

The involvement of parents in healthcare decisions where adult children are at risk of lacking decision-making capacity: a qualitative study of treatment decisions in epilepsy

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Abstract

Background Patients with intellectual disabilities (ID) receive health care by proxy. It is family members and/or paid support staff who must recognise health problems, communicate with clinicians, and report the benefits, if any, of a particular treatment. At the same time international and national statutes protect and promote the right of people with disabilities to access the highest attainable standards of health on the basis of free and informed consent.

Methods To consider the role of parent-proxies in the management of epilepsy in adult children with ID who are at risk of lacking capacity to make decisions about their health care we interviewed 21 mothers.

Findings These mothers are not pursuing changes in treatment that might improve their son or daughter's epilepsy, nor are they willing to countenance changes in treatment. Clinicians concerned to build and sustain therapeutic alliances with these

mothers, our evidence suggests, may well avoid going against their wishes.

Discussion Our research highlights the interactional contingencies of a hitherto neglected three-way clinical relationship comprising parent-proxy, an adult at risk of lacking decision-making capacity, and a treating clinician. This is a relationship, our findings suggest, where little importance is attached to either patient consent, or involvement in treatment decisions.

Keywords decision-making, epilepsy, family, human rights, intellectual disability, qualitative research

Background

The United Nations' *Convention on the Rights of Disabled Persons* (CRPD), which opened for signatures in 2007, requires States to recognise, without discrimination, the right of persons with disabilities to access the highest attainable standards of health (Article 25). Furthermore, in a direct challenge to paternalistic attitudes often taken towards people with disabilities, the CRPD requires those professionals providing health care to do so on the basis

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of 'free and informed consent' (Article 25:d). The UK signed the *Convention* in 2009; coupled to national legislation against discrimination on grounds of disability (*Equality Act 2010*), this should ensure that people with disabilities receive care and treatment on an equal basis with their non-disabled peers, and that their consent is always sought prior to any treatment commencing.

The law in England and Wales, unlike the CRPD, does, however, allow clinicians to make substitute decisions – under circumstances regulated by the *Mental Capacity Act (England and Wales) 2005* (MCA) – where a patient lacks decision-making capacity. Lawful substitute decisions can only be made in a patient's 'best interests': a decision-making process that includes, *inter alia*, a requirement upon clinicians to both ascertain, through consultation with patients and unpaid family carers, and consider the patient's wishes, values and beliefs (unless the decision is an emergency and such consultation is not possible). Although there is clearly a sharp difference between the CRPD and substitute decision-making under the MCA (see for example the report of the Office for Disability Issues 2011), patient choice and shared decision-making are, nonetheless, central tenets of health care in the UK's National Health Service (Department of Health 2010).

Patients with intellectual disabilities (ID), by and large, receive their health care by proxy. It is family members and/or paid support staff who must recognise health problems, arrange and keep appointments, communicate with clinicians, and report the benefits, if any, of a particular treatment (Cooper *et al.* 2006). Depending on the severity of a patient's ID, and other associated health problems, clinicians can have trouble understanding what is an ideal or acceptable treatment outcome (Lannon 1990) and may as a last resort have recourse to the provisions of the MCA when a patient, even with support, is unable to make and communicate an autonomous decision. Where clinicians lack an understanding of the special needs of people with an ID, and the legal provisions for making substitute decisions, this can lead to avoidable morbidity and mortality (Michael 2008). This is especially so for the management of epilepsy. Compared with the general population, where 70–80% of patients achieve seizure freedom, only 30% of people with an ID attain this outcome (McGrother *et al.* 1996; Bell & Sander 2001).

Standardised mortality rate (SMR) for people with an ID and epilepsy is 5.0 while among people in the general population who have chronic epilepsy the SMR is 2.05 (Hitiris *et al.* 2007).

In the UK the management of epilepsy in adults with IDs is generally through either specialist community learning disability services or a mainstream hospital-based neurology service, supported by primary care. Although at present it is not routinely possible to choose between these services this might become a possibility in the near future (Department of Health 2010). With at least 19 different anticonvulsant medications (NICE 2004) the process of identifying a successful treatment regime comprising a combination of one or more drugs that reduces seizure severity and frequency without disproportionate medication-related side effects [including excessive sedation, but also including distractibility, insomnia, dizziness, weight gain and skin rashes (Ortinski & Meador 2004)] can be difficult. Furthermore, changing anticonvulsant medication is not straightforward. It requires a prolonged period of carefully adjusting doses accompanied by the risk of worsening seizures, either during the changeover in medication, or once the new regimen is established should it turn out to be less effective than its predecessor. Nor is it self-evident – unless a patient attains seizure freedom with minimal side effects – what for him or her is the best possible level of seizure control. In the management of chronic conditions, like epilepsy, where a patient is at significant risk of lacking decision-making capacity the role of family members acting as proxies can have an important effect on treatment decisions and patient well-being (Mencap 2007; Michael 2008).

This article considers the role of parent-proxies in treatment decisions through a study of mothers' involvement in the management of adult children's epilepsy.

Method

A total of 21 mothers were interviewed as a consequence of their participation in a study investigating the cost effectiveness of community-based learning disability teams and mainstream hospital-based neurology services in the East of England (Pennington *et al.* 2012). This was a convenience sample

reflecting familiarity with specialist community-based learning disability services (eight mothers) and mainstream hospital neurology services (nine mothers), but also including a few instances where both services were involved in an adult child's care and no one service appeared to have overall clinical responsibility (four mothers). The sample includes mothers whose adult children had differing levels of ID and severities of epilepsy. The views of people with ID were not sought in this study because of its focus on the relationship that parent-proxies had with epilepsy services. The study was given ethical approval by an NHS clinical ethics committee.

The mothers were interviewed using a semi-structured interview schedule that addressed a range of issues: caring for an adult child with both epilepsy and an ID; the different treatment options and the different health services that had managed their son or daughter's epilepsy; and their views on treatment changes. The interviews lasted between 30 and 120 min, were audio-recorded, and conducted in the respondents' own homes. It was not our intention to interview only mothers. It just happened that as the primary carers they were available for interview during office hours, although three fathers did join their spouses at interview. For economy of expression, we will refer to all the interviewees as 'mothers' except where a father is referred to specifically.

Members of the research team transcribed the interview data. Our analysis evolved through a process of analytic induction (Silverman 2001) to present a model of the role of parent-proxies in the management of epilepsy in adult children with an ID. Pseudonyms have been used throughout. All quotations are followed by a brief description of the respondent's adult child, including: age; severity of ID (mild, moderate and severe); an informant measure of severity of epilepsy based upon observed symptoms (very severe, severe, somewhat severe, moderate); type of epilepsy service used (mainstream, specialist, or both); and place of abode (family home, independent living).

Findings

Our findings are presented in two sections: Section One documents that the mothers we interviewed were willing to live with what they considered to be

an acceptable level of seizure activity, which we consider to be a state of equipoise, and to reject possible changes in their son or daughter's treatment. Section Two presents additional interview data to address the following questions: (1) might these mothers, in actual clinical consultations, be declining opportunities to change their son or daughter's treatment; and (2) might clinicians be agreeing to, or at least assenting to, the wishes of these mothers?

1. *Rejecting changes in treatment*

The mothers we interviewed appeared reconciled to a state of equipoise. Rather than actively pursuing improvements in their disabled children's seizure control through changes in treatment, our findings suggest they take the position that the current frequency and severity of their son or daughter's epilepsy, all things considered, is understandable and acceptable. This is illustrated in excerpt 1 below: Mrs Reach, a clinically well-informed respondent, is evaluating Charlie's current medication in the light of his ongoing seizures.

Mrs Reach: [. . .] we've tried other medication, doctors have prescribed other medications and they've made Charlie unwell. We tried something called Lamotrigine, which made him, which gave him skin irritations. We tried Keppra, which completely knocked him out. He's tried combinations of different drugs together and seizures have always been very poor. And what happens when you start giving people lots of medication is their quality of life deteriorates and you know. So it's been a decision to keep him on Epilim which we think might control some [seizures], but we don't really know. I mean Charlie's always gonna have to be on some sort of medication. I think it would too dangerous to take him off it.

Interviewer: Is it always a balance between seizure frequency and the side effects for you then.

Mrs Reach: Yeah always, always he seems to be very very susceptible to other forms of medications and Epilim seems to be the only one that gives him any quality of life really. [22; severe ID; very severe epilepsy; neurology service; family home]

Mrs Reach reports that a variety of medications, and combinations of medications, have been tried in the past; these, however, have led either to worse seizure control and/or had undesirable side effects. In addition, Mrs Reach reports that a decision has been made to keep Charlie on Epilim despite uncertainties as to whether this drug actually controls any of his seizures: it is considered, 'too dangerous to take him off it'. In response the interviewer asks Mrs Reach if she is always balancing seizure frequency and side effects. Mrs Reach concurs that a balance has to be made: Epilim is the only drug, she says, that gives Charlie 'any quality of life'. Mrs Reach, based upon her past negative experiences of a range of epilepsy drugs, is reconciled to Charlie's current treatment regime and its uncertain level of seizure control. In excerpt 2 Mrs Westwick assesses her son's treatment and his current level of seizure activity.

Mrs Westwick: Well it's my perception that at the clinic they are doing the best they can for Graham and that, so that the advice that they give and the, you know the various permutations of the medication which he's taking now, the level he's at now, is them doing they best they can. And that he's, you know, one of their patients who perhaps hasn't got such a great success rate as others. I think his type of epilepsy, which I think you know, what it's, partial something or other isn't it.

Interviewer: Complex partial.

Mrs Westwick: Yes, which I think Doctor Smith has said it's one of the most difficult types [of epilepsy] to treat so they're probably at a loss to know what else they can do, and it isn't for want of trying. [40; mild ID; somewhat severe epilepsy; specialist learning disability service; family home]

In Mrs Westwick's view the clinic are doing the 'best they can' for Graham; the advice given and the current regimen of medicines 'is them doing the best they can'. Moreover, the lack of apparent success in treating Graham's epilepsy which 'isn't for want of trying', can be attributed to the fact that Graham has 'one of the most difficult types [of epilepsy] to treat'. Mrs Westwick's apparent resignation to Graham's seizures turns upon her perception that the clinical team is doing its utmost for her

son, and that his form of epilepsy is particularly difficult to treat. The mothers in excerpts 1 and 2, rather than hoping for an improvement in their sons' epilepsy treatments, are describing a state of equipoise: their sons' current seizure level is understandable and hence accepted.

All the mothers we interviewed (with one exception, discussed later) described similar states of equipoise. Given that these are 'veteran' mothers of adult children and therefore appreciative of the uncertainties of changing anticonvulsant medication, the obdurate reality of life with ID, and the sometimes-fickle nature of health services (often described at length), this is not altogether surprising.

In excerpt 3 below Mrs Thetford responds to a question asking whether she would consider changing Jess' medication:

Mrs Thetford: Unless someone come up to me and said I've got a miracle drug and it would stop all Jess's fits, 'no'. Because I don't know if it's going to work or not. And I couldn't cope with Jess fitting more than she is now. [23; severe ID; severe epilepsy; neurology service; family home]

Mrs Thetford's refusal to countenance a change in medication is based on the lack of guarantees, 'I don't know if its going to work or not', and the possibility that, rather than improving Jess's seizure control, it might leave Jess, 'fitting more than she is now': this would be an outcome that Mrs Thetford says she would be unable to 'cope with'. The status quo, short of a 'miracle drug', is preferred. Excerpt 4 below comes from Mrs Caston's account of Nina moving into adult services and her new clinician asking, 'if we wanted to try a new drug'.

Mrs Caston: And I just said, 'No, not for the time being'. Because whatever you try they're all going to have side effects and I know putting on weight is, to me, is a big side effect but I think we can have some control over it, but if you try a new drug and it gives other side effects inside or you know something more serious, I wouldn't like that at all. And as I said, to me it's always better the devil you know. We've been doing this drug for twenty-two years and so far it hasn't done, no real damage to her apart from putting

on the weight. [22; severe ID; moderate epilepsy learning disability service; family home]

Explaining her decision to decline the proffered change in medication, Mrs Caston cites the inevitability of side effects. The side effects of Nina's current medication – weight gain – can be controlled, whereas the side effects of a new drug might be unknown and/or 'more serious'. For Mrs Caston it is, 'better the devil you know', and Nina, she reports, has been on the same medication for 22 years. Current certainties are again preferred.

In excerpts 3 and 4, mothers concerned about the uncertainties inherent in changing treatment display a reluctance to sanction changes in treatment. These mothers, while concerned about their children's epilepsy, are not looking to changes in treatment as a means to improving seizure control. There was, however, one exception to this otherwise general rejection of changes in treatment. Mrs Rampton's daughter Rebecca embarked on a change of treatment following a change from a specialist learning disability service to a mainstream neurology service. The change of service was precipitated by an altercation with Rebecca's clinician. With the change in clinician came a change in medication, and Rebecca has now been seizure free for several months. In excerpt 5 below Mrs Rampton compares the specialist learning disability service with the neurology service.

Mrs Rampton: I would have gone in the beginning and seen a neurologist not a, [pause] I don't think that they [learning disability psychiatrists] should, [pause] I think if they want to see Rebecca for her disability that's fine. But I don't think they should treat her epilepsy because I don't think that they know enough about it. They seem to depend more on you to tell them the information, whereas with the neurologist he was telling me. He told me, I didn't tell him, and with the other one he was dependant on us [. . .] Now the neurologist he wasn't interested in that at all he could straight away, he seemed sort of, you know, what I mean straight away he said that's it. We weren't in there ten minutes when he, we were in with him like for a half an hour altogether, but he straight away he said, 'no this needs changing', whereas we asked.

Interviewer: The other doctor.

Mrs Rampton: The other one and he said it [changing medication] was too long it's too long and a drawn out procedure. [39; moderate ID; moderate epilepsy; neurology service; family home]

Mrs Rampton's description of the view taken by the clinician in the specialist learning disability service, that embarking on a change in medication is 'too long and a drawn out procedure', although different from the reasons given by the majority of mothers, resonates with both their seeming preference for a state of equipoise and rejection of proposed treatment changes. Furthermore, Mrs Rampton's observation that clinicians in the learning disability service 'seem to depend more on you to tell them the information' is in keeping with the wishes of many of these mothers to be consulted and listened to (see Section Two below). In contrast to this, and seemingly appreciated by Mrs Rampton, was the fact that the neurologist did not listen: 'He told me, I didn't tell him', and he unilaterally decided upon a change in medication: 'straightaway he said no this needs changing'. Precisely why Mrs Rampton was willing to accept this change in Rebecca's treatment is unclear, although the answer may lie in the disagreement that precipitated the change in service, the clinician's authoritarian manner, or Mrs Rampton's past experience as a nurse. It is our contention, however, that had the neurologist's treatment change precipitated a worsening in Rebecca's epilepsy, her mother would have described a high handed clinician who without listening to what she had to say made a unilateral decision to change Rebecca's medication (see Section Two).

That the majority of mothers were reluctant to countenance changes in treatment raises two important and interlinked questions with respect to their role as proxies: are these mothers, in actual clinical consultations, refusing proffered changes in treatment; and are clinicians agreeing to, or at least assenting to, these refusals?

2. Parent-proxies in clinical consultations

In considering the influence these mothers might exert on clinical decisions made during actual con-

sultations with clinicians we must first acknowledge the limitations of our data. Rather than having recordings of actual consultations involving clinicians, mothers, and possibly their adult children, we have mothers' sometimes-brief accounts of their relations with different clinicians who have, over the years, treated their son or daughter. It is, however, to these descriptions that we now turn.

Many of the mothers we interviewed described instances where clinicians were rude and patronising, unavailable at times of crisis and, just as the mothers in Section One feared, initiated courses of treatments that resulted in seriously adverse consequences for the health of their children. Nonetheless, some clinicians were singled out as praiseworthy. In excerpt 6 below Mrs Coltishall describes the qualities of a good clinician:

Mrs Coltishall: [. . .] And you got a very rare good doctors that will talk to you and listen to you because they know you know best, because you're living that situation twenty-four seven. And there's a handful of good'ns real good'ns that say 'what can we do to help you, what would make life easier', rather than ignoring you or whatever. [26; severe ID; somewhat severe epilepsy; learning disability service; family home]

The mothers who described the qualities they expected in a good clinician all identified a willingness to listen and involve them in decisions. A mother's involvement in clinical decisions is, however, almost inevitable. Irrespective of whether, or not, a mother wishes to be actively involved she will become a bearer of clinically important information, as well as acquiring a knowledge of epilepsy and its management, as a consequence of administering anticonvulsant medication on a daily basis, and rescue medication when seizures are particularly severe and prolonged. By virtue of attending numerous clinical consultations these mothers will have become 'veterans', and as such, difficult people to steer towards treatment options they are unhappy with (Silverman 1987). Two mothers, as a result of acquiring what they considered to be substantial clinical knowledge of epilepsy and its treatment, reported managing their adult children's epileptic medication quite independently of clinical supervision (including making adjustments to dosage), and were not pursuing overdue appointments. One of

these mothers, Mrs Reach, described herself as 'just keeping us [self and son] warm in the system'. Some mothers, it appears, are willing to withdraw from clinical services. When Mrs Westwick was asked if she was frustrated by delays to an appointment to assess her son for a Vagus nerve stimulator, she replied:

Mrs Westwick: Um, it's not something that I worry daily about because in all walks of life you find yourself waiting for all sorts of things and you just get philosophical about it and say well this is how is it these days. Um sometimes I think, well you know, when I see Graham having another seizure and I think well maybe this wouldn't have happened had he been [indistinct] although it doesn't cut out the medication. I think Graham was thinking; well if he has that he won't need to take the tablets, but I think it might be a combination of both. So I'm not sure if Graham is entirely convinced by the merits of it. [40; mild ID; somewhat severe epilepsy; learning disability service; family home]

Mrs Westwick was the only parent who reported contemplating a son or daughter's involvement in a treatment decision. Explaining her reticence to pursue the delayed appointment Mrs Westwick says that she and Graham have different understandings of whether he will still need to take medication, and suggests that Graham is not entirely convinced by the merits of a Vagus nerve stimulator. Nonetheless, the effect of not chasing this assessment is that Mrs Westwick is in control: Graham is denied an opportunity to exercise autonomy over his treatment, and the managing clinician cannot advocate for a change in treatment. Further reflection on the influence these mothers might exert on clinical decisions turns on the emotional texture of their lives. In excerpt 8 Mrs Spixworth is giving an account of why she would not consider joining a support group for parents of children with epilepsy.

Mrs Spixworth: [. . .] I'd hate to have to be talking about his [Stuart her son] epilepsy all the time because, although it is a part of our lives and it's almost like when he was a baby and he first started having seizures, I thought we'd lose him nearly every time he had a fit. It was the most frightening thing, you know you're a new

mum and that first seizure I can remember to this day [. . .] And he's going to be twenty three this year and we've never taken anything for granted [. . .] if I was at a support group and somebody came and said 'oh my child's just started having seizures' I don't think I'd cope with that because it's been like, I'd be so sorry for them and think my god, the things we've had to do with the doctors and the drugs and I just couldn't. You want to say 'oh my god' oh you'd feel so sorry for them. [22; severe ID; severe epilepsy; neurology service; family home]

In light of the above, it is our contention that were a mother (a parent-proxy) to volunteer her views on a change of treatment, or be asked her views on a proposed change of treatment, only to have those views sidelined or dismissed she may well feel that she was being ignored and that the interests of her son or daughter were being threatened. Clinicians wishing to build and sustain a therapeutic alliance with the mothers of these patients must be prepared to listen to these mothers, who hold clinically important information; they must be prepared for some degree of shared decision-making, being aware that where a mother feels her wishes are not being respected she may withdraw from the clinical service by not attending or pursuing clinical appointments, and finally clinicians must recognise, as suggested by excerpt 8, that these consultations could become emotionally charged. It is our conclusion, therefore, that clinicians may well avoid going against a mother's wishes, by agreeing to, or at least assenting to a mother's reluctance to change a son or daughter's medication. Furthermore, we found no evidence to indicate that, in the interests of building a therapeutic relationship with a parent-proxy, clinicians were following the CRPD or MCA and involving these adult patients in decisions about their own treatment.

Discussion

It is not our intention to demonise either these mothers or the clinicians treating their adult children; it is, furthermore, beyond the scope of this paper to assess whether the medical interests of these adults with epilepsy and an ID are well served by their mothers, and/or the clinicians they consult. In addition this study has a number of method-

ological limitations: the use of interview data rather than recordings of actual clinical consultations and the absence of interview data from the managing clinicians and the patients they are treating. Nonetheless, our findings raise troubling questions in need of further research: to what extent is the ability of these mothers to champion the interests of their adult children confound by (1) a wish to avoid the practical demands of a prolonged period of carefully adjusting doses accompanied by the risk of worsening seizures and/or significant side effects; (2) the existential uncertainties that a new drug or combination of drugs will with minimal side effects, result in an improvement in seizure frequency or severity; and (3) doubts over the capacity of a son or daughter to make, or even participate in decisions about his or her treatment? Caring for a disabled family member in respect of both its practical and emotional dimensions can have a detrimental effect on the quality of a carer's life, and lead to very real conflicts of interest (Hughes *et al.* 2005). The implications of these conflicts and how best to resolve them need to be better understood because patients at risk of lacking decision-making capacity do not exist in isolation from family members acting as proxies during clinical consultations (Livingston *et al.* 2010).

To date, sociological studies of treatment decisions and clinician-patient interaction have focused almost exclusively on patients assumed to have the capacity to make decisions about their treatment (see for example Blaxter 2010 especially chapter 4; Turner 2004; Mol 2006). While scholars in the field of Disability Studies have offered a sustained critique of how disabled people are oppressed by a 'medical model' that focuses exclusively on mental and physical deficiencies (Oliver 1990), little empirical research has been conducted into the provision of health care, let alone the treatment of health conditions co-morbid with disability (see for example Thomas 2007). Advocacy organisations and especially Mencap (2007) have, in contrast, highlighted inequalities in health care and how clinicians regularly fail men and women with ID by not consulting with or involving parents and family members in care and treatment decisions. Be this as it may (and our research suggests the contrary) Mencap's analysis does not begin to consider the practical dynamics of parent and family members' actual

involvement in treatment decisions. In sum, the interactional contingencies of involving a parent-proxy in a three-way relationship involving an adult at risk of lacking decision-making capacity, their proxy, and a treating clinician have not been considered. As such, our study points to an important and hitherto neglected topic: the involvement of parent-proxies in the care and treatment received by adult children at risk of lacking decision-making capacity.

Although our findings cannot begin to explain the persistent health inequalities associated with having an ID, or the institutionalised discrimination said to be a feature of the health care they receive (Mencap 2007; Michael 2008) our research does signal some of the subtleties that might underpin them. In addition our research suggests that national and international statutes promoting and protecting the rights of people with disabilities to make decisions about their own health care are not necessarily being respected in clinical consultations.

Acknowledgements

This paper presents independent research commissioned by the National Institute of Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant PB-PG-0706-10051. PI Dr H Ring). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR (UK) or the Department of Health (UK). During the time that this research was carried out H Ring, M Redley and T Croudace also received support from the NIHR (UK) CLAHRC for Cambridgeshire and Peterborough. We are grateful to the participants and to their family and paid carers for the time they generously gave to this research.

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Accepted 28 February 2012