



Putting knowledge to trial: ‘ADHD parents’ and the evaluation of alternative therapeutic regimes

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ABSTRACT

The role of patients’ organisations in shaping (medical) knowledge about particular health conditions and illnesses sheds light on notions of informed patienthood and the dynamics of lay-expert knowledge in the context of medicalisation. This paper considers dynamics of knowledge production in relation to a specific condition area, Attention Deficit Hyperactivity Disorder (ADHD), by investigating how parents of children with ADHD are intervening in knowledge creation about the effectiveness of different treatments for the disorder. It draws on qualitative research carried out between 2009 and 2011 with organisations representing parents of children with ADHD in Ireland, to explore how parents have commissioned evaluations of alternative interventions to medication. Drawing on analysis of 12 semi-structured interviews with both parents and professionals active in the arena of ADHD, documentary evidence, and observation at parent organisations’ events, the study demonstrates how parents’ interventions have sought to expand the therapeutic domain of ADHD beyond the exclusive realm of biopsychiatry, and the dilemmas they face in making their experiences count in a context where the need for evidence has become paramount in the governance of health.

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Introduction

In recent years, media reports within Ireland and the United Kingdom have brought into sharp focus the controversies that rage over the diagnosis and treatment of ADHD. Concerns over the increased use of psychotropic medication for young children have led to calls for reviews of doctors’ prescribing and treatment practices by a range of other professional bodies, including educational psychologists and teachers (Davis, 2011; Hough, 2011). These concerns have been well-documented within the American context, where the rapid increase in rates of prescribing has been a source of continued contention (Rafalovich, 2001; Singh, 2002, 2004, 2008). Such ongoing professional disputes bear witness to the unsettled nature of ADHD as a diagnosis, and the lack of consensus regarding appropriate therapeutic interventions for the condition.

Parents of children with ADHD are arguably one of the most significant lay actors within the domain of ADHD, occupying a central position at the nexus of professional and experiential discourse which characterises the condition. In the popular media, they have frequently found themselves caught in a blame game,

where their child’s condition is constructed as a result of a perceived parenting deficit (Malacrida, 2002; Singh, 2002; Taylor, O’Donoghue, & Houghton, 2006). It is perhaps unsurprising therefore that parents have sought to contest these constructions by drawing on scientific evidence regarding the biological origins of the condition in order to ‘validate’ ADHD in medical terms. Such actions are representative of the way in which parents have become promoters of medicalisation ‘from below’ (Conrad, 2007; Furedi, 2006), as an increasing distrust of experts and expertise has circumscribed the influence of medical professionals. The positions that parents assume and the relationships that they form with professionals are, however, complex and shifting. Parents are often enjoined to take decisions about treatment which they feel ill-informed to make, and are presented with little choice other than medication (Hough, 2011; Taylor et al., 2006).

This paper explores the dynamics of knowledge production in the field of ADHD in Ireland by investigating how parents of children with ADHD are intervening in knowledge creation about the effectiveness of different treatments. While diagnosis and treatment of the condition in Ireland has traditionally been the preserve of biopsychiatry, dissatisfaction with medication as the singular therapeutic option has drawn another cadre of professionals into the treatment field, offering alternative interventions. Parents’ decision-making processes regarding different therapies have been shown to take different forms, ranging from “passive recipients of

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information” (Valentine, 2010: 956) to activists who are adept at engaging with medical and scientific evidence regarding their child’s condition (Ryan & Runswick-Cole, 2009). The parents in our study have taken this commitment to evidence a stage further by commissioning evaluations of two different treatment modalities for ADHD, namely neurofeedback and a family therapy intervention. Focusing on this process of knowledge creation, we explore how parents are intervening between a number of different professionals, including neuroscientists, psychotherapists, and psychiatrists, who are seeking to lay claim to ADHD as their treatment domain. In particular, we are interested in asking how parents are creating and using evidence to open up the therapeutic field of ADHD; about the types of knowledges and expertise which are being produced and come to be valued in such evaluations; and about the relationship which exists between the parents as the ‘commissioners’ of research and professionals as the ‘commissioned’.

Medicalisation and knowledge deployment in the therapeutic field

The story of the medicalisation thesis has been the constant positioning and repositioning of different actors across the medical field. The original incarnation of the thesis constructed the medical profession as holding power over a passive lay population, and the institution of medicine as responsible for categorising ever more areas of social life as medical problems (Illich, 1977; Williams, 2001). More recent interpretations have swung the focus on to lay people as the catalyst for increasing medicalisation, driven in part by the development of consumer markets for healthcare. The notion of a passive public duped by the medical profession has been thoroughly critiqued, as late modern society has witnessed the emergence of active patients who are “better informed about risks and benefits, less trusting of medical authority and less passively accepting of the expansion of medical jurisdiction into their bodies and lives” (Moynihan, Heath, & Henry, 2002: 887). It is acknowledged that some of the consequences of this ‘lay-reskilling’ may be contradictory, however. For example, whilst patients may be suspicious of professional expertise and technical responses to health and illness, they have actively sought out diagnoses of conditions from medical professionals (Barker, 2008; Broom & Woodward, 1996).

A number of empirical studies have sought to unpack the identity work involved in being an ‘informed patient’, and the tools that lay people use in seeking to make decisions about therapeutic interventions (Ryan & Runswick-Cole, 2009; Taylor et al., 2006; Valentine, 2010). Studies of parents seeking diagnosis and treatment for their children raise a number of pertinent issues regarding the interpretation of lay-professional dynamics in the context of medicalisation. One issue that becomes apparent from these studies is that it is not just one professional group that the parents find themselves dealing with, but several allied professions, including psychologists, occupational therapists and speech therapists. It has been acknowledged that competition between professions in diagnosing and treating different conditions has led to medical boundary expansion and shifting divisions of labour (Halpern, 1990). In the case of ADHD, parents often require a medical diagnosis to gain access to other services and professionals, with doctors therefore fulfilling a gatekeeper role. But once they have the diagnosis, how do parents make judgements about the treatment modalities offered by different professionals, who often have different understandings of the condition?

The related issue of *choice* has been the focus of a number of commentators who have sought to challenge notions of the rational informed consumer emerging in more recent constructions of the

medicalisation thesis (Samerski, 2009; Tomes, 2007; Valentine, 2010). For some, the notion of choice in terms of selecting treatment options is a misnomer in situations where services are scarce, or market systems exclude certain groups of patients from treatment options on the basis of cost. In other cases, patients are enjoined to weigh up and evaluate multiple treatment options. In these contexts, choice is often constructed as ‘no choice’, and becomes a burden, rather than an empowering decision (Valentine, 2010). The notion of patient empowerment has also been challenged by those who have constructed the call to choose as an active management strategy deployed by doctors and other professionals in the self-governance of health. Using the example of genetic counselling, Samerski (2009) notes how doctors and other professionals (counsellors) have enjoined pregnant mothers to assess, and make decisions about, the risks to their unborn child through informed consent. Choosing therefore becomes an act of self-governance mitigated by scientific knowledge, rather than one’s own judgement or experience.

The latter point raises the question, central to this paper, about the tools and resources parents and patients employ in making decisions about what treatment interventions to pursue. Parents’ engagement with the medical sphere does not just involve confronting professionals and expertise in the clinical encounter, but also negotiating expert knowledge(s) and ‘evidence’. A significant body of literature has documented the increasing influence of lay groupings in shaping understandings of health and illness, and has sought to describe the modes of activism deployed by such groups (Epstein, 1995; Hess, 2009; Novas, 2006; Rabeharisoa, 2003). Lay people have intervened in the medical enterprise in different ways, interpreting and challenging biomedical knowledge and research agendas through the lens of experience. Epstein’s (1995) research on AIDS activists’ interventions into clinical drugs trials and Novas’ (2006) study of the engagement of groups concerned with rare genetic disorders illustrate how patients have actively engaged with biomedical research into treatments for specific conditions. Both cases demonstrate how lay activists can achieve a level of scientific literacy and credibility with biomedical researchers, which enables them to further their cause (Epstein, 1995). In other contexts, lay people have sought to raise awareness of particular diseases through the promotion of experiential knowledge gleaned from their embodied experience of living with the condition (Rabeharisoa, 2003).

Processes of (medical) knowledge construction are becoming increasingly complex, then, as the lay-expert divide becomes more blurred (Brown et al., 2004). Many patients’ organisations have become acutely aware of the power of evidence not only as something that must be interpreted in selecting therapeutic modalities, but also as a strategic tool to be deployed in shaping the governance of health. The evidence agenda has arguably come to occupy a central role in mediating relationships between professionals and lay people, but has been problematised by a number of commentators. In the social sciences, for example, critics have pointed to the propensity of evidence-based policy to ascribe value to, and prioritise, certain forms of knowledge (namely quantitative data) over others, and construct notions of a depoliticised policy process in which objective, value-free evidence becomes the most influential variable in decision-making (Laforest & Orsini, 2005). Meanwhile, empirical studies have shown how evidence-based medicine influences parents’ decisions as consumers of interventions in private healthcare markets; more evidence, it seems, pays (Valentine, 2010). Lay activists have had to consider what constitutes evidence in promoting their cause, and how they can convert their lay experiences into a credentialised form (Rabeharisoa, 2003). Parents of children with ADHD and other conditions are positioned in a complex field fraught with

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