

## HOW DO PEOPLE WITH A MILD/MODERATE MENTAL HANDICAP CONCEPTUALISE PHYSICAL ILLNESS AND ITS CAUSE?

Paul March

### Introduction

If we are to help a person with a mental handicap to recognise and communicate the signs of illness we must understand and give information in terms of that person's conceptual framework of illness. Surprisingly, a review of the literature reveals there to be no previous research in this field. Moreover, health education with people with a mental handicap has also been largely ignored as an area of research (Hauser, *et al.*, 1979; Noland, *et al.*, 1986). Noland *et al.* assert that both the quality and quantity of health education for people with a mental handicap should be improved. In addition, health education should use materials pitched at an appropriate level and which emphasise those health concepts that are most important to a special education student.

In contrast to the lack of information in the field of mental handicap, far more research has been published on how the concept of illness develops during childhood in the normal population

(Freud, 1952; Nagy, 1952; Brodie, 1974; Campbell, 1975; Myers-Vando, *et al.*, 1979; Caradang, *et al.*, 1979; Bibace and Walsh, 1980; Perrin and Gerrity, 1981; Millstein, *et al.*, 1981; Redpath and Rogers, 1984; Potter and Roberts, 1984; Eiser, *et al.*, 1988; Shagena, *et al.*, 1988; Siegel, 1988).

The present study uses the conceptual framework given by Bibace and Walsh (1980) which shows how a child's concept of illness changes as a function of developmental-cognitive maturity. They identified six stages through which a child's concept of illness passes as it develops (see Table I).

There are two problems with interpreting the findings of Bibace and Walsh. Firstly an ingenious experiment by Siegel (1988) demonstrated that children much younger than those predicted by Bibace and Walsh's model are capable of conceptualising illness in terms of contagion and contamination rather than magical thinking and punishment. Secondly, there is an assumption that by adulthood

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**TABLE I**  
**The Development of the concept of illness**  
(Bibace and Walsh, 1980)

**0. Incomprehension of questions.**

**Preoperational**

1. **Phenominism:** a child early in the preoperational stage attributes illness to external, concrete phenomena which have no spatial or temporal relationship to the illness such as the sun or God. A child at this stage cannot explain how these events or objects cause illness.

2. **Contagion:** a more mature child in the preoperational stage attributes the origin of illness to people or objects that are proximate but not touching the ill person. The child cannot describe the means by which contagion causes illness except by recourse to magical explanations.

**Concrete Operational.**

3. **Contamination:** a child at this stage can distinguish more clearly between itself and the external world. He or she is therefore able to differentiate the external cause of the illness from the manner in which it takes effect. The child understands the illness to be located in another object or person. The illness is transmitted by physical contact with that harmful object.

4. **Internalisation:** illness is now explained in terms of events that take place within the body although the ultimate cause may be located externally. The explanation remains vague with evidence of confusion about the function and location of internal organs.

**Formal Operational.**

5. **Physiologic:** a continued emphasis on the internal aspects of illness with a possible ultimate external cause. But the external explanations are now more specific and typically describe the illness as the result of a malfunction of an internal organ. Sequences of events culminating in the illness are often described.

6. **Psychopsiologic:** in addition to the understanding displayed at the physiologic level the person uses psychological explanations as an alternative or in conjunction with physical ones.

all people will understand illness in terms of the most complex stage. However, there is no evidence to support this assumption and it seems highly unlikely that all adults explain illness in terms of psychophysiological concepts.

Despite these difficulties, Bibace and Walsh's model does offer the best available explanation of most of the data from the normal population and it would

therefore be useful to examine the extent to which the model applies to the concepts illness held by adults with a mental handicap. The present study aimed to test the following three hypotheses.

1. A population of people with a mental handicap will show a range in the degree of complexity of their understanding of the cause of physical illness. Those

who are able to comprehend questions about the causes of physical illness will give responses which can be categorised as one of the six stages outlined by Bibace and Walsh.

2. The understanding of physical illness by a person with a mental handicap will be related to that person's understanding of physical causality in other areas. This hypothesis does not necessarily predict that a person's concepts of physical causality will develop at the same rate. Piaget (1929) suggested quite the opposite, saying, that tasks that involve abstract phenomenon such as concepts of illness will be particularly difficult to assimilate into the next developmental level. This phenomenon is known as "decalage" and it seems reasonable to predict that it will be evident in the present study.

3. There will be a correlation between the stage a person has reached concerning his or her concept of illness and that person's overall level of cognitive ability.

## **Method**

### *Participants*

The selection criteria for inclusion in the study were not rigorous. The only limitation was imposed by the need for participants to have some verbal communication ability. Likely participants were recruited as volunteers from a variety of settings, adult training centres, a group home and a college of further education. The final sample consisted of 54 adults (27 male, 27 female). Two subjects (one male, one female) failed to complete the interview and were rejected from the study. All participants lived in the com-

munity, in group homes, parental homes or hostels but a proportion had spent some years in institutions (three up to five years, and six more than five years). Their ages ranged from 23 - 51 years (mean 34.01; S.D. 7.68).

### *Measures*

Clinical interviews were used to obtain three measures of participants' concepts of physical causality. The interviews followed a model outlined by Laurendeau and Pinard (1962) and consisted of a predetermined set of questions followed by further questioning where the developmental level of the answer given was unclear. A similar experimental procedure was used by Bernstein and Cowan (1975) and Brewster (1982). In this study the following questionnaires were used.

- a. The Concept of Illness protocol (Bibace and Walsh, 1980)
- b. The traditional transformation of clay format as a measure of conservation of weight and volume.
- c. A measure of physical causality (The Origin of Night Questionnaire, Laurendeau and Pinard, 1962).

All three questionnaires were adapted for use with the intended population. They were then administered to six subjects as a pilot study in order to ensure that the questionnaires were comprehensible and that they produced responses that could be discriminated between.

The answers obtained from each measure were scored on a seven point

scale from zero to six, with zero representing apparent incomprehension of questions, one representing the least developed and six the most developed concept. (See Appendix A for scoring criteria). Participant's answers were

scored by two independent raters (see Table II for reliability coefficients). The Raven's Coloured Matrices (RCM) was also administered to each subject (Raven *et al.*, 1984).

**TABLE II**  
**Inter-rater reliability for the Concept of Illness (COI) Conservation of Weight/Volume (COW) and Origin of Night (OON) Questionnaires.**

	Percentage Agreement
COI	71.15
COW	80.77
OON	69.23

### *Procedure*

All participants were interviewed individually either at the participant's daytime placement or at home. The illness questionnaire was given first followed by the other three tasks in random order. The interviews lasted between 30-60 minutes with the more verbal participants usually taking longer.

## **Results**

### **Quantitative Analysis**

#### *Hypothesis 1*

Table III shows the spread of scores for each of the three questionnaires. On the concepts of illness questionnaires most participants scored between zero and three (incomprehension, phenonomenism, contagion and contamination). Only one participant scored 4 (internalisation) and no one scored 5 or 6 Physiological and psychophysiological).

Table II showed that in 71% of cases the raters agreed on each participant's score for the concept of illness questionnaire. This degree of reliability demonstrates that the questionnaire distinguished between real, qualitative differences between answers. The raters did however have difficulty in categorising the responses of 12 of the 52 subjects (23%).

#### *Hypothesis 2*

There was found to be a significant correlation, as measured by the Spearman Rank Correlation Test between scores on all three questionnaires and when intellectual ability was partialled out (Table IV). However, when those participants who scored 0 in one or more of the questionnaires were not included in the analysis then, in most cases correlations did not reach significance (Table V). As for evidence of "decalage", the

**TABLE III**  
**Absolute and percentage frequencies of scores on the**  
**COI, COW and OON questionnaires.**

Questionnaire	Score	Frequency	Percentage
COI	0	14	26.9
	1	11	21.2
	2	16	30.8
	3	10	19.2
	4	1	1.9
	5	0	0
	6	0	0
COW	0	21	40.4
	1	18	43.6
	2	5	9.6
	3	4	7.7
	4	4	7.7
	5	0	0
	6	0	0
OON	0	15	28.8
	1	14	26.9
	2	5	9.6
	3	9	17.3
	4	7	13.5
	5	1	1.9
	6	1	1.9

**TABLE IV**  
**Spearman Rank Correlations between scores obtained on the COI, COW and OON**  
**questionnaires and Raven's Coloured Matrices (RCM). Correlations with the effect of**  
*intellectual ability partialled out are contained in brackets. One tailed tests.*

	COI	COW	OON
RCM	.61 P < 0.001	.31 P < 0.05	.37 P < 0.01
COI		.46 (.38) P < .001 (.01)	.55 (.37) P < .001 (.01)
COW			.48 (.43) P < .001 (.001)

**TABLE V**  
**Spearman Rank Correlations between scores obtained on the COI, COW, OON questionnaires and RCM with participants scoring 0 on one or both questionnaires in each comparison excluded from the analysis. Correlations with the effect of intellectual ability partialled out are contained in brackets. One tailed tests.**

	COI	COW	OON
RCM	.46, N = 35 p < .01	.22, N = 31 p = .12	.09, N = 34 p = .32
COI		.28, N = 26 p = .08 (.21, n = 23) (p = .15)	.18, N = 32 p = .15 (.04, N = 28) (p = .41)
			.45 N = 26 p = .01 (.45 N = 23) (p = .01)

median scores of the three questionnaires were as follows (means in brackets); Concept of illness = 2.00 (1.487), Conservation of weight and volume = 1.00 (1.007) and Origin of night = 1.00 (1.731). A comparison between scores was made using a Friedman two-way ANOVA which gave a Chi-square score of 5.2596 (p = 0.0721). A series of Wilcoxon Signed

Rank tests (see Table VI) showed there to be a significant difference between the scores obtained on the conservation of weight and those on the concept of illness and origin of night questionnaires. However the evidence is equivocal because the analysis included participants who scored zero.

**TABLE VI**  
**Comparison between scores obtained on the COI, COW and OON using a series of Wilcoxon Signed Rank Tests. One tailed Tests.**

	COI	OON
COI	z = 2.41 p < .05	z = 1.12 p = .26
COW		z = 2.92 p < .01

### *Hypothesis 3*

Table IV shows a significant correlation between scores obtained on the Raven's Coloured Matrices and the Concept of Illness questionnaire. The correlation remains significant with the exclusion of participants who scored zero on either of the tests.

### *Other Statistical Tests*

A series of Mann Whitney U tests showed there to be no significant effect of sex or time spent in an institution on the scores obtained from any of the questionnaires or the Raven's Coloured Matrices and a Spearman Rank correlation showed there to be no significant effect of age on the scores obtained from the questionnaires.

### *Qualitative Analysis*

#### *Hypothesis 1*

The responses by the students to the Concept of Illness questionnaire broadly fitted Bibace and Walsh's developmental sequence. However, relatively few participants' responses fell into the category of phenomenism. On the other hand, a number of participants gave descriptions of an illness in answer to a question which clearly showed that they had understood the question but gave no opinion about causation. For example

What are measles?

They're chicken spots.

How do people get measles?

They get spots on their back and their front - a rash.

What gives them the rash?

Could be the spots. They're all prickly.

Most participants responses were found to be the products of either the contagion phase e.g.

What's a cold?

When you keep on coughing, like the flu.

How do people get colds?

Sitting in the draught. If you go into a cold bathroom, that brings on a cold.

or the contamination phase e.g.

Were you ever ill?

Sometimes I get a pain and a headache.

How do you get ill?

From being in the sun too much in the summer. The sun goes in my eyes and I get too much sun burn.

There was only one subject whose responses were judged to be within the internalisation phase. The following is an example of one of his answers.

What is cancer?

It's a disease. My dad died of cancer . . . he got it from asbestos . . . He died of asbestos. It gave him a tumour on the lung. His stomach went all hard and it swelled up.

Although participants tended to be quite knowledgeable about the names and uses of medication, the impression given by many of their responses was that their grasp of the vocabulary of medicine belied a rather less well advanced concept of illness. For example;

What are germs?

They're a disease or something. Sometimes you get them from animals. They're a virus.

What do they look like?

Like human beings . . . (placing their hands about half a metre apart) . . . they're about this big.

Some participants, who appeared to have an idea of the process of infection, when questioned further were found to be merely repeating well learned phrases with little understanding of the concepts involved. For example, many participants' understanding of the word germ was restricted to the ritual of washing their hands before a meal;

(germs) lie around . . . if you don't wash your hands before you cook then germs go into the food and people are ill.

How do people get ill?

By not washing their hands.

#### *Other Findings*

Illness took a very similar course in the eyes of many of the participants. Twenty two gave a variation of the following example which was recorded during the 1989 ambulance drivers' strike.

You go to hospital by ambulance. Dad goes to phone the ambulance but they're on strike so you go to the doctor who says he'll give you something for the pain.

Many participants had experiences of a relation, usually their mother or father dying from a heart attack or cancer and some were quite upset by questions about these diseases. Of the 22 subjects who comprehended and answered the question, "What is a heart attack?" 31.8% indicated by their answers that they saw

a heart attack as synonymous with death. A similar pattern was found when subjects were asked about cancer e.g.

What's cancer?

That's when you die. You're put in a coffin and they bury you.

Of those subjects who cited a cause for cancer or heart failure, the majority cited a single factor which they regarded as being entirely responsible for the diseases. This was invariably either smoking, drinking alcohol or eating too much unhealthy food. Often it was implied that to engage in any of these activities would inevitably lead to a heart attack or cancer e.g.

1. A heart attack - a sudden shock, feel throbbing . . . when somebody's dead. . . they eat the wrong sort of food.
2. Sugar gives you a heart attack.

#### **Discussion**

The findings from the study demonstrates that the concepts of illness held by people with a mental handicap and some verbal capacity can be broadly understood in terms of the first three of Bibace and Walsh's six stages. However, there was a marked tendency for illness to be related in terms of descriptions of observable symptoms and behaviour rather than explained in terms of cause. These participants had clearly comprehended the question but as far as they were concerned, knowledge of the course of illness was sufficient explanation of its cause.

The study showed a significant correlation between the complexity of illness concept and intellectual ability as measured by the Raven's Coloured Matrices. However, the study only provided equivocal evidence for the existence of "decalage" and for a correlation between peoples' concepts of illness and physical causation in other areas. The poor sampling procedure employed in the study is responsible for these confused findings.

More generally, there was recognition by some participants that an illness was often accompanied by a change in role. Indeed, nearly half the participants gave virtually identical descriptions of the course of illnesses, which incorporated the notion that ill people became the passive recipients of care. Very few participants saw anything but a full return to health as the eventual outcome. This view contrasted with the experience and conception that many of the same participants had of specific, serious illnesses such as heart attacks and cancer, many of whom saw them as synonymous with death. This split seems to indicate an unwillingness on the part of participants to see the outcome of illness as uncertain. Illnesses were divided into those from which one always recovered and those from which one always died. This fatalistic notion that the outcome of all illness is predetermined might cause people to be unresponsive to suggestions concerning treatment and prevention regimes.

#### *Implications for Clinicians*

This study has implications for action both in the area of prevention of illness, particularly the content of health

education programmes and in the area of communication with people concerning their treatment if they become ill.

#### *Prevention*

The study illustrates a central problem for staff running health education programmes for people with a mental handicap. Many illnesses, such as heart diseases have complex aetiologies and yet many of the participants in such programmes are likely to be able to understand illness in terms of only a single cause. If staff attempt to fit the programmes to the understanding of the students they run the risk of severely misrepresenting the cause of illness and possibly causing unnecessary distress. For example, if a person with a mental handicap is told, in a health education programme that heart disease is caused by eating too much fat, he may end up fearing that every mealtime he/she is dicing with death. The problem is compounded by the finding that adults with a mental handicap tend to be fatalistic about the outcome of illnesses. There is no straightforward solution to the problem but as a first step health workers might tackle the difficulties that these people experience in understanding that a single illness may have a number of causes, and to convince them that, far from the outcome being predetermined, their own actions can play a positive part in preventing illness and aiding recovery.

The study did demonstrate how difficult it is for people with a mental handicap to relate an illness to a specific dysfunction within their bodies. Given that the structure of the inside of the

body is to some extent abstract, it will be difficult for people in the concrete operational stage of development to comprehend. However, anatomy can be made concrete by the use of models and photographs. Use of such aids would appear to be particularly useful with this group.

### *Treatment*

The study demonstrates that verbal adults with a mental handicap can talk about their illnesses and, if prompted can give information about their symptoms. There are two reasons why it would be worthwhile examining individual's explanations of their illnesses. In the first place these explanations often reveal anxieties that have no basis in fact and which could therefore be dispelled by offering information. In the second place information can then be passed back in terms that the person will understand. The importance of good communication has been amply demonstrated by Ley (1989).

Given the finding that participants tended to conceive of illness as a course of external, visible events rather than in terms of internal, physiological changes, it might be useful to explain to patients, when possible the symptomatic course of illness, what they are likely to experience happening to their body, and how they should behave at each stage. This might help to reduce anxiety about odd and otherwise inexplicable changes in their bodies.

It is also important to remember that participants tended to see the course of an illness as invariant and many had enormous faith in the powers of medica-

tion and medical interventions in general. This bodes well for a strong placebo effect but if expectations are unrealistically high it will inevitably lead to later disappointment. It may therefore be necessary to reduce patients' expectations to the extent that they remain optimistic, but within the bounds of possibilities.

### **Summary**

The range in understanding of the causes of physical illness displayed by children and adolescents of normal intelligence can be categorised within a developmental sequence comprising six stages. This study examined whether adults with a mild to moderate mental handicap and some verbal ability understand illness in ways that are open to similar categorisation. The findings have a number of implications regarding how information about physical illness should be communicated to people with a mental handicap.

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## Appendix A

Criteria for Scoring the Concept of Illness Protocol. Origin of Night Questionnaire and Conservation of amount and Volume Tasks.

### Concept of Illness Protocol

#### 0 - Incomprehension of Question

1 - Phenomenism. Illness caused by external, concrete phenomenon which have no spatial or temporal relationship with the illness. No explanation of the manner in which the phenomenon causes illness.

2 - Contagion. Illness caused by people/objects that are proximate but not touching the ill person. No explanation of means by which contagion causes illness except by recourse to magical explanations.

3 - Contamination. Can differentiate the external cause of illness from the manner in which it takes effect. The illness is located in another object/person and is transmitted by physical contact with that object.

4 - Internalisation. Illness explained in terms of internal events with ultimate cause external. Explanation vague with confusion about function and location of internal organs.

5 - Physiological. Emphasis on internal aspects but more specific. Illness typically described as the result of a malfunction in an internal organ. Sequence of events culminating in illness often described.

6 - Psychophysiological. Can now use psychological explanations as an alternative or in conjunction with physiological ones.

#### Origin of Night Questionnaire

0 - Incomprehension.

1 - Night exists because it is useful for self/humans e.g. it is dark so that we may go to sleep.

2 - Night is brought about by artificial means e.g. God calls the dark or the weatherman makes it dark.

3 - Pseudo-physical explanations. Natural elements cause the night but they are personified e.g. the moon opens his eyes and blows the sun away.

4 - Incorrect physical explanations with elements of personification remaining.

5 - Essentially correct physical explanations but elements of personification remaining.

6 - Correct physical explanations.

#### Conservation of Amount and Volume Task

0 - Incomprehension/totally incorrect

1 - Incorrect answers with perceptual explanations e.g. it looks bigger, it is larger.

2 - Satisfactory explanations on one but not both conservation of amount tasks.

3 - Conservation of amount on both tasks with adequate explanations. No conservation of volume.

4 - Correct predictions of water height but explanations on a concrete level. e.g. it will rise the same height because it is the same amount.

5 - Correct predictions but adequate explanations in only one of the volume tasks.

6 - Conservation of amount and volume with explanations reflecting the fact that volume is preserved despite transformation in appearance.