REVIEW

Exploring diagnostic processes: social science perspectives

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Arch Dis Child 2005;**90**:284–287. doi: 10.1136/adc.2004.052118

This review explores social science analyses of diagnosis of childhood neurological disabilities. The paper moves through three sections, which capture the historical and conceptual trends within the literature. The first focuses on work identifying the need to communicate effectively with parents when giving a diagnosis, the second explores the role parents can play as ''partners'' or contributors to diagnosis, and the final section goes further in exploring the social complexity of diagnoses in order to examine the embedded nature of social practices, power relations and hierarchies, and institutions in the diagnosis encounter.

There is a long tradition of exploring the institutions and actors within medicine in the social sciences.[1] In the 1970s medical sociology focused on macro analyses, on medicine as an institution with an embedded position in society that allowed it to exercise power over patients.[2] Increasingly, influenced by broader shifts towards social constructionism, medical sociology has narrowed its interest to the micro and the everyday construction of medical knowledge and power.[3] This historical trend within medical sociology has altered the way in which key themes are analysed. No more so can this be seen than within critiques of medical professional power. Macro level analyses of the power of medical professional organisations now sit alongside micro accounts of the individual interactions between professionals and patients.[4]

The move from the macro to the micro can be seen in one of the newer social science disciplines; disability studies has developed out of and retained the political motivations and perspective of the disability movement.[5] Within disability studies the following ''social model'' distinction between impairment and disability is made:

> *Impairment* is the functional limitation within the individual caused by physical, mental or sensory impairment. *Disability* is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.[6]

This understanding of disability is in contrast to the ''medical model'' which presents disability as an individual pathology.[7] From this perspective, to have a disabled child is a tragedy that equals a life of burden and restriction (for the family as well as the child) and should be avoided if at all possible (for example, through antenatal screening and termination).[8] When the social model started being used to understand the position of disabled people it tended to concentrate on macro level analyses of institutional power; more recently micro concerns have moved into focus. In particular, disability studies writers influenced by social constructionist approaches are interested in the role of professional frameworks for understanding the body, illness, and medicine in the social construction of disability and impairment.[9]

A particular focus of medical sociology and disability studies is the area of children with disabilities; as patients they raise specific issues within medicine and the social processes that surround it. For example, the interaction is between professional, patient, and parent, complicating the relationships that inform intervention. This paper concentrates on childhood neurological disabilities as the role of developmental markers in their diagnosis brings social considerations to the fore. The paper moves through three sections; the order of the sections indicates a critical continuum from work that identifies the need to communicate effectively with parents when giving a diagnosis, to analyses exploring the role parents can play as ''partners'', and finally to work exploring the embedded nature of social practices, relations, and institutions in the diagnosis encounter. The discussion follows both a historical trend and is also structured to indicate the distinct levels of analyses being developed by social scientists.

Each section critically engages with the work discussed and concludes with recommendations for changing medical practice that emerge from them.

COMMUNICATING DIAGNOSIS

How diagnosis is communicated to parents is a well established area of social science concern. This work began in healthcare studies that identified unnecessary trauma when parents are told that a baby has a condition such as cerebral palsy.[10 11] For example, Cunningham and colleagues[12] studied how Down's syndrome was reported to parents and found that they were presented with a picture of struggle and grief, which inhibited their ability to cope and respond to their baby over the long term.

More recently Cunningham has identified three main areas of dissatisfaction among parents:

- The manner of the person giving the diagnosis; for example, unsympathetic, cold, insensitive, expressed in language too difficult or vague to understand

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Accepted 24 September 2004

- Problems with information; for example, lack of information and guidance about the diagnosis and what can be done …
- Organisational aspects: delay and difficulty in getting access to help, lack of privacy, lack of coordination between services.[13]

Cunningham asserts that the grief parents are said to experience when a diagnosis is given is not solely down to the news itself, but a product of the processes they go through, if ''the teller assumes the news is '*bad*' and needs to be '*broken*' it denotes a negative conception which is likely to be imparted on the parent''[13] (original emphasis). From within disability studies, as indicated above, the claim is that medical approaches to diagnosis and disability generate an overly pathological approach to communication that confirms for parents that this indeed is a truly awful thing that is happening to them and their child. It is something which signifies no future or quality of life for their child or for their family.[14]

Tates and colleagues[15] argue that a poor relationship and lack of communication between doctors and parents can hamper diagnosis as symptoms are missed. In addition, poor communication during initial diagnosis can leave a legacy of mistrust and anger that influences future relationships between parents and the range of health and social care professionals they come in contact with. Therefore, initial diagnosis and its discussion with parents are fundamentally important. They should frame the child's condition in a way that is honest and comprehensive, but acknowledges the child's human qualities and is still open to possible futures.

From the criticisms indicated above, recommendations for change in practice have developed. Developing a relationship with the parents that is grounded in a sensitive model of communication is vital in the area of childhood disability as parents play a role as intermediaries, discussing symptoms and issues with doctors. A wide ranging literature identifies the principles medical actors can follow to present news in a way that is more sensitive.[16] Mitchell and Sloper[17] stress the need to provide parents with information, in everyday language, which they can use to comprehend the implication of the diagnosis for their child. Communication should be culturally sensitive and involve jargon free explanations.[18] In practical terms Cunningham[13] offers some very specific advice. Parents should be told as soon as possible after a diagnosis. Parents should be told together and/or with family and/or friends present. The diagnosis should happen in a private space. Every effort should be made to ensure that the baby or child is present. Beforehand the person passing on the news should ensure there is enough time to do so. A colleague should also be present to help answer questions. Before the parents leave a follow up interview should be arranged for 24–48 hours later. They should leave with written information, which they can read when ready to do so. Finally, after the meeting is over the parents should remain in a private space with their child to reflect on what they have been told.

Cottrell and Summers[19] usefully focus on the issues that emerge, as is often the case within neurological problems, when diagnosis is a question of comparison to developmental markers of normal progression. In such contexts, the issues of communication and what parents need to be informed of is both more difficult and more vital.[20] They argue that the tendency is to hold back suspicions until something is known for certain; the cost is that parents are left in limbo. In this context, Cottrell and Summers advocate sharing concerns with parents in similar ways to those advocated by Cunningham. They also point out that a diagnosis is not the conclusion for parents, but the beginning of a journey that will continue throughout their child's life. Cunningham argues that the journey involves ''cognitive reconstruction'',[13] where parents swap the child dreamed of for their child and a new narrative for their future is written. Professionals can help that reconstruction by providing resources and support that are honest but expansive.

It is the literature summarised in this section that is beginning to have the most impact on medical practice; much work is being done—at least at the level of policy and education—to consider better methods for communicating diagnoses to parents and children. This is an important first step, but it does not go far enough in incorporating parents into diagnosis. What we have so far is how to tell parents what medical professionals have concluded; this can be taken further by considering what role parents can play, not just as recipients but also as participants in diagnosis.

PARTNERS IN DIAGNOSIS

Work discussing a larger role for parents is influenced by wider debates in medical sociology regarding the knowledge patients can bring to the medical encounter, which means that they ''are experts in the detail of everyday life''.[21] A continuum exists whereby some writers suggest that this expertise indicates that patients can play *some* part in diagnosis, to others who argue that patients can be *full* or *equal* participants in the diagnostic encounter.[22] Two such writers are Arksey and Sloper who argue that diagnosis is a form of ''active interpretative work''[23] that patients participate in. Elsewhere Arksey goes further to propose that patients can be ''lay epidemiologists'',[24] a claim that is not without challenge for denying the varied levels of expertise lay people and clinicians bring to a clinical encounter.[21]

Avdi and colleagues[25] take Arksey's ideas into the realm of childhood disability to assert that partnership reflects recognition that parents have some ''expertise'' about their child.[26] This expertise emerges from the intimacy of their familial relationship. Acknowledging this intimate expertise does not necessarily deny the expertise of the medical professionals, Avdi *et al* describe parents as ''experts … in need of expert input''.[25] Rigazio-DiGilio[27] explores a ''relational'' model of diagnoses that incorporates an awareness of the ''meaning-making processes''[27] that will enable families to work through diagnosis in a way that is manageable for them. Working in such a way requires a framework that does not judge parental reaction against templates of how they should react, which can label a ''family's familiar ways of perceiving and acting as substandard or deviant''.[27]

Drawing parents into the diagnosis as participants includes considering the references through which they draw meaning in the diagnostic encounter.[28] Diagnosis does not occur in a social vacuum; both medical professionals and parents bring with them existing discourses of disability that influence the way in which they discuss and frame a diagnosis. Work within social anthropology has been particularly useful in this respect. Two particularly excellent examples of this research are by Larson[29] and Landsman.[30] Both Larson and Landsman examine how mothers made sense of the diagnosis their child received and acted in ways considered problematic by doctors. Larson argues that parents are judged against a template for how they should behave and respond. Mothers should accept the diagnosis and display the obvious grief over the loss of their perfect child, if not they are in denial.

In Landsman's research the focus is drawn outwards to include awareness of the surrounding discourses that influence individual meanings. Such discourses include the medical model of disability as a personal tragedy inflicted on people, and popular culture celebrations of the personal triumph of individuals who have ''overcome'' their

''infliction''. Each of these narratives is based on a normalising ideology that assumes that to be disabled is to be ''outside the range of human acceptability''.[30] Landsman argues that these discourses influence the way in which mothers explore the significance of diagnosis for their child, for example, seeking to challenge professional definitions of diagnosis as certain, in order to hold open the possibility of heroic progress and a return to normality.

The recommendations for changing practice that emerge from this work stress the need to allow patients or their representatives a role in developing diagnosis and treatment. This does not necessarily suggest an equal role, but implies that knowledge from everyday life has a role in the diagnostic and treatment encounter. It also points to an acknowledgment by medical professionals of the ambiguity and contingent quality to the diagnoses they make, particularly where such diagnoses are made against developmental markers. This requires an honesty that diagnosis may be open to change as the child develops (and is supported). Such changes can benefit medicine by challenging the hierarchical models of medical practice that make it difficult for parents to speak for their children and challenge unnecessarily bleak forecasts for what the future holds.

The work above has taken us further in exploring the ways in which parents (although in some of the studies such as Landsman and Larson the focus only on mothers perpetuates the assumption that it is mothers who are the primary carers of children) can play a part in diagnosis and how their approach to diagnosis is influenced by the world around them. However, we need to remain very conscious of the embedded position of medical professionals to construct the processes through which parents move through and how such a position shapes and at times dictates the meanings developed in interactions. There are various ways in which social science examines the embedded power of medical professionals; one includes going further in deconstructing the diagnosis to consider the ways in which medical conditions are socially produced by medical practice.

DECONSTRUCTING DIAGNOSIS

There is now a significant body of work examining the social and political complexity involved in defining new medical conditions and producing the criteria that fix the condition in the diagnosis encounter. Some of this work links back into sociological work examining the power and significance of labelling social problems.[31] This work has been taken up by disability studies as a way of understanding the power of the medical model.[32] The claim is that what makes an impairment a disability is the medical framework used by professionals to name and label it.[9]

This perspective is finding its way into contemporary analyses of childhood disabilities such as autism and ADHD.[33] Two examples are those of Rosenberg[34] and Molloy and Vasil.[35] Rosenberg takes a historical approach to examine the growth of medical explanations towards variation in childhood behaviour and other areas of human life. He places the individual diagnostic encounter in a context of medical frameworks and bureaucratic institutions that shape the reading of human variation within the structures of medical diagnostic criteria and treatment. Attention deficit disorder has served to ''naturalize and legitimate conceptions of difference and deviance''.[34] The disease category provides a framework for ''assimilating the incoherence and arbitrariness of human experience to the larger system of institutions, relationships, and meanings in which we all exist as social beings''.[34]

Molloy and Vasil[35] explore the development of Asperger syndrome as a diagnostic category. Their argument is that what was once seen as ''normal'' variation in neurological development in children is now labelled as a medical condition through the production of diagnostic criteria within the Asperger category. Once this category is attached to a child, those around him or her ''view the child's behaviour as symptoms rather than as expressions of his or her unique personality''.[35] Their central argument is that without a set of diagnostic markers, Asperger syndrome does not exist. Once it does it becomes a label through which children are classified as normal or abnormal in their development. Therefore ''AS is never simply located within the individual: no gene or discovery of different neurological 'wiring' arrangements will wholly explain AS''.[35]

The next question is what lies behind the ''discovery'' of particular conditions at particular points in time? From a sociological perspective the answer does not lie in the medical lab; rather it is linked to particular social, economic, and political conditions that help produce the quest for knowledge.[36] Hedgecoe[37] examines changes in definitions of cystic fibrosis in order to argue that the criteria have shifted from a series of symptoms towards identification of a genetic marker. His account concentrates ''on the discursive mechanics of knowledge production—how a particular position is made convincing''.[37] Conrad and Potter[38] examine how ADHD in the USA has moved from a childhood condition to one now being identified among adults and argue that:

> New diagnoses rarely emerge simply as a result of new scientific discoveries. Medicalization studies have demonstrated that agents such as self-help and advocacy groups, social movements, health-related organizations, pharmaceutical companies, academic researchers, and clinicians can be central in creating specific diagnosis.[38]

Like Arskey and others,[39 40] Conrad and Potter are interested in the role patients as individuals or through representatives (parents) or collectively (support groups) play in the medicalisation of social problems through advocating a medical explanation for their difficulties. Patients or the parents of patients may seek definitive diagnosis in the hope that it will provide a gateway towards medical and social service support and redefine their child from being a ''problem'' child towards being a child with a particular legitimate condition. Nevertheless as disability studies point out, this has also the implication of placing a medical explanation and solution at the centre of understanding the differences from ''normal'' behaviour their child presents. The work by Conrad and Potter is significant as it challenges the assumption made in some disability studies accounts, for example Molloy and Vasil, that only professionals have the power to label and name. That being said, Conrad and Potter do acknowledge that patients only become successful in labelling their condition in the way they wish when it is supported by medical actors who take forward the assertion and stabilise it in a set of diagnostic criteria.

Recommendations that can emerge from the work in this section are probably the most thought provoking and difficult for medical practitioners to contemplate. However, in some ways this is not true as clinicians are often more aware of the degree to which the categories and criteria within which they work are socially produced than social scientists give them credit for. The work here points to a wider responsibility among various professional and institutional actors involved in the treatment of children with disabilities, particularly in cases such as autistic spectrum disorder, to think through the social ramifications of the label that comes with diagnosis and to guard against viewing a child only through the medical meanings that such a diagnosis generates. It points

also to wider social responsibility to consider how we treat and stigmatise those, however young, who act and behave differently, whether in the classroom, playgroup, or supermarket, and whether understanding such children through the medical model is the only way in which we can comprehend and help them.

CONCLUSION

A range of social science perspectives are examining the social and human dimensions of diagnosis. There is further work and perspectives (for example, within psychology) than can be summarised here. The work that has been summarised points to both practical issues about everyday practice and also wider critical questions about how we think about and approach the meaning and processes contained within diagnosis. What the work seeks to capture is the depth and ambiguity involved in diagnostic journeys.

Dr Mclaughlin is currently working on an Economic and Social Science Research Council Project ''Parents, Professionals and Disabled Babies: Identifying Enabling Care'' (REF RES000230129) with Dr Emma Clavering (University of Newcastle), Dr Dan Goodley (University of Sheffield), and Dr Claire Tregaskis (University of Sheffield). The ideas summarised in this review are being further explored through ethnographic work with a group of parents with babies and very young children who have been diagnosed with some form of disability.

Competing interests: none declared

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