

‘REASONABLE ADJUSTMENTS’ UNDER THE UK’S *EQUALITY ACT 2010*: AN ENQUIRY INTO THE CARE AND TREATMENT PROVIDED TO PATIENTS WITH INTELLECTUAL DISABILITIES FOLLOWING ADMISSION TO ACUTE HOSPITAL SETTINGS

INTRODUCTION

Globally, healthcare for men and women with intellectual disabilities receives very limited or no attention during medical training (Salvador-Carulla & Saxena, 2009) and is an area where a large gap exists between the health needs of this population and the provision of services (World Health Organization, 2007). Seeking to address such inequalities, Article 25 of the *UN’s Convention on the Rights of Persons with Disabilities* (UN, 2006) requires States Parties to recognise that persons with disabilities have the right to enjoyment of the highest attainable standard of health without discrimination.

Even in an economically well-resourced state such as the United Kingdom, however, people with intellectual disabilities experience poorer quality healthcare than their non-disabled peers, leading to avoidable premature deaths (Heslop, Blair, Fleming, Hoghton, Marriott & Russ, 2014). Some of these deaths take place in acute hospitals, where it has been alleged that patients with intellectual disabilities experience ‘institutional discrimination’ (p.2, Mencap, 2007). Of concern, Heslop and her colleagues’ data were collected after the introduction of the *Equality Act 2010*. According to the *Equality Act 2010*, which replaces previous disability discrimination legislation, specifies that all public services, including acute hospitals, are required to make ‘reasonable adjustments’ to ensure that people with disabilities, including those with intellectual disabilities, are not ‘substantially disadvantaged’ (*Equality Act* s.20: (1)-(5)).

A survey of ‘reasonable adjustments’ in acute hospitals (Hatton, Roberts, & Baines, 2011) noted the introduction of a range of measures for acute hospital patients with intellectual disabilities. These included the provision of specialist nurses (‘learning disability’) liaison nurses and ‘passports’ detailing individuals’ support and communication needs. At the same time, autonomous decision-making by patients with intellectual disabilities was supported by the provision of easier-read information, while staff received training in the *Mental Capacity (England & Wales) Act 2005 (MCA)*. The *MCA* both promotes decision-making by adults with ‘an impairment of, or disturbance in the functioning of, the mind or brain’ (s.2(1)) and regulates substitute decision-making for those individuals judged to lack capacity to make for

themselves one or more decisions about their care and treatment. Hatton et al. (2013), however, comment that insufficient data were available regarding the effectiveness of these measures. Nevertheless, there have been a number of small-scale and largely qualitative studies investigating the effectiveness of efforts to improve the quality of the care received by patients with intellectual disabilities: the findings have not been encouraging. For example, Atkinson (2016), using self-report from fifteen nurses, found that, even when they were available, patients' hospital passports seemed not to be used. In a larger study, Northway and her colleagues (Northway, Rees, Davies, & Williams, 2017) examined 60 passports developed by healthcare provider Trusts across the UK. Key information, for example, relating to allergies, risk assessments, and the need for reasonable adjustments, was either not included, or was difficult to locate. Furthermore, a review of fourteen research papers relating to the experiences of nurses in acute settings suggested that they felt unprepared for caring for people with intellectual disabilities, found it hard to communicate with them, and were uncertain about the support they might expect from paid and family caregivers (Lewis, Gaffney, & Wilson, 2016).

Despite many initiatives since Mencap's (2007) ground-breaking report in the UK, patients with intellectual disabilities continue to have poor experiences during admissions to acute hospitals (Iacono, Bigby, Unsworth, Douglas, & Fitzpatrick, 2014).

Much of the research into the care and treatment received by patients with intellectual disabilities in acute hospitals is published in nursing journals, and is focused on the work and/or experiences of nurses. This creates the impression that of all the healthcare practitioners working in acute hospitals, it is nurses who are primarily responsible for improving the care and treatment received by patients with intellectual disabilities. In an attempt to engage critically with this orthodoxy, we sought to introduce another voice, that of medically qualified doctors working in acute hospitals; from hereon, referred to as 'medical practitioners'.

Medical practitioners have a lead role in the care and treatment received by all patients. Through their responsibility for explaining patients' symptoms by taking oral histories, and carrying out physical examinations, and investigations, they aim to arrive at a list of possible diagnoses (differential diagnoses), and ultimately a final diagnosis that will inform the intervention (Peterson, Holbrook, Von Hales, Smith, & Staker, 1992). To carry out these tasks, medical practitioners are dependent upon patients being able to provide an account of their symptoms, recall their medical history and, if needed, give consent for investigations, which in some cases may be invasive, distressing, and not without risk. As such, the views and experiences of medical practitioners may help to further our understanding of how best to ensure that patients with intellectual disabilities receive equitable care and treatment.

METHOD

Following ethical approval from the National Research Ethics Service (14/WA/0148, semi-structured interviews were conducted with a sample of medical practitioners at two acute hospitals in the UK. The interviews were designed to solicit participants' views about, and experiences of, a) the care and treatment of patients with intellectual disabilities; b) 'reasonable adjustments' to improve the quality of care and treatment; and c) working with family members and paid social caregivers. In addition, d) participants were asked to consider whether patients with intellectual disabilities might receive poorer quality care and treatment than their nondisabled peers.

Medical practitioners were considered eligible for inclusion in the study if: a) they had been involved in the care and treatment of a patient identified as having an intellectual disability *and* b) consent for us to invite them to participate had been given by the patient themselves (or a family carer of someone judged to lack capacity to give or withhold consent to taking part) had given favourable advice (s. 30 ff., *MCA*). Consent/favourable advice was obtained from thirty patients, relating to 40 eligible participants (some patients had been cared for by more than one medical practitioner). Consent was then sought from the potential participants. Eventually, interviews were conducted with fourteen participating medical practitioners, seven from each hospital. This was a convenience sample, with the sample comprising: three specialists in each of renal medicine and acute care; two in each of the following specialisms, surgery, neurology, and respiratory medicine; and one each in, respectively, trauma and hepatology. The duration of the interviews varied, ranging from 15-60 minutes, as we needed to accommodate demands of the participants' clinical work. It should be noted that, while medical practitioners were recruited through their association with a specific patient, they were not specifically asked to comment on that person's care and treatment since it was not our intention to compare the views of the medical practitioner – patient dyad. All interviews were conducted face-to-face and audio-recorded. As we wanted to understand why patients with intellectual disabilities might receive poor quality care, the interviewers were encouraged to adopt a challenging stance in order to develop a lively discussion so that medical practitioners might be called upon to defend their practice (Holstein & Gubrium, 1997).

The interviews were transcribed verbatim. Since these were semi-structured interviews, each interview question corresponded with a different interpretative theme (Cicourel, 1964). Participants' responses were, consequently, coded question by question, using NVivo, and then summarised. These summaries were refined and validated through meetings of the

research team. Our analysis takes respondents accounts at face value (Silverman, 2017), no attempt is made to explore how respondents' rhetorical construction and justify their practice (Wetherell & Potter, 1988), consequently the quotations presented serve purely to illustrate the kinds of observations respondents made. Nor, is any attempt was made to examine differences between the respondents in the two hospitals.

RESULTS

Introduction

When asked about the relevance of patients' intellectual disabilities to the provision of care and treatment, all the medical practitioners reported that it was highly significant, with both diagnosis and treatment being perceived as 'challenging' The majority of respondents made much of the difficulties they experienced in communicating with, and managing what was perceived as the nonconformist behaviour of, patients with intellectual disabilities. In contrast, a minority focused primarily on the biomedical complexities of this patient group. When the challenges of treating patients with intellectual disabilities were formulated in terms of communication, medical practitioners reported that it was difficult to obtain accounts of any current pain or discomfort and, even harder to construct the history of previous experiences of the symptoms (see Box 1 Excerpt 1). In addition, they described difficulties in providing care and treatment for patients who were judged to lack decision-making capacity and/ whose nonconformist behaviour, such as shouting and walking about, was viewed as likely to disrupt the smooth running of a ward. In contrast, when the challenges of treating patients with an intellectual disability were formulated in terms of their biomedical complexity, medical practitioners referred to the presence of multiple co-morbid health conditions; the prevalence of polypharmacy, particularly with regard to anticonvulsant medication for epilepsy; and the prevalence of neurodevelopmental syndromes with a genetic origin (see Box 1 Excerpt 2). These two narratives, while not mutually exclusive, because some participants referred to both, nevertheless presented dissimilar ways of understanding the significance of any individual patient's intellectual disability, with differing implications for addressing inequalities in healthcare. We begin this account of our findings by reviewing the dominant narrative, before describing medical practitioners' reported use of 'reasonable adjustments', and their responses to the allegation that patients with intellectual disabilities may receive poorer quality care. Finally, we turn to descriptions of the impact of their biomedical complexity on treating patients with an intellectual disability.

Difficulties in managing communication problems and nonconformist behaviours

When describing their responses to the communication and behavioural challenges presented by patients with intellectual disabilities, medical practitioners reported a number of strategies. These included trying to spend more time with the patient, simplifying the complexity of their language, reducing the number of investigations such as blood tests and scans that might cause distress (Box 2 excerpt 1) and the use of proxies. Proxies, mainly family members, were described as invaluable since they were perceived as being able to give information about a patient's symptoms and medical history; provide a biomedical benchmark against which treatment goals could be set and evaluated by describing the patient in optimal health; facilitate communication between hospital staff and the patient; and manage any anxieties (Box 2 excerpt 2), anxieties that can in extreme cases lead to nonconformist behaviours, such as removing cannulas or distressing other patients. While making little distinction between family members and paid caregivers, since both were seen as holders of details of a patient's symptoms and medical history, some of the medical practitioners asserted the need to get family carers, in particular, 'on board'. By this, they appeared to mean being sensitive to family members' concerns about the patient's health, and listening to accounts of previous hospital admissions that had been particularly distressing for the patient and/or their family member. But equally, it could also mean explaining to family members that the level of personalised support available at home could not be reproduced in hospital. Further, it was reported that the need to involve family members, paid care-givers, and other relevant persons, such as advocates, could delay the commencement of treatment.

'Reasonable adjustments'

Only half of the fourteen participants recalled working with a 'learning disability' liaison nurse and amongst those medical practitioners who had, knowledge of this specialist nurse's involvement could be vague (see Box 3 Excerpt 1). That said three respondents did give accounts where a 'learning disability' liaison nurse had supported patient and their family by alleviating anxieties about a complex investigation (MRI scanning); provided a sense of continuity at a time when patients and their family member are meeting a bewildering variety of clinical staff; and providing useful assistance when making complex clinical decisions (see Box 3 Excerpt 2). However, respondents also noted that the information provided by the 'learning disability' liaison nurse was no fuller than that provided by patients' caregivers. As for patient 'passports', which just over half of our sample reported having seen, participants' views were again sharply divided. While passports were viewed by some as a useful source of information, for example, about patients' expressive and receptive communication skills and support needs, others reported that they were often unnecessarily, and impracticably long, or raised doubts about the accuracy of the information they contained (see

Box 3 Excerpt 3). While the medical practitioners were aware of other kinds of 'reasonable adjustments' such as 'flags' alerting staff to a patient's intellectual disability, easier-read documentation about health conditions and medication, and specialist communication support, these were mentioned only in passing.

Poorer quality care

When asked about family carers' complaints about having to provide the same basic information repeatedly (Michael, 2008), our medical practitioners were unapologetic. They explained that it was important for them to hear information first-hand, or from a proxy who knew the patient very well. Healthcare records, they reported, did not provide the detail, nor the immediacy, of a face-to-face exchange. They reported that interviews with patient and/or their proxies provided valuable material relevant to their medical histories, allowed them to corroborate information from different sources, and provided an insight into the care and treatment needs of particular patients (see Box 4 Excerpt 1). We gained the impression that repeated requests for the same information were regarded as inherent to care and treatment within acute hospitals and were not a particular feature associated with admissions of patients with intellectual disabilities.

When asked whether patients with intellectual disabilities were likely to receive care and treatment than was of a poorer quality than that of other patients, most participants agreed. Their responses drew on factors that characterise or are associated with an intellectual disability (communication difficulties (see Box 4 Excerpt 2) and/or problems conforming to the 'rules' of care and treatment in hospital. Importantly, those few participants who offered different accounts attributed their views to the introduction of 'learning disability' liaison nurses, and, as a result, increased awareness among hospital staff of the needs of patients with intellectual disabilities (see Box 4 Excerpt 3). Two participants did not subscribe to either account. One suggested that staff shortages and increased workloads meant that 'quieter' patients, including, contrary to other participants' views, those with intellectual disabilities, were at greater risk of neglect. The other participant's account focussed on the negative impact of 'over-zealous' campaigning on behalf of people with intellectual disabilities. Apparently, this led medical practitioners and other staff to be so fearful of 'getting it wrong' that they sought to avoid these patients as much as possible. When asked specifically about why avoidable readmissions to hospital might be proportionately greater among patients with intellectual disabilities than their peers (Kelly et al., 2015), most participants attributed the finding to deficiencies in community services (see Box 4 Excerpt 4). It was reported that General Practitioners, family and paid care-givers either failed to follow post-discharge care plans, or if signs of ill-health persisted, 'played it safe' by referring patients back to hospital.

There were, however, a small number of medical practitioners who reported that data relating to patients with intellectual disabilities could not reasonably be compared with that of their peers: in their view, those with intellectual disabilities were simply 'more unwell' in that they had a much greater number of physical health co-morbidities (see Box 4 Excerpt 5).

Biomedical complexity

By emphasising the biomedical realities of the lives of some patients with intellectual disabilities, a minority of participants drew our attention to the complexities of providing treatment for individuals who might, in addition to their presenting healthcare need, be individuals with a neurodevelopmental syndrome associated with specific physical complications, be prescribed an idiosyncratic combination of medications, have extensive healthcare records, and have co-morbid health conditions (see Box 5 Excerpt 1). To illustrate this point, three participants provided brief accounts of the challenges they had experienced in providing healthcare to this biomedically complex group.

The *first* account related to a woman with Down syndrome (Trisomy 21) who was diagnosed with pneumonia. The participant described feeling uncertain about whether the low oxygen levels in this patient's blood were attributable to the pneumonia or to the long-term effects of Eisenmenger's syndrome, a congenital heart defects associated with Down syndrome. With no knowledge of the patient's 'normal' blood-oxygen level, the respondent felt unable to formulate an appropriate treatment. Reflecting their concern about the patient's low oxygen level in her blood, nursing staff seemed insistent on giving supplementary oxygen; however, this is contra-indicated in Eisenmenger's syndrome. In an example of the important role that care-givers can play, the medical practitioner's dilemma was resolved when the patient's family provided information about her optimal blood-oxygen level obtained from the specialist outpatient clinic she attended at another hospital (see Box 5 Excerpt 1)

The *second* account also concerns a person with Down syndrome: a man whose description of his symptoms initially led the treating medical practitioner to make an erroneous diagnosis. The patient's description of diarrhoea and vomiting were consistent with gastroenteritis. Following a rapid and serious deterioration in his health, however, it became clear that the correct diagnosis was that of pneumonia. The delay in diagnosing the patient correctly, which the participant attributed, in part, to the patient's difficulties in providing accurate information about his symptoms, led to the clinician having to decide between admitting the patient to intensive care or withdrawing active treatment. In the medical practitioner's view, an intensive care admission would not prolong his life and would in all likelihood result in an unpleasant death. The decision was described as one that was very difficult to share with the man's

family. Indeed, it led to the medical practitioner being the subject of a complaint and formal investigation (see Box 5 Excerpt 2).

Thirdly, and finally, we were told about a patient with an intellectual disability and Parkinson's disease who was admitted for recurrent aspiration pneumonia. The medical practitioner reported that it was unclear whether the patient's weak swallow was due to their pneumonia, and so likely to improve with treatment, or were an irremediable consequence of the Parkinson's disease. While the patient had some spoken language, he was not able to convey whether his swallow had deteriorated. Aiming to minimise the risk of any further worsening of the patient's health, the respondent decided that while receiving antibiotics for the pneumonia the patient should be *nil by mouth*. However, nursing staff, following advice from the speech and language team, started feeding the patient with pureed food. In concluding his account of this breakdown in communication, which could have endangered the patient's health, the participant observed that this situation could have been avoided if the person with a learning disability had been able to inform the nursing staff that he should not be eating (see Box 5 Excerpt 3).

These three accounts of the biomedical complexities of treating patients with an intellectual disability, carry intimations of poor practice: a delay in diagnosis, resulting in pressure from nurses for the administration of inappropriate supplementary oxygen (account 1); an over-reliance on the testimony of a person with an intellectual disabilities, with tragic consequences (account 2), and a failure in communication between the medical and nursing staff, potentially endangering the life of a very unwell patient (account 3). These accounts raise questions about the extent to which the implementation of s. 20 of the *Equality Act* might have ameliorated, or even avoided, challenging clinical situations.

DISCUSSION

This study of medical practitioners' views and experiences is limited by its small sample size, by the practicalities of carrying out interviews in a clinical setting, and, more significantly, by the absence of complementary direct clinical observations that would support the interview data. Nevertheless, the findings reported here provide an opportunity to reflect upon the quality of the care and treatment that medical practitioners self-report that they provide to patients identified as having an intellectual disability.

Describing the challenges of providing care and treatment to patients with intellectual disabilities, medical practitioners focused on two accounts: the patients' communication

difficulties and vulnerability to behaviours that did not conform to a hospital's expectations, or their biomedical complexities. Of these different accounts, the first was dominant; it represented what might be considered the orthodoxy established in the Michael Report (2008), with its focus on the importance of making 'reasonable adjustments' consistent with equalities legislation. Similarly, studies of nurses working in acute settings (see review by Lewis et al. 2016) have reported overwhelmingly that communication and non-conformist behaviours present the most complex challenges. Yet what was striking about our findings is that, while the majority of medical practitioners subscribed to this view, they reported making limited use of 'reasonable adjustments'. Instead, they apparently turned to caregivers to facilitate communication, and manage behaviours likely to upset hospital routines. With many family carers apparently remaining at the bedside throughout an admission of a person with an intellectual disability (Mencap, 2012), a certain reliance upon family care is perhaps understandable. However, while likely to satisfy family members' desire for involvement, there could also be some unintended adverse consequences. For example, it may, in part, contribute to the repeated requests by medical practitioners for the same information, about which family carers complain, (Michael, 2008). At the same time, their constant presence may contribute to the evidence that, contrary to the *Mental Capacity Act*, medical practitioners (and other clinicians) believe that family members can make decisions on behalf of *any* adult identified as a person with intellectual disabilities. Moreover, there is a danger that, by focusing on 'reasonable adjustments' to minimise the impact of reported challenges might eclipse no less significant biomedical complexities: co-morbid health conditions (Cooper, McLean, Guthrie, McConnachie, Mercer, Sullivan, & Morrison, 2015), polypharmacy (Haider, Ansari, Vaughan, Matters, & Emerson, 2014), and rare neurodevelopmental disorders (Redley, Holland, & Pannebakker, 2016). That the clinical needs of patients with intellectual disabilities are at risk of being overlooked should be of serious concern because they appear, as the three accounts illustrate, to be associated with sub-optimal care and treatment. In keeping with the general neglect of people with intellectual disabilities during medical education and training (Salvador-Carulla & Saxena, 2009), there is no recognised medical specialism relating to the care and treatment of this group of patients in acute settings. This contrasts strikingly with the situation relating to infants and children, and older people. Of concern, in response to questions about the high incidence of potential avoidable readmissions in this population, medical practitioners referred to deficiencies in the care being provided in community settings, rather than, as we would have hoped, reflecting on their own professional practice.

What action might be taken? Changes to medical education to include a much stronger focus on the *clinical* importance of compliance with equalities legislation, and the relationship

between the *Equality Act* and the *Mental Capacity Act* could go some way towards improving the situation. In this context, 'reasonable adjustments' may assume greater relevance. Our recommendation that trainee medical practitioners in all specialisms should receive mandatory education and training in intellectual disability is hardly new: it was the first of the Recommendations made by Michael (2008). Surprisingly, though material about the involvement of people with intellectual disabilities in medical education and training was already available (Owen, Butler and Hollins, 2004), no guidance was provided about the curriculum or format that might be adopted. This is an area of work that requires further development. More broadly, the findings of this study were also consistent with an earlier analysis (Barnett, Mercer, Norbury, Watt, Wyke, & Guthrie, 2012), subsequently incorporated into the guidance about medical education and training produced by the UK's General Medical Council (2017). Both the analysis and the subsequent guidance emphasise the importance of generalist skills in responding to the increasing prevalence among patients of multi-morbidities, often accompanied by polypharmacy. While the guidance was initially a response to the highlighted needs of an ageing population, patients with intellectual disabilities are also very likely to benefit from such an approach.

Notwithstanding the challenges that were identified by the respondents in this study, there remains the possibility that the care and treatment of patients with intellectual disabilities is related to more general problems in hospital care (Francis, 2013; Keogh, 2013). The observation by one respondent that 'quiet patients' might be disadvantaged by staff shortages and increased workloads, is consistent with research linking low levels of nurse staff to higher mortality rates (Rafferty, Clarke, Coles, Ball, James, McKee, & Aiken (2007). However, the relationship between staffing levels and mortality is complicated. There are variations between hospitals, wards. and the medical needs of patients (NHS Improvement, 2018); substantiating any proposed link will not be easy. In the meantime, there is a need for observational and ethnographic studies to document in more detail the relationships between medical practitioners' self-reported views and their actual care and treatment of patients with intellectual disabilities.

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