

The parental role in illness representation among children

28 Gennaio 2021
AA. VV.

Abstract

Researchers have proven interest for the way children perceive and represent illness, especially in terms of the implications upon the quality of life and the treatment adherence among children with an illness. Our purpose is to summarize information concerning the theoretical model according to which we can study illness representation among children, with a focus on the sources providing children with the information that organizes the contents of this concept. Parents – who are generally also the main carers of the child – have the most important responsibility because their own information and beliefs have a significant impact on the way children represent the disease to themselves. When a parent decides to talk to the child about the diseases, it is recommended for said parent to be very well informed, to discuss with the child as honestly as possible and to make sure all questions get an answer.

The parent must also ensure emotional support, by making the child feel secured and accepted.

Table of Contents:

- 1. Parental representation of the paediatric disease**
- 2. Illness representation among children**
- 3. The sources of information contributing to outlining illness representations among children**
 - 3.1 *The parental role in outlining illness representation among children***
- 4. Conclusions**

- 1. Parental representation of the paediatric disease**

The prevalence of chronic diseases among children is rising [1]; every 3.5 minutes, a parent is told that their child has a serious chronic medical illness, disability, sensory impairment or mental retardation [2, 3]. Such news determines a significant impact on the entire familial system, as the parents experience intense reactions of shock, panic, rage, anxiety, stress or even shame and denial [4, 5, 6]. A process begins where the parents, as protagonists, must accept the existence of a health problem for their child; they have to seek professional help, to procure and implement treatment and then to make efforts to support a positive evolution of their child's health condition [7]. The way the parents manage all of these stages can be influenced by the way they represent their child's illness [8]. The concept of illness representation refers to the subjective viewpoint of a person, to their beliefs and expectations concerning the disease [9, 10]. It is the main concept of the Common-sense model of illness [11]. According to this model, when a person faces a stimulus endangering their health status, a cognitive and emotional process is triggered that leads to the emergence of a coherent illness representation. Five dimensions structure the content of this representation: identity, causes, cure/treatment, consequences and duration [12].

Identity represents the label or name of the illness, outlined by the symptoms experienced by an individual [13]. The *causes* refer to the factors suspected of having triggered the onset of symptoms and their identification depends on the information available to a person, which may pertain to a previous experience with the illness, to discussions with medical staff or to the media [14, 15]. *Time-line* refers to the course of the illness and to how long it lasts, thus being perceived as acute, chronic or episodic [16]. Furthermore, an individual will analyse the expected results of the illness and its physiological, social, emotional and economic effects, thus establishing the *consequences* of the illness [17]. The fifth dimension, *control*, includes the individual's beliefs concerning the extent to which the illness can be controlled or cured [7, 18].

This model focuses on the personal experience of a person and on their role in the process of adaptation to the factors threatening their health status [19]. Whereas they are the main engine leading the coping strategies and the assessment of the outcomes, illness representations may not be consistent with objective medical information [17]. These constructs are dynamic and ever changing; three sources of information exercise their influence upon them.

The first source of information is represented by the medical history of a person, by their experience with the illness, by an individual's perceptions of the somatic symptoms or by the information derived from observing a sick person. The second source comprises the information obtained by an individual from persons with authority in the field of health and medicine, such as physicians and nurses; not least, the cultural setting of a person is a source of information with a significant impact on the beliefs concerning the illness [19, 20].

The applicability of this model is broad and it serves as a theoretical background for the existing studies whose objective was to investigate illness representation among both adults [13, 14, 21-24] and children and adolescents [25-27]. It uses both qualitative [28] and quantitative research methods [29]. The special attention paid to this construct is due to the significant correlations found with adherence to treatment, quality of life, physical and mental health, as well as coping strategies used [30-33]. In the recent years, this theoretical model has served as guide for the researches that focused on identifying the way children and adolescents understand the illness and outline representations of the illness [27-29, 34, 35].

2. Illness representation among children

A better insight into children's understanding of the illness has significant theoretical and mostly practical implications. Understanding the way, a child represents the illness will allow us to provide age-appropriate information and explanations [36]. Piko and Bak (2006), using the drawing technique, have obtained results according to which children's representation of their health is rather holistic: they believe to be healthy when their body is clean, microbe-free, and when they can enjoy their leisure time doing outdoor activities and being surrounded by others. Moreover, the 11-year old children who took part in the aforementioned study highlighted that health was the most important aspect of life. In what concerns the illness, children often chose to refer to ways they could get sick, as they found it easier to provide information and to represent graphically the factors that may determine the emergence of an illness rather than the illness per se [37]. The sources of information for outlining the representation of the illness are the same in case of children.

3. The sources of information contributing to outlining illness representations among children

1. Hence, the first source of information is represented by *the category of lay information*, assimilated by a child through the social interactions with the others; they are generally cultural notions about the illness. Culture determines a significant influence, especially on the beliefs concerning the causes leading to the emergence of an illness. For instance, in Haitian culture, it is believed that illnesses emerge due to an imbalance between man and nature or that they can be determined by magic [38]. On the other hand, in India, illnesses are believed to be caused by actions conducted in a previous life [39]; while people in Korea think that the source of the illness is a punishment from God or from the ancestors, a curse of maleficent forces [40]. In order to help a patient, the physician must act observing the patient's cultural background.

2. Among *persons who represent an authority* for children and who provide them with information on the illness, we mention first of all the doctors and the parents [41-44]. The efficient communication between a doctor and his patient is a complicated process even when the two interlocutors are adults. When the patient is a child, things get even more sensitive due to the differences between the developmental levels of the two interlocutors. For the dialogue between a physician and his child patient to be effective, it is extremely important for the physician to learn the particularities of the cognitive development level of the patient and the way children limit their grasping of the concepts of health and illness [45]. Konstantynowicz *et al.*, (2016) interviewed 22 children with a chronic disease, aged between 10 and 16, as well as 26 parents; the purpose was to identify their opinion concerning their interaction with the doctors. The most important aspects reported by children and by their parents were the significant lack of friendship and empathy from the doctors, the lack of clear explanations concerning the diagnosis and the causes of the illness, as well as the use of medical jargon. More precisely, the aforementioned study highlights that parents and children with a chronic disease need relevant and precise information on the disease, on medical procedures and treatments, using a language they can understand. All of these aspects actually help outlining a more accurate representation of the illness, closely related to the five afore-presented dimensions.

3.1 The parental role in outlining illness representation among children

Besides doctors, parents also have an important role in the providing of information concerning their child's illness, given that their attitude influences the child's attitude towards the illness [8, 41, 46]. When a parent decides to talk to the child about the diseases, it is recommended for said parent to be very well informed, to discuss with the child as honestly as possible and to make sure all questions get an answer. The parent must also ensure emotional support, by making the child feel secured and accepted [47]. If the parent provides the child with information that outlines a reliable identity of the illness, the child will feel less anxious and guilty for the ongoing matter. Studies attest that a clear understanding of what a chronic disease represents is associated among children with improved emotional status, with better quality of life and, maybe most importantly, with higher compliance to treatment [27, 48, 49].

Regarding the causes leading to the emergence of the illness, the most important role of the parents is to let the children know that they are not responsible for the illness. Unfortunately, parents often choose certain educational practices that can instil in children the idea that their own illness is a punishment, a shame [50, 51], triggered by the fact that they had broken a rule or that they had done a bad thing.

In what regards the dimension of control/treatment, parents play an important role in determining the behaviour of their child during medical procedures. Often, when parents take the child to the doctor for a certain medical procedure, the child sees it as negative and punitive because he/she cannot understand its purpose [36]. Such an example is represented by the visits to the dentist. Because they are not given information concerning to way a dentist's practice looks, the procedure to be applied and its purpose, as well as the issue leading to the visit, children will get scared; they will refuse to collaborate with the dentist and, in the worst case, they will always be terrified of the dentist. Very young children often perceive the treatment as a punishment [52]. Some parents may be tempted to believe that they protect their children by withholding them the fact that the procedures to undergo may be uncomfortable or painful. However, children are always more worried of the unknown; thus, by providing them with appropriate information for their development level, the level of anxiety and perceived stress may be mitigated [27].

Depending on the extent to which parents manage to maintain a normal life for the child, the dimension of illness consequences will be determined in the children's mind. It is quite difficult to maintain the balance between observing the treatment and ensuring a normal life.

Whereas no perfect recipe has been found thus far, there are certain things that the parents can do to help the child adapt to the illness and lead as normal a life as possible. Hence, depending on the child's capacity, a parent may consider to give certain chores to the child [53], which the latter can finalize without difficulty. The involvement in such activities by the parents can determine the feeling of usefulness and it may help the child develop personal autonomy skills [54]. The encouraging of responsibility is the foundation on which health care autonomy may develop [47]. Another strategy to be applied by parents is encouraging the child to participate in activities involving the collaboration with peers and creating for them opportunities for spending time with friends, which may contribute to an improvement in the quality of life [55].

Another thing that parents can do to instil in a child with a chronic disease the idea of stability and predictability is to maintain family routines [42]. Children feel more secure and in control over the environment when their daily routine is predictable and consistent [56], then they have more chances to assimilate rapidly certain activities characteristic to the management of a treatment [57-59]. Whereas some parents may be sceptical, just like any other children, sick children also need discipline and rules. Because chronic disease can often prevent the children from fulfilling their school duties and from taking part in activities with friends, they can become shy, excessively dependent on the others or, on the contrary, aggressive and non-compliant. However, the application of appropriate corrective measures may lead to a stimulation of the harmonious collaboration between a child and their parents [60].

It is very important to establish reasonable limits for the sick children, because they help them self-discipline and understand that each type of behaviour determines a result, including those related to the observation of the treatment [61]. Not lastly, because they want to help their children, parents may fall into the trap of being hyper-protective, thus taking on the entire responsibility of caring for them. However, they should give children the possibility of choice, thus helping them acquire a greater feeling of control over their own life. A child's decisions may take into account aspects concerning daily activities or even treatment. In fact, a family manages optimally the chronic disease of a child when, as the child grows, they pass on to the child the responsibility of managing their own medical condition [47].

3. Previous experiences with the illness: not least, children will outline their illness representation based on their *past symptoms and experiences*. Studies have highlighted that those children with experience of the illness prove a better understanding of it, but their knowledge is not conveyable to another medical condition [43, 62].

4. Conclusions

There are several similarities between the sources and the dimensions of illness representations among children and adults; the Common-sense model of illness is appropriate as foundation for the studies that take into account the researching of illness representation in both adults and children. Whereas cultural beliefs and previous experience with the illness have a heavy word to say, the main role in instilling an accurate perception of the illness in children is reserved to parents and doctors. In a reassuring atmosphere of unconditional acceptance and empathy, the adult must convey reliable information to the child, using a language adapted to his/her developmental level. However, parents also have the difficult mission of maintaining a balance between the child's compliance to treatment and making sure they have a life as normal as possible.

The Authors:

BOJIAN Ancu?a [1]

IORGA Magdalena [2]

DÎR?U C?t?lin [1]

SOPONARU Camelia [1]

[1] Department of Psychology, University "Alexandru Ioan Cuza" (ROMANIA)

[2] Department of Behavioral Sciences, University of Medicine and Pharmacy “Grigore T. Popa” (ROMANIA)

Contributo selezionato da Filodiritto tra quelli pubblicati nei Proceedings “13th National Conference on Bioethics with International Participation - 2018”

Per acquistare i Proceedings [clicca qui](#).

Contribution selected by Filodiritto among those published in the Proceedings “13th National Conference on Bioethics with International Participation - 2018”

To buy the Proceedings [click here](#).

TAG: *proceedings, illness*

Avvertenza

La pubblicazione di contributi, approfondimenti, articoli e in genere di tutte le opere dottrinarie e di commento (ivi comprese le news) presenti su Filodiritto è stata concessa (e richiesta) dai rispettivi autori, titolari di tutti i diritti morali e patrimoniali ai sensi della legge sul diritto d'autore e sui diritti connessi (Legge 633/1941). La riproduzione ed ogni altra forma di diffusione al pubblico delle predette opere (anche in parte), in difetto di autorizzazione dell'autore, è punita a norma degli articoli 171, 171-bis, 171-ter, 174-bis e 174-ter della menzionata Legge 633/1941. È consentito scaricare, prendere visione, estrarre copia o stampare i documenti pubblicati su Filodiritto nella sezione Dottrina per ragioni esclusivamente personali, a scopo informativo-culturale e non commerciale, esclusa ogni modifica o alterazione. Sono parimenti consentite le citazioni a titolo di cronaca, studio, critica o recensione, purché accompagnate dal nome dell'autore dell'articolo e dall'indicazione della fonte, ad esempio: Luca Martini, La discrezionalità del sanitario nella qualificazione di reato perseguibile d'ufficio ai fini dell'obbligo di referto ex. art 365 cod. pen., in "Filodiritto" (<https://www.filodiritto.com>), con relativo collegamento ipertestuale. Se l'autore non è altrimenti indicato i diritti sono di Inforomatica S.r.l. e la riproduzione è vietata senza il consenso esplicito della stessa. È sempre gradita la comunicazione del testo, telematico o cartaceo, ove è avvenuta la citazione.