

Does he have sugar in his tea? Communication between people with learning disabilities, their carers and hospital staff

Ruth Bell

Ruth Bell MSc, BA (Hons) is a specialist practitioner learning disability hospital liaison nurse at Pennine Care NHS Foundation Trust, UK.

Abstract

Purpose – *This study seeks to evaluate a Hospital Passport tool designed to provide information and improve communication between people with learning disabilities and hospital staff.*

Design/methodology/approach – *This paper is a qualitative study, which explores people's experiences of good and bad communication in hospital and their experiences of how a Hospital Passport impacts on that process of communication.*

Findings – *The paper finds that a Hospital Passport can act as a useful multi-agency resource to improve communication and continuity of care for people with learning disabilities.*

Originality/value – *The study leads to insights and suggestions for health and social care professionals and organisations as to how communication can be improved to benefit vulnerable groups in hospital.*

Keywords *Hospital passports, Hospital care, Learning disabilities, Improving communication, Carers*

Paper type *Research paper*

Hospital care for people with learning disabilities is under increased scrutiny; this has been provoked by a steady stream of reports, published over the last few years, which have suggested the care provided is often poor (Mencap, 2004; National Patient Safety Agency, 2004; Disability Rights Commission, 2006). Sadly the warnings and recommendations contained in these reports did not prevent the loss of life so emotively and powerfully recorded in Mencap's Death By Indifference (2007). The findings of the inquiry reports that followed were disturbing (Michael, 2008; Parliamentary and Health Service Ombudsmen, 2009). They highlighted, yet again, the all too familiar scenario of NHS organisations addressing inadequately the barriers and inequalities to health care provision experienced by many people with learning disabilities.

A consistent theme in the above literature has been the detrimental and far reaching effects of poor communication. Whilst the primary focus of interest has been the lack of effective communication between hospital staff and people with learning disabilities and their carers, poor communication is also found between different agencies involved in the person's support.

Hospital passports

A hospital passport is a familiar resource with many learning disability practitioners who support people with learning disabilities in hospital settings. Currently, there are over 79 different hospital passports being used across the UK. Many of these are very similar in their design and, consequently, there have been calls from learning disability practitioners for the development of one common passport to be used as a universal tool in hospitals across the country (Access To Acute, 2011). The passport format has become a popular way to provide clear information to hospital staff about a person with a learning disability who is going into hospital. It is usually presented as a short, simple, colourful document, often with pictures and symbols, that contains “must know” information about an individual. It includes things like how the person communicates, their mental capacity to engage in decisions about their health care, how to recognise if the person is in pain and how to offer comfort. It also gives information about the person's likes and dislikes, any concerns and worries they may have about being in hospital, any “reasonable adjustments” that need to be made by the hospital to address the person's specific needs, who their main carers are and how to contact key people involved in their care.

Anecdotally, there have been reports that hospital passports are effective in providing important information and improving communication between people with learning disabilities and hospital staff and that this can have a positive impact on health outcomes. Indeed the use of a hospital passport is commended as an example of good practice in Healthcare for All (Michael, 2008) and, more recently, Equal Access (DH, 2009); however, no systematic evidence of its efficacy has been published. The current evaluation sought, therefore, to explore the validity of the claims made for passport schemes.

In the absence of a generic national document, the hospital passport evaluated was one developed by the author in her role as an Acute Liaison Nurse for people with learning disabilities. It is called the Traffic Light Hospital Assessment. The name reflects its use of red, amber and green grading of information, a popular way of highlighting the importance of information within many healthcare organisations.

The Traffic Light Hospital Assessment[1] was developed through consultation with people with learning disabilities, their carers and health and social care staff. It is designed to provide essential information to hospital staff, in a “user friendly” format, in order to promote improved continuity of care in hospital from pre-admission to post-discharge. It is an A4 size, coloured booklet which has red, amber and green sections providing important, person-centered information. There is also a Vital Information Sheet to clearly emphasise potentially life – saving information – for example, if the person has dysphagia (swallowing problems) and how to manage this safely. The inconsistent recognition of dysphagia in patients with learning disabilities by hospital staff and the potential life threatening consequences of this have been highlighted in the literature (National Patient Safety Agency, 2004).

Additionally, there is a Discharge Planning/Information Sheet designed to be completed jointly by the person's community and hospital “care team” prior to the person leaving hospital. This is intended to facilitate a comprehensive “handover” of information. The process supports and promotes a timely, multi-agency, planned discharge pathway and a reduction in potentially avoidable, upsetting and costly readmissions.

The study

This was a qualitative study underpinned by interpretative and action research principles. These, and the importance of learning something new that would directly influence practice, informed the choices and decisions made in exploring the research question which was, “Does the Traffic Light Hospital Assessment improve communication between people with learning disabilities, their carers and hospital staff?” The study included: semi-structured interviews with family carers and health and social care staff; a focus group for adults with learning disabilities; and a reflexive journal analysis which included the author's review of a specific recent example of the passport in practice. The varied perspectives allowed for triangulation – the similarity of findings from different sources being used as one indication of their validity.

Participants

Purposive sampling was employed to recruit participants. Time limitations dictated this “hand picking” of a sample and allowed the researcher to directly approach people who had experience using the Traffic Light Hospital Assessment. They included people with learning disabilities, family carers, hospital, health (members of the Learning Disability Team) and social care staff. There were a total of 20 participants. Although this number is relatively small, the main interest in this study was in the insights that the information could elicit and, as Denscombe (1998) suggests, provided restrictions are acknowledged and taken into account, the limited size of the sample need not invalidate the findings.

12 participants including health, hospital and social care workers as well as family carers, were asked a series of five questions about their experiences, both positive and negative, of using the Traffic Light Hospital Assessment. Additionally, eight participants, all of whom were adults with learning disabilities attending a self-advocacy group, took part in a focus group discussion about their experiences of going into hospital. Particular attention was given to exploring the things, which had and had not helped them feel more comfortable whilst in hospital. Prior to the Focus Group, staff supporting the self-advocacy group were given information about the subject matter to be discussed. This was intended to facilitate a more informed choice by potential participants about whether or not to take part. Only one person in the group had experience using the Traffic Light Hospital Assessment although most said they had heard of it. Others had come to talk about their experience of hospital care. The lack of experience in the focus group of the Traffic Light Hospital Assessment, combined with the reflections of the acute liaison nurse, drew attention to the absence of participants with more complex or profound communication problems. The challenge of capturing data from this group of people highlights the importance of creating more accessible, inclusive research methods.

Consent to participate was overseen by the service manager who ensured that individuals were supported with the most appropriate and accessible information for them to make a decision. Careful consideration was given to the choice and accessibility of the venue, comfort, timing and support. The author, who facilitated the focus group, was mindful that consent should be viewed as a continuous process rather than a discrete event. Support from trained and familiar carers was arranged as there seemed potential for the subject matter to cause upset to some people depending on their experience of hospitals. This turned out to be important as several people in the group used the opportunity to discuss personal situations, they had experienced in hospital that had clearly been upsetting at the time.

Findings

The findings consistently reflected the view that the Traffic Light Hospital Assessment made a significant contribution towards improving communication between all agencies. It was also felt to expose an underlying concern with the implications of poor communication both on individual and organisational levels. This theme strongly resonated with the *Six Lives* report (Parliamentary and Health Service Ombudsmen, 2009), which noted the need for organizations to ask critical questions about their communication systems and about the accurate and effective dissemination of information between families and professionals.

Participants described what poor communication actually meant to them and how it created barriers to health care in hospital for both individuals with a learning disability and their carers. What follows is an overview of the major themes which emerged from the study together with recommendations for practice development.

Barriers to communication

Participants, both carers and people with learning disabilities, were concerned about not being listened to or consulted by hospital staff. For example, in the focus group one person with a learning disability said:

Some people listen to you and some people don't.

Participants reported feeling vulnerable and powerless, “at the mercy” of a system that did not value their views and, consequently, did not share important information.

Hospital staff expressed a lack of confidence in their ability to help people with a learning disability because of their limited knowledge and particularly when they could not fully understand how to communicate with the person. They felt that the Traffic Light Hospital Assessment provided information which supported them to do this in a more person-centered way. For example, a hospital nurse said:

The Traffic Light Hospital Assessment really helps us. It taps into the patient's information, things they may not be able to articulate themselves, what they like to do, their routines and things they don't like and how they respond to other people. It tells you exactly the needs of the client and includes body language and facial expressions, if they can do sign language, if they can shake or nod their heads so you can involve your client in their own care.

Whilst personalised information will always be necessary, the general lack of confidence reported raises concerns about training curricula for student nurses and other health professionals. It suggests current course content may not fully equip students to feel confident in their practice with people with learning disabilities.

Inevitably, the (hospital or community) staff supporting the individual with a learning disability did not always know the person well, reflecting, for example, an increasing reliance on agency staff. The assessment played a key role in supporting these staff:

I only knew her name, age and address, because I knew so little about this lady the Traffic Light made it possible for me to support her to be treated (community carer).

Participants were unanimous that the Traffic Light Hospital Assessment played a key role in supporting better information transfer between hospital and community. However, they consistently reported frustration with hospital organizational structures and felt that "the system" failed to support multi-agency communication and that this often obstructed the recognition of the importance and use of the Traffic Light Hospital Assessment tool. They believed this, subsequently, had a negative impact on the healthcare people received:

Its (Traffic Light Assessment) only weakness is when it's not read, but that's the weakness of the part of the system [...] when I went back on the ward where the lady I was supporting was, they were trying to ask her questions and if they'd have read the Traffic Light they would have seen that she couldn't actually speak back to them. She could understand but she couldn't actually verbally speak back. I don't think they were reading it, I found it very, very sad that they didn't read it when it was in place for that lady. It's not a big thing to read is it? Maybe they're too busy to be reading things or it's lack of communication between themselves to make sure they know that this person has a Traffic Light (community carer).

This further reinforces the need for hospitals to develop clearer pathways and information systems to enable all staff to support people with learning disabilities in hospital. Providing it was read, the Traffic Light Hospital Assessment was perceived, in this study, as one way of doing this.

Enhancing communication

The findings demonstrated that the quality of human interaction was fundamental in how people with learning disabilities, and carers, experienced the hospital stay. Participants with learning disabilities gave examples of positive communication and the difference it had made to them. They described how empathy and kindness helped them to form a connection, a trusting relationship with the nurse or doctor and how it had reassured them. For example:

Some nurses were kind and couldn't do enough for me they helped me to get better (Person with a learning disability who had been a hospital inpatient).

Humanity, in the form of kindness, empathy, listening to people, genuinely consulting with them, working together, all of these things helped people feel valued and, ultimately, more positive about their hospital experience. It helped create relationships that communicated shared meaning and mutual understanding. Whilst healthcare organisations may need to strengthen their commitment to improving services for people with learning disabilities, individuals also, through their behaviour and demeanour, fundamentally influence the experience of patients and their carers:

The doctor came and was wonderful, what made him so was that essentially his core attitude was that R. was someone who was worth treating despite his very complex needs, he wasn't afraid. He asked the carers questions and really listened to what they said, he involved them in the decision making process and was guided by their responses and used this to compliment his own expertise (Extract from the author's reflexive journal).

Recommendations for practice

The following recommendations for practice are based on the findings reported above as well as the existing literature. They are intended as discussion points for further exploration of the key issues raised in this article.

Developing a hospital passport for other vulnerable groups

In the current study, the Traffic Light Hospital Assessment was perceived by all as a tool that enhanced communication. It was described as: "a communication tool", "a good system", "a second voice", "a link", a "handy, at a glance information booklet" and "a most important document because it covers everything".

The value of the Traffic Light Hospital Assessment as a document that promoted continuity of care by offering a single, shared source of information was recognised clearly in the findings. This example is typical of others which were given to illustrate this:

We phoned paramedics to come out. We passed the Traffic Light onto them which they read. It gave them details of medication, her likes and dislikes and explained that she couldn't speak but could understand some things that were said. They passed it over at A&E to the nursing team there who said it's a very important document that explained everything that they would need to know about a particular person they are supporting. The doctor actually commented what a wonderful piece of information it was (Community Carer).

Many participants thought that the Traffic Light Hospital Assessment tool could be beneficial for other vulnerable patient groups, particularly the elderly:

The Traffic Light is good for people with learning disabilities but I can see similarities for people in the elderly and the adult world. I'm facing the same issues with supporting my mother who has dementia when she has to go into hospital. She too can't communicate and I can't always be with her [...] there are lots of people with dementia who this document would fare well for (Family Carer).

The literature confirms that elderly people and their carers share similar experiences and concerns around the negative impact of poor communication systems in hospital (Carers National Association, 2001; Health Service Ombudsman, 2011). It has not been possible within the scope of this study to look at all other potentially vulnerable groups such as children and people with mental health problems. However, it would not be unreasonable to surmise, given the concerns raised in the literature and from anecdotal evidence, that poor communication systems in hospital affect many people and contribute to frustration, deep distress and sometimes life threatening situations. One nurse said of many elderly, confused patients coming into hospital from care homes:

We don't even know the basics like if they have sugar in their tea. I'm a vegetarian and I'm going to have it tattooed on my chest so that when I'm old and if I can't talk they (hospital staff) won't try and force feed me meat and then label me as aggressive and non-compliant when I refuse to eat it!

This surely begs the question: why is the collection and dissemination of such fundamental, essential information not being treated as central to the provision of good, person-centered care when we know how much difference it makes to patient experience and ultimately health outcomes?

Enhanced training programmes which normalise different aspects of communication

Most people with learning disabilities do not want to be treated differently. They want services and support that are flexible and centered around their needs and for hospital staff to listen and react accordingly (DH, 2001). Family and carers want similar things; to have their

knowledge of the needs of that person taken seriously and to be included in decisions about their care (DH, 2010). Specialist training or knowledge is not always required to achieve this. It is sometimes simply about enhancing existing training to include all people's needs. One suggestion would be to include information about different types of communication as part of generic training programmes. Such training could teach basic Signalong, a signing system for people with learning disabilities used to support language, and could include an awareness of the value of simplifying language for some people and how to enhance understanding by the use of objects, photographs and symbols. Giving staff these skills could boost their ability and confidence to communicate more fully with people who may struggle with verbal communication. This, in turn, would encourage inclusion which is a core principle enshrined in all the current NHS standards (DH, 2001), which if observed, offer many of the safeguards essential to ensuring that the needs of people with learning disabilities, and other vulnerable groups, are addressed.

Disseminating and embedding new practice into organisational structures

Whilst the research demonstrated convincingly the benefits of the Traffic Light Hospital Assessment, it also revealed a major problem with it. This was that it is not always recognised in the hospital and subsequently not always read. Ensuring that it becomes routine good practice and embedded in established procedure is an ongoing challenge and raises the issue of how new ideas and innovation are diffused into practice. Commissioners and managers need to lead strongly if we are to avoid what Michael (2008, p. 42) describes as "isolated, patchy good practice attributed to the energies of individual enthusiasts battling against the odds". They need to actively work towards disseminating information and supporting practitioners to achieve a proactive and sustained approach by promoting systems which are designed with people with learning disabilities in mind (DH, 2010). Many Acute Learning Disability Liaison Nurses are expanding the traditional boundaries of the role of the learning disability nurse by leading on innovation in this area, working alongside colleagues in the acute sector and affecting significant change. Mencap's (2010) *Getting It Right Campaign* calls for hospitals to sign up to a national charter to support these issues. This is a concept that the Royal College of Nursing (2009) embraces in its recent report *Dignity in Health Care for People with Learning Disabilities*.

Conclusion

This study confirms that a hospital passport tool can help to improve communication between people with learning disabilities, their carers and hospital staff. It suggests that better organizational communication systems can have a direct impact on the quality of care people with learning disabilities and their carers feel they receive, and also that hospital staff feel they can give. Reasons for poor communication have been identified and discussed and it seems clear that there are benefits to be gained from suggesting guidance for each aspect of poor communication and how it can be improved rather than just stating that "communication" *per se* needs to be improved.

Whilst it would be naïve to underestimate the challenges involved in changing systems, a much stronger and more genuine commitment, at both practice and leadership levels, to listen to the voices of people with learning disabilities and their carers is essential in order to embed positive change into practice. But, perhaps most importantly, the foundation of success appears to lie in promoting practices that support hospital staff to establish reciprocal communication relationships with people with learning disabilities and their carers. Such relationships should not only demonstrate a knowledge of the person's specific needs but also offer kindness, empathy and respect.

Note

1. An example of the Traffic Light Hospital Assessment can be obtained from Ruth Bell at: ruth.bell3@nhs.net

References

Access To Acute (2011), available at: A2anetwork.co.uk

Carers National Association (2001), *"You Can Take Him Home Now". Carers' Experiences of Hospital Discharge*, Carers National Association, London.

Denscombe, M. (1998), *The Good Research Guide for Small Scale Social Research Projects*, Open University Press, Buckingham.

DH (2001), *Valuing People: A New Strategy for Learning Disability in the 21st Century*, The Stationery Office, London.

DH (2009), *Equal Access? A Practical Guide for the NHS: Creating a Single Scheme that includes Improving Access for People with Learning Disabilities*, The Stationery Office, London.

DH (2010), *Six Lives: Progress Report*, Department of Health, London.

Disability Rights Commission (2006), *Equal Treatment: Closing the Gap. A Formal Investigation into Physical Health Inequalities Experienced by People with Learning Disabilities and/or Mental Health Problems*, Disability Rights Commission, London.

Health Service Ombudsman (2011), *Care and Compassion? Report of the Health Service Ombudsman into the NHS Care of Older People*, The Stationery Office, London.

Mencap (2004), *Treat Me Right! Better Healthcare for People with Learning Disability*, Mencap, London.

Mencap (2007), *Death by Indifference*, Mencap, London.

Mencap (2010), *Getting It Right Campaign*, Mencap, London.

Michael, J. (2008), *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, Aldridge Press, London.

National Patient Safety Agency (2004), *Understanding the Patient Safety Issues for People with Learning Disabilities*, The Stationery Office, London.

Parliamentary and Health Service Ombudsmen (2009), *Six Lives: The Provision of Public Services to People with Learning Disabilities*, The Stationery Office, London.

Royal College of Nursing (2009), *Dignity in Health Care for People with Learning Disabilities*, Royal College of Nursing, London.

Corresponding author

Ruth Bell can be contacted at: ruth.bell3@nhs.net

To purchase reprints of this article please e-mail: reprints@emeraldinsight.com
Or visit our web site for further details: www.emeraldinsight.com/reprints