The child's world of illness

THE DEVELOPMENT OF HEALTH AND ILLNESS BEHAVIOUR

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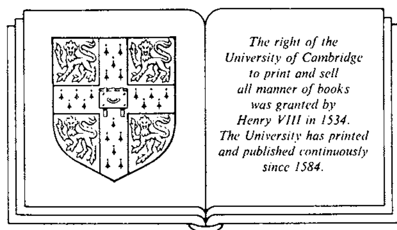

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1

Presenting a problem

From time to time we all have difficulties knowing how to be certain that another person knows what we mean. At times this is unimportant,but when we want a response from that person we need to know that they have understood. When it comes to complaining about our own discomforts, the uncertainty of knowing whether our message has been adequately received is pressing. It becomes an acute problem when we rest in hope that those to whom we have presented our discomforts will take what we feel is appropriate action to help us feel better.

Sometimes we have opportunities to appraise beforehand relative strangers who might help us. Children like to be familiar with teachers who might have to help them in a crisis. They have their own ways of finding out whether they could rely on them in an emergency. People can visit their future general practitioner before they register with a practice, although this is seldom encouraged. It is sometimes very difficult to find answers on such a preliminary visit, as we remain uncertain which questions to ask and uncertain to what degree we can rely on the answers we receive.

Whether the potential care-giver is a parent, doctor or teacher, the aim of a child often appears to be to find out what makes a difference to that person. 'Will he react to what is important for me or will I have to adapt to his way of doing things in order to be "heard"?' 'Is it even possible for me to work out how to be heard?' At other times the whole process of presenting the problem occurs intuitively without a conscious appraisal of the care-giver, instead relying on the experience that what has occurred before is likely to occur again. This is not to suggest that there exists some basic natural 'illness behaviour' which is revealed in such emergencies but that the way of presenting the problems reflects the well-tried methods of old.

People appear to have a very wide range of ways of making public their discomforts. Children are known to cry with pain and distress, throw tantrums and literally pull their hair out. At the moment I will loosely refer to discomforts rather than illness because I wish to stress that what

is conveyed is the state of the individual. I do this rather than moving on to discriminate between different forms of discomfort some of which will be interpreted as illness. The ways in which illness is deduced from children's behaviour will become clearer in the course of this book. Illness represents an *interpretation* of the child's state based on the observed behaviour. This point becomes particularly important when looking at how the states of young children are remarked on and responded to by the 'others' around them. The child's discomfort is first noted before the possible description 'illness' is applied to the child's state. With young children their states of discomfort are initially offered for public inspection rather than being presented in a direct way to another for consideration as a complaint. In a two-stage process the children are dependent both on others being observant, that is being cued in to observe their form of presenting their distress, and on these others recognising this as illness.

Mechanic (1962) introduced the term illness behaviour to account for 'the ways in which given symptoms may be differentially perceived, evaluated and acted (or not acted) upon by different kinds of persons'. He chose to use the word symptom. I interpret a symptom here as conveying something closer to an aspect of experience which has been recognised as a signal by that person. A symptom is a body 'state' which has been recognised as signalling something, whereas initially natural states of individuals need not necessarily have attached signalling properties learnt by the individual. In other words, how children have learnt to transmit their state is built onto a foundation of being with other people who noted their state before they had found significant movements or words to convey it to others. 'Symptoms' are the result of this dynamic developmental process (see also Mannoni, 1973 ch 2). It is this developmental process I hope to elucidate here.

In investigating the origins of health and illness behaviour it is necessary to go back to the perception of discomfort, back to before the time that children could overtly evaluate or act on it themselves. This would potentially involve going back to the stage when the states of young babies are 'perceived, evaluated and acted (or not acted) upon' by their parents. This is the time when the interpersonal dance is dependent on moderately accurate interpretation of the baby's state, and the baby has barely begun to develop a signalling system in response to the parent's handling (see chapter 2). Neonatal learning research suggests that some learning can occur before birth, so it will always be difficult to achieve observation of demonstrably naïve subjects. Here I am going to take up the story of the development of health and illness behaviour from the point at which children can first present and reflect on their views on illness – about 3 years

old. By this age they are discriminating the state of illness from that of health. It is from this point on that it becomes possible to carry out a verbal enquiry into both the nature of a child's discomforts and how he appraises them. Much learning has already preceded this stage.

It is particularly the verbal discussion of discomforts which lies at the core of a clinical consultation. In my clinical practice as a child psychiatrist my problem in that particular form of consultation is often how to facilitate children and their parents presenting their discomforts in a way which enables them to be shared – for the meaning of them to be understood by others. We know that the meaning of his illness affects the child's response to it (Willis, Elliott & Jay, 1982). An additional but related problem involves understanding how children and parents come to attribute intention in their individual ways to what they observe each other doing and experience being done to them. I will return to these elements later, particularly in chapter 8, for the effect styles of attribution of intention can have on the development of delinquent or illness behaviour.

The research which constitutes a large proportion of what I am presenting here arose from a need to know more about how people learn to present their discomforts, how their illness behaviour evolves both before the consultation and in the consultation. The behaviour patterns established in childhood are of great significance in the causes of disease and death occurring in later life (Graham, 1985). It is through an exploration of the origin of these patterns that I believe it possible to evolve better consultation practices; and so use the drug 'doctor' (Balint, 1964; see also chapter 9) as helpfully and effectively as possible. I will here concentrate primarily on what happens prior to a consultation but in chapter 9 make some suggestions about how these results can be used to review consultation practices. It will be seen that these suggestions lead naturally to integrating health education approaches into our daily life when listening to other people's problems.

When patients come to see me, they arrive with their own set of assumptions about what is likely to happen in the consultation. I approach the patient with my own set of assumptions – assumptions which I have not always made explicit to myself, and rarely made explicit to the patient. The differing expectations that are involved in the interview may lead to a clash of perspectives in which there is little mutual understanding of the other's position (HESU, 1982 p. 80), ineffectual communication (Mayer & Timms, 1969; Burck, 1978; Lewis, 1980), and, to borrow a phrase from family therapists, no engagement. The same can happen between parents and their own children.

Usually children are brought to consultations with doctors by their parents or care-givers. The adult who brings the child often carries assumptions about the aim of consultation (Stoeckle, Zola & Davidson, 1963) built up through discussion with others in the social network prior to making the decision to consult. The decision-making involved here uses what Freidson (1960) terms 'the lay referral system', and through this cultural values are mediated. Additionally the adult has ideas about what would be helpful for the child based on an opinion of what caused the condition and the appropriate remedy. The child has his own ideas about the nature of the problem which are likely to have developed from his experiences both at home and at school with his teachers and peers. They may not necessarily be the same as those of his parents and his parents may not both share the same viewpoint. In these circumstances a clash of perspective in the surgery may be just the start of a continuing process of discussion and negotiation on return home as the different family members and even neighbours make sense of the consultation from their own viewpoints (Stimson & Webb, 1975).

A clash of perspectives can occur at the many levels mentioned above. It can occur between adult and doctor, child and doctor, child and adult, or between children when they recount their experiences to each other. My aim here is to explore the child's world, so that it is possible to build up a picture of how the child sees illness, and the causes of illness in particular. The research was organised so that I obtained a picture of the child's world when it was uninfluenced by the circumstances of acute illness or hospitalisation, aspects generally controlled by adults. Causes of illness are commonly seen as central to the consultation, in the belief that understanding the cause will explain what should happen next and how the illness could be prevented in the future (Posner, 1980; Blaxter, 1983). A clash of perspectives about the cause of illness could be at the heart of a dissatisfying and unhelpful consultation, as constructs about the causes of illness have potent social organising potential. This relates to taking responsibility for one's condition. Pill & Stott (1982) pointed out that 'readiness to accept responsibility for one's health depends partly on the views held about the aetiology of illness'. It is these views that link lay illness models with the disease models attributed to professionals and leave people to varying degrees with a sense of their own effectiveness in combating illness and preventing it in the future.

An awareness of these issues seems to have moulded the conclusion presented in the Health Education Studies Unit (England) report with regard to the educatory potential of consultations. The first conclusion of

'The Patient Project' was 'that little attention was being paid to patients' ideas and theories and that this fact was a major barrier to successful educational outcomes of consultation' (HESU, 1982 p. 80).

Much of the child's behaviour when ill is determined by others rather than being moulded by the child. The youngest children are the most constrained within the limits set by their parents. What constitutes acceptable behaviour conforms primarily to the values of others rather than those of the children themselves. This balance in the importance of the values of the adult and child can be anticipated to change throughout development. The social pressures of others push the child into what has been termed a sick role whilst his own developing autonomous sense of how one is when ill leads him to present ever more forcefully his own illness behaviour within these role constraints. Instead of concentrating on observations of the child's behaviour when ill I will therefore concentrate on the subjective element for the child – how his views on illness become established and part of his own repertoire to be called upon in future consultations. My assumption here is that these views will come to occupy an ever more important place in determining the form of the child's illness behaviour as he grows up. Nevertheless the language he has developed for sharing his discomforts has been shaped by the dynamics of the responses made to him by important others. A study of the different origins of children's views will reveal how this balance between role, a social construct, and individual behaviour evolves. It appears to be linked to the developmental dynamic between individual and social factors in enculturation and socialisation.

This emphasis poses problems of methodology as children's views are initially very labile because more of their constructs, compared with those of adults, are loosely held (Bannister & Fransella, 1980 p. 30). Different views are elicited in different circumstances and are held with varying degrees of conviction. This appears to be necessary to cope with the lack of a coherent framework into which children can fit their experiences, and leads to a state of 'mental fluidity' (Tizard & Hughes, 1984 p. 131).

The children's constructs I will be describing here were dependent to varying degrees on the contexts within which I saw them. The children were seen in everyday settings such as home or school, rather than hospital or doctors' surgeries. The emphasis was therefore on the views which a previously healthy child might bring to a consultation, rather than how these views are modified by the sickness setting. It is the factors which will potentially influence illness behaviour that I want to elucidate rather than the social pressures to occupy particular sick roles.

Through looking at how a child's views on the causality of illness change, not just with context but also with age, a developmental perspective is added which can bridge the gap between the child's views and those of the adult. The developmental perspective emphasises the mixture of biological development, individual experience, social responses to the child throughout development and the transmission to the child of cultural values in his socialisation (Piaget, 1970). Nevertheless children of the same age are at different developmental levels due to variations along these different dimensions. A study of development emphasises the processes which affect their changing views to set beside the content of those views. It can be anticipated that a wide variation in the views of different children will be found, but that the developmental processes which affect the children will have much in common. It is these shared processes which I believe it is necessary to find in order to extrapolate the results of this research to other situations.

There is a continuous reciprocal interaction between the different elements in these processes: the biological, the individual psychological and the social. At the same time as the child's state is modifying the behaviour of others towards him, he is changing in response to the way he is handled by those same people. The ways in which adults communicate with children and facilitate particular forms of their communication mould the processes of this coevolution. A similar process must occur in the gathering of their views, and a 'clash of perspectives' could well have been the outcome in this research if it had not been possible for researcher and child to adapt communication patterns to each other. The ways in which such a clash of perspectives seems to have been avoided in the research reported here suggest some pointers towards how consultations can be as productive as possible for all involved. These are observations on the process of the research and how it can mirror the consultation process, the presenting of a discomfort to another, whereas the views obtained are the content of the discussion. I will return to this in chapter 9. Throughout the following presentation of the child's world of illness this mutual reciprocity and coevolution of process and content must always be kept in mind.

I am suggesting here a communication model of how illness behaviour is built up throughout development without having presented any evidence for why I believe this to be the case. I have so far begun to point out similarities between the form of communication in the consultation process and the research method. Additionally the interpretation of what constitutes a consultation can be broadened to include a child's 'consultation' with his parents – in other words to all situations in which there is presen-

tation of the child's discomforts and an associated expectation on his part that others will take some initiative on the basis of that 'consultation' to help him. For the youngest children that expectation is poorly developed, as that in itself is learnt on the basis of experience; but when studying verbal 3–4 year-olds it is in my view appropriate to use the term consultation. Some of the evidence for this assumption will be presented in chapter 4, 'The primary structure to the child's world of illness', where the ways in which children present their discomforts and have them evaluated by their parents are described. When consultation is seen to include what occurs with parents, similarities between processes in development, consultation with professionals and the research method become clearer. The 'processes' I refer to are the forms of communication.

Information on the development of communication is presented in chapter 2, which is the background for the intersubjective communication model I use and which links the form of communication in the consultation and the research to a developmental perspective. The fundamental principle in that presentation is that I allocate a primary role in the developmental process to intersubjectivity, rather than building up an ego psychology in which understanding is based primarily on individual qualities in the child or adult. Should this primary role of intersubjectivity be subsequently cast aside by future research then the results reported here will require a reinterpretation. Nevertheless I include a pointer in the review of the development of children's communication to illustrate how an ego psychology could develop from a primary intersubjective psychology.

Besides needing to illuminate communication processes for their effect on the *content* of children's views on illness as well as on the *form* of the consultation process, it is necessary to orientate the reader with reference to what is known so far about the nature of children's views on illness. Chapter 3 reviews some of the background research which illuminates such themes as how children view illness as being caused, and how these views are mirrored in the adult world to which they are becoming socialised. As I have described above, interpretation lies at the base of attributing the label 'illness' to particular forms of a child's behaviour. This means that adults are dependent on using categories from their own experiences and intuition to interpret the child's underlying subjective state: parents of young children use certain categories, and researchers use categories based on what is known so far about the nature of illness. I note particularly which categories from research on adults as well as children can be useful in building up an interpretative system which is coherent with the intersubjective framework I have adopted. My purpose is not to present a treatise

on child development and socialisation but to provide enough details to enable connections to be made with the literature.

I have mentioned the value of exploring the child's views on illness for the way in which they can help the consultation process. The last three chapters explore some of the implications of this intersubjective communication model. In chapter 9 the consultation process is considered in more detail, especially the implications of what is presented here for facilitating consultation. In this way I aim to widen the applicability of my observations of children. I suggest that it is to these consultation processes that psychotherapy directs itself in the establishment of an (as near as possible) 'ideal discourse' (McCarthy, 1973). The ideal discourse emphasises the intersubjective element necessary for elucidating the nature of a child's discomforts, but it does nothing to help develop expectations about what forms of presentation the child might use to describe his discomforts. It is to these expectations that the results presented here are also relevant. Knowing which views are typical of different ages allows a certain degree of identification with the child's position, but it must not be forgotten that one can never be certain that one knows exactly what is going on inside another person. This degree of uncertainty appears to be necessary for establishing the 'ideal discourse' in which there is enough respect for the uniqueness of each individual.

The positive value of uncertainty becomes clearer in the example of a communication analysis of 'pretend illness' states which constitutes chapter 8. In this detailed analysis of how a particular form of illness label can be attached to a child's behaviour I apply the rules for deciding about children's behaviour as deduced from my observations and described in chapter 4. Some of the implications that can follow should parents, teachers, doctors or others have diminished communicative competences in particular areas are then considered. This study was primarily observational and I did not set out to test these implications; this testing represents a necessary second stage in the research. All the time people are dependent on observations, interpretations and the testing of these, just as parents are with their children. Gradually though we can approximate our understanding to the child's state, and I hope the results presented here are a good enough approximation to the child's world of illness to be practically useful, both in consultations and in formulating models of illness behaviour to facilitate further research.

There remains one further application of these results, which I consider very important: knowledge of developmental processes can be used to produce strategies for health education and improve preventive medicine.

Chapter 10 describes some of these potential implications of my observations for health education strategies. These strategies are dependent on communication for putting over their message in such a way that the content is understood by the target population. That population must also have some desire to make use of the information. In this sense the model presented here should be suitable for reviewing both the strategies and content of health education. Currently it adopts a teaching approach which lends itself in some degree to a classroom but hardly at all to the mass media campaigns we are familiar with. It is essential to take into account the balance between social role pressures and individual initiatives when designing helpful health education campaigns. (It is with some care that I have chosen to use the word helpful in this context rather than effective, as I hope will become clearer in chapter 10.) Illness and sickness models are the appropriate ones for health education, yet information tends to be provided according to disease models (see pp. 37–39).

It is also necessary to direct information to people in age-appropriate ways. Different age groups differentiate between information which they interpret as being directed at controlling them (social information) and 'facts' useful for them personally (personal information) using various strategies. There must be awareness of how 'facts' are digested by particular age groups and differentiated from attempts at controlling their freedom. These communication aspects are ones already emphasised by the Health Education Studies Unit: 'The best interests of health education can be served by focusing attention on communication, and within that explanation' (HESU, 1982 p. 125). Additionally, more effective communication in consultations would, I believe, lead to improved consensus on treatment strategies and better patient cooperation (see also Millstein, Adler & Irwin, 1981). Although I tend here to look at what adults can do to facilitate things for children, it must not be forgotten that communication is a two-way process. Adults have responsibility for children, doctors have responsibility for the medical consultation, and those who have that responsibility must make certain that they carry out their duties as effectively and helpfully as possible. My hopes are that the research presented here will help communication between adults and children concerning health and illness matters.