families and carers. In their systematic review, Bradbury-Jones et al. (2013) identified eight studies related to the care and support of people with intellectual disabilities in general hospitals. Analysis identified six key factors found to influence care, set out in Table 1.

[TABLE 1 ABOUT HERE]

Compassionate care

The concept of compassion has become central to UK healthcare policy in recent years (Department of Health 2009, Scottish Government 2010). According to the Department of Health (2012), the *Compassion in Practice* vision centres on the '6Cs': "care, compassion, competence, communication, courage and commitment" and is driving nursing strategy in England. In Scotland the focus on compassion has been framed within a wider national "*Person Centred Health and Social Care agenda*" which centres on improvements in care experience, staff experience and co-production (NHS Education for Scotland 2012).

According to Cole-King and Gilbert (2011, p.30), compassion is "*a sensitivity to the distress of self and others with a commitment to try to do something about it and prevent it*".

Compassion was identified as a 'Core NHS Value' within the Department of Health's *NHS Constitution* (Department of Health, 2009). The emergent explanation of compassion within the Constitution focused on 'being with' the patient and being proactive to address 'the little things'. Whilst previous literature refers to compassion as one of the key components of person-centred care, the mechanisms that might connect these two in day-to-day practice and in patient experience requires further development (MacArthur, 2014).

Within the United Kingdom there have been a number initiatives that have focussed directly on embedding and sustaining compassionate care within the NHS. In England this has included The King's Fund *Point of Care Programme* (Firth-Cozens and Cornwell 2009) and in Scotland the *Leadership in Compassionate Care Programme* (Edinburgh Napier University and NHS Lothian, 2012).

Person-centred care

The concept of person-centred care is wider than compassionate care and provides care and treatment that responds to and respects the preferences, needs and values of the patient's personal preferences, thereby seeking to ensure that patient values guide clinical decisions (Scottish Government 2010; WHO, 2010). The concept of person-centred care is strongly linked to Kitwood's (1997) work in relation to dementia care, which emphasises a belief that all people can lead fulfilling lives. In England the White Paper, "*Liberating the NHS: Equity and Excellence*", highlights the need to ensure that patients are afforded autonomy and control over decisions about their healthcare (Department of Health 2010). Person-centred care is one of the three core tenets of the NHS Scotland Quality Strategy (Scottish Government 2010), focusing on delivering "Person-centred, safe and effective care" to all. It is also an important part of the Government's agenda with the recent publication of the Patient Rights (Scotland) Act 2011. The focus of the quality strategy in Northern Ireland is on encouraging partnerships between staff, patients and carers to enable decision-making (DHSSPS, 2009).

Previous evidence supported the effectiveness of person-centred care, notably for patients with chronic physical and mental health conditions and it is effective in improving both treatment and patient outcomes and therefore is cost effective (Kwan & Sandercock 2004). Although there is significant literature on definitions and components, it is recognised that there is a need for further clarity about the elements of person-centred care for different patient groups and how it could be applied into practice (Casarett et al. 2002). Such lack of clarity is one of the barriers in the application of person-centred care. Other barriers, which are consistent across patient groups and conditions, include, time (Chan 2002), dissolution of professional power (Ashby & Dowding 2001), limited autonomy to practice (McCormack 2003), limiting organisational structures (McCormack 2001) and poor care environments (Nolan et al. 2004). Important gaps in the literature include a lack of understanding of person-centred care as applied to specific vulnerable patient groups such as older people and people with intellectual disabilities, and a lack empirical evidence on the effectiveness and effective application and operationalise the approach.

Jukes and Aldridge (2006) highlight the importance of person-centred approaches with people with intellectual disabilities based on professional relationships that put the person at the centre. Effective person-centred practices are based around skilled interactional and interpersonal processes, which focus on the need to understand the individual's needs, perceptions and motivations in life. They argue that these needs should be seen in the context of the person's life-stage development and adjustments as well as the traumas and distress experienced in everyday life.

While recognising the important role that can be played by families and other carers in providing information about the needs of patients with intellectual disabilities and how their care needs can be addressed in the general hospital environment, there has been no specific research focus on the experiences of patients with intellectual disabilities and their carers on the care and support provided by intellectual disability liaison nurses (Bradbury-Jones et al. 2013). This paper seeks to address the above gap and contribute to building a stronger evidence-base.

METHODS

The findings presented here arise from the secondary analysis of primary qualitative data relating to patients with intellectual disabilities and their carers regarding the care and support provided by the Intellectual Disability Liaison Nurses in the acute hospital environment. The findings of the main study have been reported elsewhere (Brown et al., 2012).

The primary study set out to focus on Intellectual Disability Liaison Nursing (IDLN) services, in four separate health services areas in Scotland: Fife, Lothian, Borders and Forth Valley. Intellectual Disability Liaison Nurses offer a means of operationalising person-centred care in the general hospital environment and therefore, in this secondary analysis of the primary data, the following questions were identified:

1. What are the components of person-centred as identified by patients with learning disabilities, their families and paid carers?
2. What are the barriers to and challenges in achieving person-centred care?
3. What are the benefits of person-centred care for patients, their families and paid carers?

DESIGN

The qualitative data was collected from two groups of participants (i) patients with intellectual disabilities (n=5), (ii) their families or paid carers (n=13). Adults with an intellectual disability who had direct contact with a liaison nurse, and who was judged to be capable of consenting, were approached by the IDLN with whom they were familiar and were given information about the study that included an invitation to make contact with the research assistant. Carers (family or paid) of adults or children with a learning disability were approached in a similar manner. Of the 18 participants 7 were involved in individual interviews and 11 within focus groups. The researcher undertaking the interviews was an experienced intellectual disability nurse and was able to adjust communication techniques as appropriate to ensure effective participation of the former general hospital patients. The interviews were digitally recorded and transcribed verbatim for analysis and were undertaken in settings convenient to the participants.

The transcripts were analysed and coded using Interpretative Phenomenological Analysis (IPA), a method that enables the analysis of the experiences and views and identification of key themes (Smith 2007). IPA is more suitable in comparison to other qualitative approaches due to the vulnerability of the population and the sensitive nature of the issues. The transcripts were read and reread by two experienced researchers in the project team (ZC and MB) and then coded to identify emergent themes and further analysed to identify recurrent themes across transcripts. The recurrent emergent themes were discussed and agreed with the wider team to reflect the shared understandings by participants of the issues under investigation. Data were compared and analysed until all the emerging themes were comprehensively identified and saturation reached (O'Callaghan & Hiscock 2007). To ensure rigour, reflexivity and applicability, criteria by Lincoln & Guba (1985) were used. The involvement of team members in this process ensured that the interpretive processes involved were collaborative and insightful. The data was then analysed further in order to explore the situated nature of each theme within the context of the analysis to highlight the similarities and differences in the participants' accounts (Lofland & Lofland 1995). No negative cases were identified and the accounts demonstrated strong consensus in the views and experiences expressed and no cases were identified which contradicted consensus. Links between emergent themes were then identified and modelled to build a clinically meaningful framework embedded in the experience of participants.

Ethical considerations

The study was independently reviewed by the NHS Research and Development Committee and by a University in South East Scotland. Ethics approval was granted, with the researchers recognising the potential capacity issues of some of the patients with intellectual disabilities to consent to participate in the study. The researchers all have extensive clinical and research experience with patients with intellectual disabilities and also collaborated with carers to assess capacity to independently consent and be recruited to participate in the study.

RESULTS

The interviews focused on the role of liaison nurses as an innovative mechanism of supporting and facilitating compassionate and person-centred care for patients with intellectual disabilities when attending general hospitals for investigations and treatment, thus giving an 'anatomy' of compassionate, person centred care (or the lack of) in the clinical practice setting. Through accounts of this role, participants were able to talk about what worked and what did not in their experience of care and treatment. There was consensus in the themes identified across stakeholders and these were collapsed into one hermeneutic report. The 6 main themes identified are set out in Table 2 and are organised into those referring to (i) Communication & the Interpersonal Experience and (ii) Systems & Co-ordination of Care.

[TABLE 2 ABOUT HERE]

1. Vulnerability, Presence & 'The Human Interface'

Participants talked strongly about the importance of having a stable and compassionate presence in times of great physical and emotional vulnerability when attending the acute hospital for investigations and treatments. They highlighted the importance of the presence of the liaison nurses when they were feeling scared and confused and how this presence supported them at their most vulnerable, thereby helping to ensure consistency and stability throughout the care journey.

'I don't remember back about it really...you've got to think forward...I was really ill and they told my brother to expect the worst, in case... they thought I was going to go... she (the liaison nurse) was there. I couldn't speak to her but I held her hand for quite a while, but she came a few times...She says anything that's bothering you and you want to talk, you can always phone me and I will try to pop in and talk over any problems like that. I'll sort it out.'

(Service User P3)

Participants talked about the importance of health professionals who know how to manage the boundaries between the personal and humane with the professional aspects of their role as required by the needs of the service user.

2. Information Balance

It was evident in all stakeholders' accounts that patients with intellectual disabilities can have significant difficulties with understanding, retaining and processing information provided to them regarding their treatment and care. They do therefore require support in that respect; the liaison nurses played a key role in this regard.

'I think it was good for her (the liaison nurse) to come in with me, because if I didn't have her I wouldn't have understood the questions...' (Service User P4)

Care appeared to be person-centred when it addressed these challenges and also respected and accommodated the delicate balance in information provision for patients with intellectual disabilities, by way of matching the information with the capacity and capability of the service user at any given stage of their care. With their wealth of expertise and clinical experience of working with patients with intellectual disabilities with complex co-morbidities and communication issues, the liaison nurses played a central role in facilitating communication, notably in relation to capacity to consent to treatment and helping to ensure that 'things happened', thereby aiming to ensure that decisions about care and treatment had the patient at the centre.

'I was anxious this time because we've not been in for a long time and how to explain things to him...what was going to be happening... because if you tell them too early it prays on their mind a lot and it's just questions, questions, questions that you can't answer. But then you don't want to tell them too late what's happening because it has another effect. It was hard to get the balance...' (Family Carer 1)

3. Critical Points and Broken Trust

Participants described instances where miscommunication, limited resources, and unclear care pathways combined with the complexities of patients with intellectual disabilities resulted in care which was not compassionate or person-centred and was, therefore, unsatisfactory. These critical points in care appeared to act as catalysts in exposing the weaknesses in the healthcare system, thus highlighting an absence of care that was both compassionate and person-centred. Such critical points demonstrated a failure to recognise

and respond to the needs of the patient, leaving some feeling lost in a complex system, isolated and ignored. By establishing and developing relationships with patients with intellectual disabilities and their carers, the liaison nurses were able to minimise weaknesses in the care system and facilitate compassionate, person-centred care.

'There have been confusions there (in communication). That does seem to be an area where things have often slipped. I can think of several instances with different service users at different times where that has slipped. One of my service users has epilepsy and his consultant ...the information form have not been relayed to the GP, 'cause when he went back for his appointment, the consultant worked in the basis that his instruction had been passed to the GP and it hadn't. Oh, there does seem to be perhaps a grey area there, gaps that things can slip through' (Paid Carer, C2)

Mishandling of critical points seemed to result in serious breaks in trust to health professionals and the healthcare system, leaving patients and carers feeling ignored and confused, and even resulting in formal complaints. The early involvement of the liaison nurses and their on-going support was viewed as important in seeking to minimise such issues.

'...There was an element of frustration from all of us (carers and liaison nurses). And we did pursue a formal complaint...and we got our complaints addressed, and great promises of how it will be different be different the next time, but I take it all with a pinch of salt' (Family Carer C3)

4. Roles and Responsibilities

Given the fact that multiple professionals are involved in the care of patients with intellectual disabilities in the general hospital environment, it was seen as important for participants that the roles and responsibilities of each of these professionals are well defined and clearly communicated to all, including individual patients, their family and carers, in order to avoid slips in care and anxiety. By virtue of the liaison nurses being based within and integral to the acute care systems, patients with intellectual disabilities and their carers valued their knowledge about the complex organisation and the relationships that they had, thereby enabling effective communication and information sharing.

'...It was a catalogue of errors...But of course the nurse would say, 'well you know, you guys are here, you can do it', but (the carers) were saying, well actually we're carers, we're not nurses... and he's here for medical reasons, and he's not getting nursing care. And of course, the doctor only comes round sort of five, ten minutes, if you're lucky. So, it was scary' (Paid Carer C3).

5. Managing Multiple Transitions

Transitions referred mainly to transitions from child to adult services, but also between and within acute hospital units and departments. Although the inevitability of transitions was well understood by patients and carers, it was apparent that such transitions involved significant loss of long term trusting relationships and familiarity with the professionals providing care, thereby increasing anxiety and affecting communication and on-going care and support.

Transitions seemed to be a time of significant challenge and adjustment and as a consequence having in place the liaison nurses acted as a means to minimise concerns by ensuring that information about care needs were identified and communicated, thereby helping to contribute to coordinated care.

'He (the service user) was involved with (this hospital) since he was a tiny baby, so sort of twenty years. ...I think it was quite difficult and daunting, and they had to get used to us, and we had to get used to them. But after twenty years so many staff knew him and his sort of little quirks.... I mean there were only seven wards, but we've visited them all and felt quite comfortable. And I knew it would be hard moving on, and I knew it had to happen' (Family Carer C3)

6. 'Flagging up' and Communication

Participants highlighted the importance of 'flagging up' important information about vulnerable patients and effective sharing of such information. It was thought that such information should be readily accessible especially at critical points by the range of professionals involved in the care of the patients. The flexibility of the liaison nursing role across and within the acute care environment facilitated communication and information sharing.

'I know there's issues about privacy and confidentiality and data protection and things... But for my service users if there was an accident for example they were out somewhere and there was a car crash and the service user had to be taken to hospital, short notice, no planning, no notification, no background information, is there some kind of way or is it a thought that perhaps information could be kept about individuals like that on medical records so it could be referred to in those sort of circumstances?' (Paid Carer C2)

DISCUSSION

The findings from this study suggest that vulnerable groups such as those with intellectual disabilities present with a number of challenges, including high comorbidity and complex needs, as well as individual and specific informational needs (Heslop et al. 2013). As a

result, they require multi-professional involvement, including access to specialist liaison nurses due to the frequent number of transition across general hospital departments and services and the risks associated with poor communication and information sharing (Bradbury-Jones et al. 2013, Department of Health 2008, Heslop et al. 2013). Providing person-centred care can potentially act as a buffer by preventing poor care for patients with intellectual disabilities. By facilitating better resolution when these points do occur, the liaison nurses are in a prime position to achieve this as they have a presence across all areas of the general hospital environment (Brown et al. 2012). The absence of the additional support and expertise provided by the liaison nurses through the complexities of the acute care pathways can lead to confusion, manifesting as patient and carer dissatisfaction, anxiety and broken trust, unclear roles and decision making challenges, risk and muddled care pathways which in turn result in care that lacks compassion and is not person-centred.

The findings confirm the outcomes from reports and investigations about the vulnerability of some patients with intellectual disabilities and their families within the general hospital environment and add to the concern of the risks of increased mortality and morbidity for this group (Mencap 2007, Department of Health 2008, NHS Quality Improvement Scotland 2009, Heslop et al. 2013). Liaison nurses are a clear example of attempts to operationalise and facilitate compassionate, person-centred care for patients with intellectual disabilities and the impact and contribution of the role increasingly recognised and valued (World Health Organisation 2010, Brown et al. 2012, Bradbury-Jones et al. 2013, Heslop et al. 2013, Royal College of Nursing 2014). Person-centred care has been difficult to operationalise and shifts in models of care may take a long time to be a reality across healthcare systems. Training in compassionate and person-centred approaches is also notoriously challenging and requires considerable organisation and personal practitioner investment, an issue already evident in the psychotherapy context and has attracted attention in the nursing literature and government policy (Royal College of Nursing 2012).

Our findings highlights that the presence of an effective and relationally competent practitioner who knows the system and pathways, gets to know the patient, their family and carers is able and willing to work on the edge of professional boundaries and the human interface makes a difference in the patient and carer experience – the very essence and heart of compassionate, person-centred care. Thus far, the studies that have been undertaken on liaison nursing models have been restricted to the United Kingdom (Backer et al. 2009, Brown et al. 2012, Bradbury-Jones et al. 2013). With the intellectually disabled population increasing and ageing globally and coupled with the evidence of their high health needs and the need to access acute hospital care, liaison nurses offer part of the solution to

ensure the delivery of compassionate, person-centred care that is now clearly articulated in policy and now requires to be demonstrated in practice (Cole-King & Gilbert 2011, Department of Health 2012, McCarron et al. 2013).

There is therefore an opportunity to develop a new model that can help to identify the elements that need to be present to enable person-centred care for people with intellectual disabilities in healthcare settings and which can potentially be replicated across clinical areas with other vulnerable groups. The issues set out in Table 3 have informed the development of a model of Person-Centred Care for Vulnerable Groups

[TABLE 3 ABOUT HERE]

A Model of Person-centred Care for Vulnerable Groups

A tangible outcome of this data is a new model developed from a synthesis of all the master and subthemes identified from the experiences of the participants. Qualitative modelling was conducted by utilising a method developed by Chouliara (2014), which consists of thematic synthesis of identified themes and subthemes, treating them as original data, and identifying further links emerging between the identified themes. This structured process enables the creation of themes that capture wider patterns and connections between the themes. The themes identified in this process formed the basis for the development of a clinically relevant model for operationalising person-centred care for individuals with learning disabilities and other vulnerable groups in the acute care setting. This analysis approach has been successfully developed and utilised in previous work with vulnerable groups in health care (Chouliara & Kearney, 2007; Chouliara et al., 2004; 2011; 2014). The advantages of this technique are that it makes IPA analysis directly applicable to practice and can be operationalised and translated into clinical strategies. A more detailed description of qualitative modelling method is beyond the scope of this paper.

The *Model of Person-centred Care for Vulnerable Groups* identifies the main components of care as well as key challenges which need to be overcome to ensure that individual patient care is both person-centred thereby meeting the individual needs of patients with intellectual disabilities, necessary given their distinct needs within the acute care environment. Most importantly the model presents clinically meaningful strategies that if implemented will contribute to addressing the challenges and facilitate person-centred care, set out in Table 3. The Model highlights that vulnerable groups such as those with intellectual disabilities present with a number of challenges, including high comorbidity and complex needs, as well

as individual and specific informational needs. As a consequence of their needs, they require multi-professional involvement, due to the frequent number of transition between and across health and social care services and the risk of potential harm associated with poor communication and lack of information sharing which has been shown to contribute to their premature and avoidable deaths (Heslop et al., 2013). The contributions to care and support made by the liaison nurses brings in to the acute care environment access to additional expertise and knowledge that facilitates and enables person centred care that can potentially act as a buffer by preventing poor care for people with intellectual disabilities and by facilitating better resolution when these points occur (Brown et al., 2012; Bradbury-Jones et al., 2013). The absence of person-centred care to provide the additional support through the complexities of the acute care pathways can lead to confusion, manifesting in patient and carer dissatisfaction, anxiety and broken trust, unclear roles and decision making challenges, risk and muddled care pathways. By drawing out the themes that can contribute to poor and ineffective care from the perspectives of people with intellectual disabilities, their families and carers and the expertise of the liaison nurses, the model presents a new conceptualisation of how the needs of this population can be met in a way that promotes patient safety and person-centred care. To our knowledge these links have never been drawn before in such a clinically meaningful way in the literature.

[Insert Figure 1 about here]

There are limitations to this study. Whilst the primary study that this data is drawn from (Brown et al. 2012) had an overall sample of 85 participants, the numbers of service users and carers was comparatively small (n=18). It was also recognised that there was some risk of bias given that the liaison nurses were the first point of contact for recruitment with service users and carers; however because of the challenge of access to potential participants it was decided by the research team that this was the most appropriate method.

CONCLUSION

Vulnerable groups, such as those with intellectual disabilities, are faced with numerous challenges that make their journey through the healthcare system more challenging and stressful. There is an increasing focus on compassionate care that is person-centred and meets the needs of the individual within government policy and clinical practice; however what this looks like in reality from the perspective of service users with an intellectual disability has not been the subject of research. When these challenges are met through

compassionate, person-centred care, risks to patient safety can be minimised and the care journey managed effectively and sensitively.

Intellectual liaison nurses can have a significant impact within the general hospital environment in enabling compassionate and person centred care, thereby meeting the needs of patients with intellectual disabilities and by providing support for their carers. The findings from this study has enabled the development of *Model of Person-Centred Care for Vulnerable Groups* that can be applied to the care of people with intellectual disabilities in the general hospital environment with implementation being possible with the support of intellectual disability liaison nurses, thereby providing safe, effective and person-centred care.

RELEVANCE to CLINICAL PRACTICE

The findings from this study offers the first 'anatomy' of compassionate, person centred care from the perspective of patients with intellectual disabilities and their carers. The model that has been presented here articulates the elements that need to be in place to enable compassionate, person centred care for one vulnerable group within the general hospital environment and clinical strategies to enable operationalisation. The model therefore seeks to start to address the concerns of patients with intellectual disabilities and their carers by responding to the issues that are now well articulated and contribute to poor care and avoidable deaths. The model suggests that the presence of intellectual disability liaison nurses is a key mechanism in operationalising compassionate, person-centred care for patients with intellectual disabilities and is an issue that needs to be addressed internationally. The model can be adopted across the general hospital environment to enable the care experiences of this group to be improved thereby achieving quality, efficiency and safety of care.

REFERENCES

- Ashby ME & Dowding C (2001) Hospice care and patients' pain: communication between patients, relatives, nurses and doctors. *International Journal of Palliative Nursing*, 7 (2), 58.
- Backer C, Chapman M & Mitchell D (2009) Access to secondary healthcare for people with intellectual disabilities: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 22, 514–25.
- Bradbury-Jones C, Rattray J, MacGillivray S & Jones M (2013) Promoting the health, safety and welfare of adults with learning disabilities in acute care settings: A structured literature review. *Journal of Clinical Nursing*, 22, (11-12), 1497-1509.
- Brown M, MacArthur J, McKechnie, Mack S, Hayes M & Fletcher J (2012) Learning Disability Liaison Nursing Services in south-east Scotland: A mixed-methods impact and outcome study. *Journal of Intellectual Disability Research*, 56, (12), 1161 – 74.
- Casarett DJ, Karlawish JH & Byock I (2002). Advocacy and activism: Missing pieces in the quest to improve end-of-life care. *Journal of Palliative Medicine*, 5(1), 3-12.
- Chan RCK (2002). Active participation and autonomy: An ultimate target for rehabilitation. *Disability and Rehabilitation: An International Multidisciplinary Journal*, 24 (18), 983-4.
- Cole-King A & Gilbert P (2011) Compassionate care: The theory and the reality *Journal of Holistic Healthcare* 8 (3) 29-37.
- Chouliara Z, Miller M, Stott D, Molassiotis A, Twelves C & Kearney N (2004) Older People with Cancer: Perceptions and Feelings about Information, Decision Making and Treatment – A Pilot Study. *European Journal of Oncology Nursing*, 8, 257-261.
- Chouliara Z & Kearney N (2007) Working with Older People with Cancer: Challenges in Research and Clinical Practice. In F. Anagnostopoulos & E. Karadimas (eds), *Special Issues in Health Psychology* (pp131-151). Athens: Livani Publishers.
- Chouliara Z, Karatzias T, Scott-Brien G, Macdonald A, MacArthur J & Frazer N (2011). Talking Therapy Services for Adult Survivors of Childhood Sexual Abuse (CSA) in Scotland: Perspectives of Service Users and Professionals. *Journal of Child Sexual Abuse*, 20, 1-29.
- Chouliara Z, Karatzias T, & Gullone A (2014). Recovering from Childhood Sexual Abuse: A Theoretical Framework for Practice and Research. *Journal of Psychiatric & Mental Health Nursing*, 21, (1), 69-78.
- Department of Health (2008). *Healthcare for all: The independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: HMSO.
- Department of Health (2009) *The NHS Constitution for England: The NHS Belongs to Us All*. London: HMSO.
- Department of Health (2010) *Equity and excellence: Liberating the NHS*. London: HMSO.
- Department of Health, (2012). *Compassion in Practice: Nursing, Midwifery and Care Staff. Our Vision and Strategy*. London: HMSO.
- DHSSPS (2009) Review of the Nursing and Midwifery Workforce. ASM Horwath. http://www.dhsspsni.gov.uk/qpi_quality_standards_for_health_social_care.pdf

Firth-Cozens J, Cornwell J (2009) *The Point of Care: Enabling Compassionate Care in Acute Hospital Settings*. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/poc-enabling-compassionate-care-hospital-settings-apr09.pdf

Heslop P, Blair P, Fleming P, Hoghton M, Marriot A & Russ L (2013) *Confidential Inquiry into the premature deaths of people with learning disabilities*. Bristol: Norah Fry Research Centre.

Jukes M & Aldridge J (Eds) (2006) *Person-Centred Practices: A Therapeutic Perspective*. London: Quay Books.

Kitwood T (1997) *Dementia Re-discovered: The Person Comes First*. Buckingham: Open University Press.

Kwan J & Sandercock P (2003). In hospital care pathways for stroke. *The Cochrane Database of Systematic Reviews*, 34, 587-588.

Lincoln YS & Guba EG (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lofland J & LH Lofland (1995) *Analyzing Social Settings: A guide to qualitative observation and analysis*. Belmont: Wadsworth Publishing Company.

MacArthur J (2014) *Embedding compassionate care in local NHS practice: A realistic evaluation of the Leadership in compassionate Care Programme*. Unpublished PhD thesis. Edinburgh Napier University.

McCarron M, Swinbourne J, Burke E, McGlinchey E, Carol R & McCallion P (2013) Patterns of multimorbidity in an older population of persons with an intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Research in Developmental Disabilities*, 34, 521-527.

McCormack B & McKenna H (2001) Challenges to quality monitoring systems in care homes. *Quality in Health Care*, 10 (4), 200-201.

McCormack B (2003). Researching nursing practice: Does person-centredness matter? *Nursing Philosophy*, 4(3), 179-88.

Mencap (2007) *Death by Indifference: Following up the Treat me right! report*. London: Mencap.

Mencap (2012) *Death by Indifference: 74 Lives and Counting*. London: Mencap

NHS Education for Scotland (2012). *People at the Centre of Health and Care*. Edinburgh: NHS Education for Scotland.

NHS Quality Improvement Scotland (2009) *Tackling Indifference: Healthcare services for people with learning disabilities national overview report*. Edinburgh: NHS Quality Improvement Scotland.

Nolan M, Davies, S, Brown J, Keady J & Nolan J (2004) Beyond person-centred care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, 13(3a), 45-53.

O'Callaghan C & Hiscock R (2007) Interpretive subgroup analysis extends modified grounded theory research findings in oncologic music therapy. *Journal of Music Therapy* 44(3), 256-81.

Royal College of Nursing (2012) *Quality with Compassion: the future of nursing education*. London: Royal College of Nursing

Royal College of Nursing (2014) *Learning from the past, setting out the future; Developing learning disability nursing in the United Kingdom*. London: Royal College of Nursing.

Scottish Government (2010) *The Healthcare Quality Strategy for Scotland*. Edinburgh: The Stationery Office.

Smith J A (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies On Health And Well-Being*, 2, 3-11

World Health Organization (2010) *Better health, better lives: children and young people with intellectual disabilities and their families; Empower children and young people with intellectual disabilities*. EUR/51298/17/PP/7 Geneva: WHO Regional Office for Europe.
http://www.euro.who.int/_data/assets/pdf_file/0003/126570/e94430.pdf

Table 1. Factors influencing care in general hospitals

1. Communication systems within the general hospital environment2. Safety and welfare in the general hospital setting3. Adjustments to the care environment to enable reasonable adjustments to be made4. Staff attitudes and values regarding people with intellectual disabilities5. Staff knowledge about care and support needs6. Recognising and harnessing the role of families and contributions of families and carers in providing support and advice

Table 2. Themes related to liaison nurses and their contributions to the provision of compassionate and person centred care

Themes	Subthemes
Communication & The Interpersonal Experience	
1. Vulnerability, Presence & 'The Human Interface'	<ul style="list-style-type: none"> • Fear - 'Scared' • Physically and psychologically frail – 'Very ill' • Consistency & stability • Personal - Familiar person who knows you • Trouble shooting • Manages uncertainty and confusion • Not alone – someone to turn to • Safe and secure- 'Not like home' • 'Problem shared, problem halved'
2. Information Balance	<ul style="list-style-type: none"> • Too much information too soon • Explain what and when • Matching info with capacity to understand • Managing anxiety • Empowering & increasing confidence
3 Critical Points & Broken Trust	<ul style="list-style-type: none"> • Gaps & 'slips' in care • Lost in the system, bureaucracy & complex care pathways • Feeling ignored • 'Hitting a brick wall' • Communication break downs • Broken trust • Complaints procedures
Systems & Co-ordination of Care	
4. Roles & Responsibilities	<ul style="list-style-type: none"> • Boundaries • Who does what • Lack of information and expertise • Critical decisions under pressure • Emotional overload
5. Managing Multiple Transitions	<ul style="list-style-type: none"> • From child to adult services • From service to service • Loss of relationships • Adjustments
6. 'Flagging up' & Communication	<ul style="list-style-type: none"> • Timely 'flagging up' of information • Effectively passing on information

Table 3. Operationalising Person-Centred Care for Vulnerable Groups

Aim to...	By	With this result...
<i>Assessing Vulnerability</i>		
Consider patients' capacity, needs and position in the care system	<ul style="list-style-type: none"> • Establishing their information and communication needs • Assessing complex needs, i.e. comorbidity, cognitive and physical frailty, isolation/support networks, mental health /emotional state • Establishing communication with other health/care professionals involved • Identifying/following up recent or imminent transitions/outstanding referrals 	<ul style="list-style-type: none"> • Establishing degree of vulnerability • Establishing communication • Being proactive rather than reactive
<i>Critical points & Trust</i>		
Establish and maintain trust	<ul style="list-style-type: none"> • Getting to know the person/ considering patient's and carers' views • Explaining and providing information at their level of understanding • Being available to provide information and support • Being consistently present, especially in crisis and distress 	<ul style="list-style-type: none"> • Providing a safe caring environment • Providing a consistent relationship • Managing anxiety and distress • Preventing broken trust and critical points/crisis
<i>The 'Human Interface'</i>		
Adjust quality, quantity and context of information to patients' abilities and needs	<ul style="list-style-type: none"> • Be known to your patient • Be prepared to working on the edge of 'personal' and 'professional', as and if required • Be human and compassionate • Stay competent and current 	<ul style="list-style-type: none"> • Integrating professional and personal realms • Empowering patients and carers / managing power in caring relationship • Keeping communication channels open
<i>Information Balance</i>		
Provide tailored and appropriately timed information	<ul style="list-style-type: none"> • Adjusting information to patients' level of understanding and limitations • Choosing carefully the timing of information provision 	<ul style="list-style-type: none"> • Avoiding misunderstanding • Managing distress and confusion • Preparing the patient and managing expectations
<i>Roles & Responsibilities</i>		
Clarify and communicate roles and responsibilities	<ul style="list-style-type: none"> • Clarifying who does what • Communicating roles and responsibilities to patients and carers 	<ul style="list-style-type: none"> • Avoiding distress and confusion • Preventing crisis
<i>'Flagging up' & Communication</i>		
Make information about IDs available and accessible	<ul style="list-style-type: none"> • Sharing information appropriately • Making critical information accessible appropriately 	<ul style="list-style-type: none"> • Enabling timely and efficient response in critical situations • Avoiding delays, errors and distress

Figure 1: Model of Person Centred Care for Vulnerable Groups