

The perspective of children

Development of children's conception of illness

Child and youth psychologist Hendrik Koopman obtained his doctorate in 1993 with a thesis on how children perceive and conceptualize illness. In 1997, he wrote an article on this subject in *Kind en Ziekenhuis*. According to Koopman, preparing a child can only be successful if care providers convey their message in a way that relates to the vision that the child in question has of his or her own illness. The development of children in their thoughts about illness can be demonstrated in a model.

It was a beautiful, sunny, winter's afternoon in February 1981. Two doctors came into the room and asked me how they should break the news to a boy of twelve, who had been admitted to the Buitenkliniek of the Leiden University Hospital in Noordwijk, that he did not have much longer to live. During the exchange of views that followed, certain problems came to light, such as: what should he and should he not (yet) be told; how much detail should the doctor go into in terms of the physical background; what information does he need to be able to understand his situation? I had to admit that I could not give a clear-cut answer to these questions. A sense of malaise persisted within me since that day. Attempts to gain an insight into the thought processes of children in regard to illness had largely foundered. The literature in this field focused primarily on the emotional responses of children prior to, during and after hospitalisation and on the possibilities for dealing with, or better still, preventing these responses. It became evident that very little was known about the cognitive aspects of how children perceive illness. It was found, for example, that many information leaflets had been written on the basis of working in practice with children. There was a distinct lack of

attempts to formulate more general theoretical principles.

Why, what, how

An exception to this was an academic article on children's conceptions of illness by Roger Bibace and Mary Walsh in the journal *Pediatrics* (1980). They built on the foundations of the Piaget theory. Piaget's theory provides a framework for describing the development of a child's thought as he or she gets older. The child's attempts to gain an understanding of and control over the world around him are central to this theory. In this regard, Piaget makes a distinction between a number of developmental stages in thought:

- the sensorimotor stage (from birth to around two years old);
- the pre-logical period (2-7 years of age);
- the concrete-logical period (7-11 years of age);
- the formal-logical period (11+).

Bibace and Walsh used this classification as a basis for determining their own model of the different stages in relation to children's conceptions of illness. In order to establish this model, they collected data by means of conducting interviews with children. 'Why, what and how' were the recurring core questions in relation to the subjects of *Own illnesses*,

Illness of a loved one, Pain and Colds. The children were first asked to describe an illness. They were then asked to give explanations for the cause of the illness. Finally, they were asked for their insights into the possibilities for curing the illness. Bibace and Walsh's stage model was then adapted by me and presented in a uni-dimensional model, the so-called *Kijk-model* [View Model].

Incomprehension

According to the View Model, the first stage in the development of conception about disease is characterised by incomprehension. This stage coincides with the sensorimotor stage of general cognitive development within Piaget's model. At this stage, children are not concerned with the whats, whys and hows of the illness. In most cases the child would not respond to the content of the question. The answer given would be an association from the child's own experiences.

Example (1): how do you catch a cold?

'A cold is what you get on holiday. I once threw up and my two brothers have also been sick in bed before when they were little.'

Detachment

The second stage concerns detachment. This stage coincides with the pre-logical period of Piaget's model. During this period, illness is defined by an external event that has attracted the attention of the child. The event may be a sound or an observation. The causal link between

the event and the question more or less comes down to chance. In some cases, magical aspects play a role. The child's thoughts focus on a single aspect. The child is unable to sufficiently differentiate between his or her own body and the external world.

Example: how do you catch a cold?
'If you leave the window open, then your sheets get very cold and that can make you a bit ill.'

Proximity

In the third stage, which also falls within the pre-logical period, the concept of proximity plays a prominent role. The child now describes and experiences illness in terms of persons, objects and events from their immediate environment. People become ill as a result of infection by other people in proximity to them. The child will always lay emphasis on spatial or temporal proximity. The child sees himself as a victim of events that overcome him. In this stage, the descriptions of the causes become clearer and less vague.

Example: how do you catch a cold?
'Well, for example when somebody else has a cold and you get close, and the next day she is better and you have a cold.'

Contact

The fourth stage is characterised by contact. This stage falls within the concrete-logical period of conception. The child is not yet capable of differentiating between mind and body. Both aspects can play a role in causing an illness. The definition of disease is becoming more extensive and can include various symptoms. Bad behaviour, just like contact with dirt or germs can cause illnesses.

Bodily functions are included in the explanations about illness, particularly the functions that are observable from the outside. The source of illness is often physical contact. The illness can be cured by means of medication that is applied to the surface of the body.

Example: how do you catch a cold?
'Well, when you sneeze really hard, little drops land on your face and there are germs in there that make you ill.'

Internalisation

In the fifth stage, which also falls within the concrete-logical period, the concept of internalisation is established. For the first time, the child (roughly) looks within the body for a possible cause of a disorder.

The child identifies an external contaminant (such as smoke, germs) or an unhealthy physical condition (obesity, high blood pressure) as the source of illness. These factors have a direct effect on the organs within the body. According to the child, the illness can be cured by means of medication which must be ingested. It is during this stage that the child first discovers his or her own role in combating illness. Illness can, for example, be prevented by taking the proper precautions. It is also during this same stage that analogical reasoning develops (the heart as a pump, the stomach as storage place for food).

Example: how do you catch a cold?
'When you cough, those germs go through the air and someone else can breathe them in and then I think it gets into your blood. Then you also get a cold.'

1. The examples originate from the author's own research conducted among chronically ill children and healthy children.

Physiological

In the sixth stage, which corresponds to the highest development stage of conception, namely the formal-logical period, the statements can be substantiated by physiological explanations. The child can describe and explain the occurrence of an illness in terms of organs and organ functions within the body. Structures and effects that are not directly visible can be described. The child is capable of constructing hypotheses on the relationship between the environment and the body. Associations can also be made with causes of an illness. There is a growing awareness of control over the development and curing of illnesses. The child realises that his own actions can substantially influence the final outcome.

Example: how do you catch a cold? *'Well the germs get into your blood and the white blood cells will fight them and try to kill them but if they lose you will get ill.'*

Psycho-physiological

The seventh and final stage of this sub-classification, which also coincides with the formal-logical period, is characterised by psycho-physiological insight (body and mind).

The child is now capable of including the role of the mind in explanations concerning the development of disease. He or she has a growing awareness of the fact that a person's thoughts and feelings can influence and change bodily functions. Physiological components are the principal cause of the development of an illness, but the role of the mind is also of importance. A person's thoughts and feelings can also have a significant influence on their recovery.

Example: how do you catch a cold? *This can happen in various ways. Sometimes a cold is not so bad. It depends on how you feel.'*

Television

The View Model is an attempt to map out the development of children's conceptions of illness in a comprehensible manner. It is however possible that variables other than age and the associated cognitive maturation may influence the development of children's conceptions of illness. Firstly in this regard, the *history of illness* of the child can affect this development. Furthermore, *television* plays a significant role. Children aged between ten and thirteen years were given health-related advertisements to watch. Almost half of all the children believed the advertisements that were shown to them. This influencing effect was particularly perceptible among the younger children and children from less privileged social backgrounds. The television was found to be the most significant source of information for all age groups (approximately half), followed by information from parents (approximately a quarter).

The literature in this field presents a diverse range of views and research results on the influence of the *family* on children's conceptions. The role of the mother cannot be interpreted without ambiguity. A child with a mother who has an over-protective attitude in terms of illness does not necessarily develop the same or opposing ideas. The ideas of the mother in relation to illness are not necessarily indicative of the ideas of the child. The older children become, the more their explanations tend to resemble those of their mother's. In other words: their conceptions of

illness become increasingly similar to those of adults. Therefore, children do not learn about illness as a result of adults directly passing on definitions and values, but more as part of the general process of socialisation involved in becoming an adult. Children learn more from what their parents do and how they react than from their attitudes. If the parents have a higher *level of education*, this aids the development. A child's *social background* has also been found to have an influence on children's conceptions of illness. Children from higher social classes take a more individual and a less passive standpoint in their views on the causes of illness.

Feelings of guilt

Children in the first five stages of the View Model often think that an illness or admission to hospital is a punishment for bad or excessive behaviour. For them, it is not important whether the actions in question have taken place in reality or in their imagination. In this belief, they differ very little from their ancestors who regarded illness as a punishment for the collective or individual sins of man.

Research conducted as early as 1936 showed that ninety percent of children believed that their illness was a result of their 'bad' behaviour. Eighty-five percent of the children with diabetes said that they had eaten too much sugar and ninety percent of children with heart problems believed that they were ill because they used to run too much. Many authors over the years have established that children have a tendency to blame themselves for an illness. This trend can even be identified among children with congenital disorders.



Margreet van Bergen-Rodts

Children are not concerned with the whats, whys and hows of the illness

The fact that the child forms the idea that he or she has fallen ill because he or she has done something wrong is probably a defence mechanism. Feelings of guilt can help the child to cope with an emotion, such as helplessness. It appears that children (for the most part unconsciously) prefer to hold themselves responsible instead of admitting that illness can be caused by chance and that nothing can be done to prevent this.

Warnings

A possible explanation for this way of thinking lies in the fact that the cause of the illness is usually not clear to children. It is therefore

natural for the child to implicate his or her own actions in an attempt to understand and explain the illness. Thoughts of guilt in children can, for example, originate as a result of a method of communication used by adults. Warnings from parents reinforce every latent fear that the child may have, that becoming ill is a form of punishment. A cold develops because the child disobeys instructions and does not want to wear his boots. A bone gets broken because the child does not take heed of his mother's warnings not to roller skate on the street. An upset stomach could have been avoided if only the child had eaten what was expected

of him. Poor eyesight is caused by reading small text, reading in bad light or persistently reading comic strips. These warnings about what can happen are often accompanied by the remark: 'I told you so' when something actually happens to the child.

Punishment

Children can also regard examination procedures or treatment as a punishment for bad behaviour. Healthy, non-anxious children dismiss the possibility that poor behaviour can cause illness. Ill and anxious children on the other hand use this type of explanation more frequently and over a longer period and do

The development of children's conceptions of illness

Stages	Age	Conceptions of illness	Example question: <i>how do you catch a cold?</i>
Stage 1: incomprehension	0 – 2 years	At this stage, children are not concerned about the whats, whys and hows of the illness.	'A cold is what you get on holiday.' 'I once threw up and my two brothers have also been sick in bed before when they were little.'
Stage 2: detachment	2 – 7 years	Illness is defined by an external event that has attracted the attention of the child. The causal link between the event and the question more or less comes down to chance.	'If you leave the window open, then your sheets get very cold and that can make you a bit ill.'
Stage 3: proximity	2 – 7 years	The child describes and experiences illness in terms of persons, objects and events from their immediate environment. People become ill as a result of infection by other people in proximity to them. The child sees himself as a victim of events that overcome him.	'Well, for example when somebody else has a cold and you get close and the next day she is better and you have a cold.'
Stage 4: contact	7 – 11 years	The definition of disease is becoming more extensive and can include various symptoms. Bad behaviour, just as contact with dirt or germs can cause illnesses. The source of illness is often physical contact.	'Well, when you sneeze really hard, little drops land on your face and there are germs in there that make you ill.'
Stage 5: internalisation	7 – 11 years	The child looks within the body for the cause of a disorder. The child discovers his or her own role in combating illness (ingestion of medicines). Analogical reasoning can be understood (heart as a pump).	'When you cough, those germs go through the air and someone else can breathe them in and then I think it gets into your blood. Then you also get a cold.'
Stage 6: physiological	11 years and above	The child can explain the occurrence of an illness in terms of organ functions within the body. Growing awareness of control over the development and curing of illnesses.	'Well the germs get into your blood and the white blood cells will fight them and try to kill them but if they lose you will get ill.'

make a connection between illness and poor behaviour or carelessness. A child's conceptions of the causes of illness change when the child himself becomes ill. It also makes a difference whether the conceptions concerned relate to the child's own illness or that of another. It has been found, for example, that children who do not have diabetes frequently attribute the disease to a person's own actions (eating too much, drinking too much, too much sugar), whereas children with diabetes are more likely to put the cause down to chance. The danger of emphasising the child's own actions as a cause of an illness is that this can amplify the feelings of guilt that the child may experience upon developing that illness. After all, they will think that the illness could have been prevented. As far as adolescents, and certainly adults, are concerned, it is increasingly taken for granted that their conceptions of illness are commonsensical and rational in nature and are not clouded by feelings of guilt as a result of their own actions. Phenomena such as self-blame and egocentrism, however, have been found to arise among even the most intelligent of children. For example, a twelve-year-old leukaemia patient said: 'I know that the doctor has told me that my illness is caused by too many white blood cells, but I still wonder whether I got it because of something that I've done.' It is also often the case that the conceptions of adults are to a significant degree influenced by thoughts of guilt. 'Searching for meaning' is characteristic of the way in which many parents deal with their situation. In their search for an explanation for their child's illness, many parents place blame on themselves.

Organs

One of the most striking characteristics of the View Model classification is that the use of physiological mechanisms as an explanation for the cause of illness only comes into play in the formal-logical period (aged eleven years and above). The information in the literature available on this subject largely supports this assumption. Among children aged from five to eighteen years, who have been admitted to hospital for various reasons, the five most frequently named internal parts of the body are: bones, veins, the heart, blood and the brain. Many children name organs that are associated with their illness or operation (appendix, tonsils). There is often some confusion about the correct number of certain organs in the body (for example, two livers). Children under eight years of age are commonly of the opinion that the skin holds the body together, so that the blood cannot fall out (compare: fear of certain medical operations). Children's ideas on the structure of the body and the functioning of organs and organ systems are for the most part vague, incomplete or even absent altogether. It has been found that children aged five to twelve years are generally capable of indicating the correct location of the brain. Young children, however, believe that the brain only has a function in mental processes. They do not consider that the brain could also be involved in motor function and believe that arms and legs move by themselves. Only half of the children realise that the brain is involved in activities such as swimming. The others appear to believe that their arms and legs swim of their own accord. Young children have little to no

knowledge of their body, except for what they can see for themselves or in relation to what they have consumed. Their drawings of the body often include the stomach containing all the things that they have eaten (unchanged in terms of consistency). There is a fixed order in which children acquire knowledge of the insides of the human body. First they obtain knowledge about the heart, then the brain and the stomach, and later the lungs. Just as with adults, knowledge of other organs, such as the liver, pancreas, kidneys or bladder, remains relatively small.

Processing

Knowledge of the development of children's conceptions and perceptions of illness is an important condition for being able to treat children in an appropriate manner. With this knowledge, the care provider (or parent) will be able to connect with the child more easily and will be in a better position to ascertain what can and cannot be said to the child. With regard to the form, organisation and content of knowledge and the transfer of information, children continually have to make choices about what is relevant and has a function in the management and treatment of an illness or disorder. It is insufficiently clear from the literature in this field as to when children should be informed about a chronic illness. In general, information is given to the child without any knowledge of his or her current illness behaviour or reactions to his or her medical situation. Likewise, it is often not known whether the child has already been given information, in whatever form, about his or her illness, or what the child's family situation is. Other

characteristics are also frequently unknown. It is advisable to take into account the stage of information processing in which the child is presently engaged in respect of his or her illness. Education at the onset of the illness should remain limited to the most essential information. The View Model demonstrates the undeniable importance of re-education.

Dialogue

Furthermore, the focus must be on informing the child by means of an exchange of information (dialogue) as opposed to a one-sided statement of details (monologue). It is more important for the care provider to listen to and understand what the child says than it is for the child to listen to and understand what the care provider is telling him. In order to achieve an effective approach, the gathering of information must precede the provision of information. It is important to tailor the information to the child's stage of thinking in relation to the subject of illness. The terminology must be carefully selected (consider whether words have double meanings). The information provided should preferably already be partly familiar to the child and only partly new. A child has difficulty in understanding the reason for a prescription if it concerns an internal bodily process. Only around the age of 11 years, when the child is capable of understanding bodily processes (stage six), can an attempt be made to inform the child at an 'adult' level. Knowledge on insight and practical consequences for the treatment must be assessed on a regular basis.

Observation

Observation is a determining factor in the thought processes of children.

In general, observation of the causes of illness is initially principally directed towards the outside world and external conditions (exogenous). This manifests itself among other things in children's behaviour and the way in which they react to illnesses and admissions to hospital. As the development progresses, the child obtains the ability to use information from his observations in a reflective manner to form an understanding of the illness, to distance himself from direct observations and to incorporate the internal functions of the body in the explanations (endogenous). Observation can be regarded as a cognitive system because it partly determines how the area for attention is perceived. Observation is initially global, whereby the undifferentiated whole dominates. This is followed by an analytical stage, whereby observation is selectively focused on components. The final stage is synthetic, whereby components are combined to form a whole.

Aware

This classification can be applied to the progress of the development processes in conceptions of illness. The research data indicate that it is relevant to give observation a more central place in the original stages model. Based upon the perspective of the View Model, a process can be described whereby the child, via characteristic stages, is finally able to differentiate between several aspects at the same time in his explanations of the cause of illness and to also implicate the role of the psyche in these explanations. The child gradually becomes more aware of the internal functions of his body. Observations become more differentiated and descriptions increasingly

resemble adult views. The highest thinking stage does not always have to be achieved, as is evident for example from research conducted among mothers.

By means of this View Model, the explanations of children can be interpreted in a more generally applicable manner. Possible causes of an illness are associated ever more closely with the body and ultimately internalised. The model has a sort of general universality and progression through the stages takes place irrespective of the illness and variations in personal development and circumstances.

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