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Illness Representation among Adolescents: A Qualitative Approach

Ancuta Elena PADURARU[1], Camelia SOPONARU[2]

Abstract

There is a significant increase in the studies investigating illness representation through quantitative methods, which is due to a certain extent to the valid psychometric instruments that measure this construct. This phenomenon is especially intense among people who have a certain diagnosis. Not the same can be said about the existing research for the study of the representation that healthy people have about illness, in which the qualitative methods predominate. The purpose of this study is to outline how adolescents perceive the disease, given that they go through a period of change with significant implications for adult-related health behaviours. In this study, 132 adolescents aged between 11 and 18 were included (M =14.60; SD= 2.54). Because we wanted to obtain complex and accurate information, we chose to collect the data through three qualitative methods: drawing, the free association method, and the open-ended questionnaire. Based on the common-sense model, we were able to identify the most frequently cited causes of disease onset, which are the indicators of its occurrence, the effects adolescents perceive as occurring over time and how they think we can treat it. One of the most important dimensions represented through the three methods of data collection was that of emotions. This result draws attention to the importance that people attach to the emotional sphere when it comes to illness. Unfortunately, medical staff are well prepared for the assessment of biomedical aspects, but less so for understanding the psychosocial, social, and cultural dimensions of health and illness.

Keywords: common-sense model, illness representation, adolescents, disease understanding, graphic representation of illness, qualitative research.

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Introduction

One in five adolescents has a special health need and 1 in 10 has important activity constraints due to a chronic disease (Sawyer, Drew, & Yeo, 2007). Besides an increase in the prevalence of diagnostics, an increase was noted concerning health and healthcare services provided to adolescents suffering from a chronic illness. Most studies focus on researching the disease as perceived by the children suffering from it and by their parents. However, it is also very important to identify the way adolescents without a chronic diagnostic view illness, given that illness perception is closely related to disease protection and prevention behaviours (Žaloudiková, 2010; Mouratidi, Nonoti, & Leondari, 2015).

Adolescence has been defined biologically, psychologically, and socially, thus being perceived as a stage, a crossroad, a transition, or a process (Young-Ho, 1970). This specific stage of life is encountered between puberty and adulthood; it involves particular bio-psychosocial changes, habit changes, and behavioural reinforcements. New experiences make way in the life of an adolescent; experiences for which risk and entailing vulnerabilities are not always accurately appraised (Faial *et al.*, 2019). One of the aspects worth highlighting is related to their health state, to vulnerability to illness (to be more precise). In order to determine the extent to which we are vulnerable in face of a danger, it is necessary to point out and understand the danger in question. Consequently, we are interested in identifying what and how much children during puberty and adolescents understand about illness. Adolescence is the period when – besides other obvious transformations – teenagers start claiming and manifesting their independence (Kim & White, 2018). This independence is also noted and even encouraged when it comes to self-care and health protection behaviours. However, it is essential for these young people to have clear indications for guidance, to serve as a compass in healthcare and avoidance of becoming sick. In order to be able to formulate such indications – this guideline of good practices – we need to find out what they know, what they believe about the disease, the extent to which they are correct, and the information they need.

Hence, we believe it is crucial to find out and understand the way adolescents define illness, by referring to the five dimensions of illness representation, in order to formulate educational programmes of information and illness prevention among this population. Furthermore, the identification and modification of adolescents' negative attitudes and perceptions of illness may hinder their development into adults stigmatising the sick (Corrigan *et al.*, 2005). The need for health and wellness education is a need highlighted and supported by scientific evidence, among teenagers (Weiss & Ferrand, 2019).

Literature review

Illness representations is a cognitive construct the contents of which are influenced by the personal experiences of the individual, by the experiences of other persons, by knowledge, personality traits, and culture. The five components of representations – identity, causal beliefs, timeline, control or healing and consequences – alter over time (Silva, Lima, & Lemos, 2018). Starting from these representations, coping mechanisms are triggered and the healthcare behaviours of a person are influenced (Weinman *et al.*, 1996). These representations are also liable for the emotional reactions of a person, though they may be medically inaccurate (Petrie & Weinman, 2006). This is the Common-Sense Model, developed by Leventhal *et al.* in 1980 (Leventhal, Brissette, & Leventhal, 2003). Depending on the cultural background, the personal experience with illness and on the information receiving from the professionals, a person holds knowledge at the level of the five illness dimensions (Leventhal, Phillips, & Burns, 2016). The identity dimension includes the symptoms displayed by an individual, as well as the name of the disease (Huston & Houk, 2011). The factors considered responsible for the disease onset define the dimension of causes (Žugelj, Komidar, & Zupančič, 2016). Whether an illness is acute, chronic, or episodic reflects in the dimension of illness timeline (Leventhal & Nerenz, 1985), while its effects define the dimension of consequences (Diefenbach & Leventhal, 1996). Depending on the extent to which a person feels and believes that the disease may be managed or cured, they formulate the control dimension (Shanley & Reid, 2015). At empirical level, studies have demonstrated that CSM may be used as a theoretical base effectively, in order to describe children's representations of a disease (Babooram, Mullan, & Sharpe, 2011).

The present study is qualitative: through data triangulation, it proposes to outline a comprehensive image of the way the teenagers included in the research sample perceive illness. The three data collection methods were: drawing, free association method, and open-ended question surveys. Drawing is considered the universal language of childhood, which may be used as a means through which children may express their experiences; it is a commonly used research tool, because it allows the researchers to access children's conceptualisations about health and illness (McWhirter, 2014; Backett-Milburn & McKie, 1999). Through data triangulation, the weaknesses of a research method are assessed by the strong points of another method, the conclusions being thus valid (Onyango-Ouma, Aagaard-Hansen, & Jensen, 2004). Furthermore, Franck *et al.* (2008 apud. Lima & Lemos, 2014) argue that this technique ensures the validity of the response provided by the fact that its does not assume beforehand children's answers.

Methodology

Goals

Our study had three main goals. First, we wanted to identify the most common elements in the graphic representation of the disease. Second, we set out to compare the three age groups, in order to identify the existing differences in the perception and representation of the disease. Finally, we aimed to corroborate the data obtained through the three qualitative research methods, in order to outline a more comprehensive image of the representation of the disease.

Design

Starting from the Common-Sense Model of illness representation – theorised by Leventhal and his colleagues (Leventhal, Brissette, & Leventhal, 2003) – a qualitative research design was developed, in order to obtain the detailed descriptions of adolescents' perceptions of illness. Data were collected in the period October – December 2019, thus using three qualitative methods: drawing, free association method, and open-ended question surveys. The generous data obtained were analysed through content analysis. Given that the concept of illness has not been studied enough among teenagers, qualitative research is reliable, because it provides a deeper perspective (Strauss & Corbin, 1998).

Participants

Within this study, we have included 132 subjects aged between 10 and 18 (M =14.60; SD= 2.54). 56.4% of them have a rural background, while 41.4% have an urban background. From among the 132 participants, 40% are male and 60% are female. Their current health state is poor for 3.8%, good for 39.8%, and very good for 55.6%. Upon researching the previous relationship with illness, we have identified that 98.5% of the subjects have heard about illness, 78.2% have been ill in the past, while 19.5 % have never had an illness. From among the 132 subjects, 99 have known someone ill, while 33 have never known anyone ill.

Procedure

This study has used a triangular research method: drawing, free association method, and open-ended question surveys. Triangulation provides the advantage of comparing data concerning the same phenomenon (illness) collected through different methods (Žaloudiková, 2010). Each participant was given a blank A4 sheet of paper and a set of coloured pencils, hence having standardised materials (Villanueva-Noble, 1998).

Please, draw the first thing that comes to your mind when you think about illness. This instruction was formulated based on the findings obtained by Lima & de Lemos (2014) and Broadbent *et al.*, (2018), arguing that this personal manner of formulating the instructions given to children in order to study illness representations entail rich and important data, which may be triangled with other findings (Ezan, Gollety, & Hemar-Nicolas, 2015). *After you have finished drawing, please, write the words coming to your mind when you think about illness* – This was the instruction given for free association. The instruction for open-ended question surveys was: *We will ask you to answer a few questions about what illness means to you. It is important to know that, if you do not know what to answer to a question, you can say "I don't know" or "I don't want to answer this question". There are no right or wrong answers; it is important for us to know your opinion about it.*

When designing the open-ended questions within the questionnaire, we took into account the dimensions of illness representation, stipulated within the Common-Sense Model developed by Leventhal (Leventhal, Brissette, & Leventhal, 2003). Finally, we have expressed our gratitude to the participants for their time and mostly for their priceless help for attaining the research purpose.

Data interpretation

In order to analyse the drawings made by children and the information obtained through the written method, we have used the content analysis method. According to Downe-Wamboldt (1992, p. 314 cit. in Villanueva-Noble, 1998) content analysis is "a research method that provides a systematic and objective means to make valid inferences from verbal, visual, or written data in order to describe and quantify specific phenomena". This process involved the analysis of each drawing, text written by children, and answers provided, in order to point out the main topics inherent to the materials analysed. Nevertheless, we have taken into account the five dimensions of illness representation, in agreement with the theoretical model on which this study is based.

Results

Drawing

In order to get the bigger picture of the graphic representations concerning the concept of illness, the contents analysis method was used. The following categories were identified:

– *Biomedical aspects*: hospital, body images, ambulance, organs, body wounds, protection elements (surgical mask, umbrella, blanket), medical items (prosthesis, thermometer, stethoscope), treatments (pills, vitamins, tea, IVs), medical

symbols (death-head, heartbeat, bacteria);
– *Psychosocial aspects*: (1) emotions: sadness, happiness, anger;
– *Social life*: lying in bed, staying in the hospital, grave;
– *Thoughts*: abstract (negative manifestations of natural elements and phenomena) and concrete (thoughts about emotions, illness, and harmful elements for health);
– *Lifestyle aspects*: house, clothes, alcohol, cigarettes, sodas.

Content analysis within qualitative research depends on the contents of the data per se. In qualitative research, data may be counted in order to highlight a certain pattern, while in quantitative research, counting has the purpose of determining the most important data (Villanueva-Noble, 1998). Consequently, the frequency of the occurrence was determined for the elements recorded in the analysis grid. The analysis underlined that, in order to represent illness, participants have used mainly biomedical elements (eyes oc. = 69, head oc. = 64, bacteria oc. = 29), followed by the psychosocial elements (sadness oc. = 46, lying in bed oc. = 28).

We have sought to identify the differences for each element within the analysis grid, thus obtaining a great amount of data. In order to attain this objective, we have used the One Way ANOVA method. The most important findings highlight that:
– The subjects aged 10 – 11 are more prone to using in their drawings biomedical aspects related to the human body, thus obtaining a higher average compared to the other two age groups, regarding the following elements: head ($p = 0.007$; $M = 0.71$), eyes ($p = 0.001$; $M = 0.75$), neck ($p \leq 0.001$; $M = 0.53$), hair ($p = 0.046$; $M = 0.51$), torso ($p \leq 0.001$; $M = 0.50$), right arm ($p \leq 0.001$; $M = 0.50$), right leg ($p \leq 0.001$; $M = 0.50$), left leg ($p \leq 0.001$; $M = 0.46$), clothes ($p = 0.006$; $M = 0.39$), spots of the face and body ($p \leq 0.001$; $M = 0.28$) and signs of cold (running nose, coughing) ($p \leq 0.001$; $M = 0.28$).
– The subjects within the group aged 14 – 15 also use in their drawings mostly biomedical aspects, but they are more abstract, such as a red cross ($p = 0.034$; $M = 0.08$);
– Unlike the two other age categories, the adolescents aged 17 – 18 use mainly messages about illness in their drawings ($p = 0.025$; $M = 0.13$), namely psychosocial aspects.

Thus, it may be stated that at the age of 10 – 11 illness experience is closely related to the human body, which they represent in details, thus paying attention – besides the body elements – to decorative elements, namely to clothes. The same age category uses commonly cold signs as illness representations, as well as red spots on the face and body. As they grow older, children start using symbols in their drawings, such as the red cross, as well as messages about illness. Such modifications may be explained by the transformations in their cognitive development, abstract thought, and language development.

In the drawings made by children aged 10 – 11 – whereas dominated by people – there are no social interactions, metaphors, or symbols, as it occurs in the drawings made by the two other age categories; illness is mainly represented by biomedical factors. Whereas there is no social interaction, this age category has paid special attention to the drawing of the entire human body, but schematically. Children aged 10 – 11 illustrate mainly the identity dimension of illness, through the red spots and symptoms such as coughing, running nose, sneezing, nausea.

The age category of 14 – 15 – unlike the other two – represents illness through the organs (heart, lungs, kidneys) affected. Besides this change in the representation of illness identity, infirmity emerges (short or missing limbs). The dimension of illness onset is also present, illustrated by images of bacteria and viruses. The very interesting aspect is that both bacteria and viruses are humanised, by drawing faces with emotions (sadness or happiness). As for underlying factors, drawings illustrate alcohol bottles and packs of cigarettes, similarly to those aged 17 – 18. If signs of illness emerge on the faces of the characters drawn, they are much more subtly represented, in a more realistic manner. This age category also includes the dimension of consequences, through psychosocial consequences, being represented by images of houses, suggesting lockdown for curing and preventing the spread of illness, as well as activity restraints. This dimension is also featured among the subjects aged 17 – 18, but in a much more concrete manner, using images of people in hospital beds, connected to IVs.

The adolescents aged 17 – 18 usually draw faces of people affected by illness, focusing on the emotions experienced. Unlike the two other age categories, they represent the psychosocial aspects through abstract thoughts (negative manifestations of natural phenomena, by climbing trees or trees with holes in their trunks). Compared to the two other age categories, they represent several dimensions of illness in the same drawing (causes, consequences, treatment) and symbols illustrating death as the finality of illness (death-head, grave). There are also elements denoting stigma and avoidance of sick persons.

Words

The answers of the 132 subjects were introduced in an Excel document, first of all determining their occurrence. Subsequently, we identified the main themes and we have categorised the words depending on these themes: (1) Biomedical aspects: symptoms (headaches, stomach aches, fever, fatigue, sleepiness, etc), illness names, categories of illness (physical vs. mental), treatment (pills, injections), medical staff (physician, nurse); (2) Psychosocial aspects: Emotions: sadness, suffering, hope, lack of hope, lack of trust; Social life: lying in bed, staying in hospital, lack of interaction with friends; Thoughts: about emotions, illness, and harmful things, injustice.

In the subsequent stage, we have identified – for each age group – the words with the highest frequencies. The results considered significant are featured in the *Table 1*. Upon analysing the *Table 1*, we have noticed several similarities and differences between the three age groups, from the first word in the *Table 1* for each group with the highest frequency.

Table 1. The words with the highest frequencies

Group 10 – 11		Group 14 - 15		Group 17 - 18	
Word	Frequency	Word	Frequency	Word	Frequency
pain	17	sadness	35	sadness	24
medication	14	pain	27	pain	21
cold	14	medication	25	medication	19
cancer	10	suffering	14	hospital	17
doctor	7	depression	14	surgery	16

Thus, for the age category 10 – 11 years old, the word with the highest frequency is "pain", while for the two other groups, the word with the highest frequency is the same, namely "sadness". It would appear that the subjects aged 10- and 11-years old focus on the physiological experiences of illness, because they think first of all about physical pain, while the other age categories automatically think about the emotional experiences associated to illness, namely "sadness" – a functional unpleasant emotion. Both words concern negative experiences, but they belong to different registers – physical and emotional. The word "pain" ranks the second, though, in the age groups 14 – 15 years old and 17 – 18 years old, with physiological sensations following closely the emotional concerns of the subjects. Another similarity between the two groups is the third ranking for the word "medication", a word ranking the second in the age group 10 – 11 years old. Hence, upon identifying the most obvious physiological and emotional sensations, all three groups thought of a way to fight against them, namely medication – a way to treat and control illness. Besides the identity dimension of illness, the control dimension is the next one activated in the mind of subjects aged 10 – 18 years old. Starting from the data recorded in the Table 1 – illustrating, at first glance, that the age group 14 – 15 years old used wider array of words for this test – we have counted the words used by the three groups concerning this test.

Table 2. The number of words for each group

Age group	10 – 11 years old	14 – 15 years old	17 – 18 years old
Number of words	63	163	100

The significant difference between the number of words used by the age group 10 – 11 years old and the two other groups may be related to language development, cognitive development, as well as greater experience related to illness.

Open-ended question surveys

The subjects in the age group 10 – 11 years old define illness as "a very bad thing, a dangerous microbe". For the adolescents aged 14 – 15 years old, illness is "an unpleasant physical or mental condition that a person may experience; something provoking a setback in daily life; something undesired that doesn't help in any way and estranges you from the things you like". While young people aged 17 and 18 years old define illness mainly as "an imbalance with negative repercussions on the body. It determines a decrease in the capacity of adjusting to social and environmental demands. It may be physical or mental." Hence, illness acquires an ever more complex definition, evolving from a very bad microbe to a state of imbalance that may manifest physically or mentally.

In the second section of the questionnaire – concerning the identification of causes – we asked questions on the causes of getting sick in general, on the causes they got sick themselves, on the contagion process, and on ways to prevent the spread of illness. Among the causes identified by the age group 10 – 11 years old, we mention cold, unhealthy diet, inadequate clothing, sweets, bacteria, ice-cream. All these aspects are closely related to the messages that children receive about the most common illness they had to face up to that age, namely the cold. In the age group 14 – 15 years old, besides diet, it is worth noting other factors, such as negligence, sadness, stress, heredity, contagion, morality, bad things done in the past, and God's will. We feature below the adolescents' discourse on the correlation between morality and illness, divinity and illness, karmic power and illness. Concerning the respondents within the group 17 – 18 years old, no significant evolution was recorded concerning the identification of illness causes, unlike those within the group 14 – 15 years old; the only factor highlighted is sexual contact.

The participants to our study believe that, after becoming ill, a person's body is *"very weak; it changes, it transforms*". The person feels "*pain, sadness, suffering, along with nausea and feeling generally bad*". The most frequent thoughts include "*I'll feel better*", "*I hope I'll get better soon*", but also the extremes "*I'll never get better*", "*I'll die*". At behavioural level, in the adolescents' opinion, a sick person is "*getting estranged from everyone else*" and "*behaves strangely*", "*lifeless*", is "*different*".

Thus, they underline one of the postulates of Common-Sense Model; the subjects' knowledge of illness is closely related to their own experience with illness.

Though they focus both on protection measures from the sick person and on the same measures from the healthy persons, they discuss "*separating the sick from the healthy*" as a method of preventing the spread of illness. This strategy may

derive from certain views and discriminations acquired. The question concerning the identification of illness consequences on people has generated the following answers: "*I can't have an active life anymore*", "*I can't see my friends anymore*", "*I can't go out any longer*", "*I can't move anymore*", "*I can't eat anything anymore*", "*I can't be happy anymore*". These answers suggest, again, the emotional, social, physiological dimension of people, being very close to the definition of health as provided by WHO (1948). In the age group 17 – 18 years old, the feeling of being misunderstood and the social withdrawal emerge.

To the question What could a person do to feel better? – the most common answer was "take pills", dominant in the group 10 – 11 years old, followed by "family support", "being encouraged", "have the friends' support", "follow the treatment", "care provided by others". Again, the emotional and social dimension are dominant: young people believe that – besides medication – the support of others is very important. However, the social dimension is more apparent for ages 17 – 18 years old. It is interesting that – from 14 years old – the adolescents remind that medication has both positive and adverse effects on a person. Finally, young people have also added and highlighted the message according to which illness is something unwanted, causing suffering to both the ill persons and the dear ones; it is, thus, essential to apply healthcare and illness prevention strategies: "I wouldn't wish it upon anyone – to get sick. It is hard being sick; it is hard to overcome it… You suffer a lot… Illness causes pain for both that person and those around. The best we can do is take care of ourselves".

Discussion

The interest concerning studies of the subjective perception of adolescents in what regards health and illness is of recent date; it has not been developed enough (Ott *et al.*, 2011; Borraccino, Pera, & Lemma, 2019; Boardman, 2006), but it has already underlined the importance of this topic among adolescents' concerns. There has been a slow trend attempting to put a distance between the experts' view of health and illness for adolescents, in order to focus more on their subjective experiences, which are really crucial for the programmes aiming at preserving health and preventing illness (Ott *et al.*, 2011; Burbach & Peterson, 1986). In addition, researchers have begun to be concerned of the way healthy children perceive these constructs (Detmar, Bruil, & Ravens-Sieberer, 2006). The current study tries to extend knowledge precisely in this delicate direction, by researching the way healthy adolescents perceive illness, considering them as experts. Since the age of 10 years old, a child perceives illness as the result of external contamination, of inadequate diet or clothing (Perrin and Gerrity, 1981). The best represented dimension of illness by the participants to this study – regardless of their age – was the one of identity, a finding similar to data recorded in the literature (Broadbent *et al.*, 2018). From 14 years old, they are able to

identify the psychological causes; they become aware that emotional state may have an impact upon physiological functioning; there is also a change at the level of personal control degree (Žaloudiková, 2010). Starting from this age, persons hold a more sophisticated view of illness; they understand the physiological functioning of the body and the way organs are affected (Williams & Binnie, 2002). Several causal factors are identified: as they grow older, adolescents become more aware of the psychophysiological sources of illness; in terms of treatment, several options emerge (Régnier Denois *et al.*, 2018). Within this study, children aged 14 – 15 years old list, among the causes, punishment for past actions and God's will. This may also be explained by their specific culture and religion (Cace, Tomescu, & Cojocaru, 2012). As their complexity level increases, children acquire the social dimension. They perceive the sick person as different from others, as different from before getting sick, as well as more isolated from social interactions (Goldson, 1992).

Adolescents understand there are several interdependent causes of illness; that the body may react differently to specific agents or to a combination hereof; and that illness may be cured due to a complex interaction between the host body and medication. They are more aware of the body's role in the healing process; they understand that medication is necessary but not sufficient; the body's response is a critical element for treatment efficiency in healing (Perrin & Gerrity, 1981).

Regarding the graphic representation of illness, children aged 10 – 11 have drawn mainly persons, without indication of interactions between characters; they have focused on specific biomedical signs (Buchanan-Barrow, Barret, & Bati, 2003; Fernandes, Liamputtong, & Wollersheim, 2015), emerged on the skin or as signs of a cold. Such findings may be related to the closest experience of children with illness, cold and chicken pox being often experienced by children younger than 10; their prevalence decreases by age (Suryam & Das, 2009; Allan & Arrol, 2014). As they grow older, adolescents begin introducing symbols in their drawings: red cross among those aged 14 – 15, while messages about illness are specific to those aged 17 – 18. These modifications may be explained by the transformations occurring in what regards cognitive development, abstract thought, and language development. Such trends are also noticed among the findings obtained in the free association test. For the age category 10 – 11, the word with the highest frequency is "pain", while for the two other groups, it is "sadness". Once again, it appears that the subjects aged 10 and 11 focus on the physiological perceptions of illness; they think mostly about physical pain, while the two other age categories focus on the emotional experiences associated to illness, thus invoking the word "sadness" - information that supports the need to humanize the doctor-patient relationship (Iliescu & Carauleanu, 2014). Both words concern unpleasant experiences, but they belong to different registers – physical and emotional. The word "pain" ranks second, though, in the age groups 14 – 15 and 17 – 18, with physiological sensations following closely the emotional concerns of the subjects. After pointing out the physiological sensations and the

emotional experiences (Broadbent *et al.*, 2018), all three groups thought of a way to combat them, namely medication – a way to treat and control an illness. More precisely, besides outlining the identity of illness, the control dimension is the next to activate in the minds of subjects aged 10 – 18.

Limitations of research

One of the most important limits is that data collection and interpretation methods may seem simplistic. However, data were collected using three qualitative methods, starting from a theoretical model used within research studies on illness representations. Another limit is that the sample comprised mostly female subjects, which may have affected the dominance of the emotional dimension in this study. Of course, the study findings cannot be generalised, given that they are specific to our research sample. More comprehensive studies would be necessary, with the objective of getting a better insight into the way children and adolescents perceive illness, in order to formulate and implement health education programmes. An effective health education will help adolescents become adults who pay attention to and preserve their health; who prevent and treat any illness (Žaloudiková, 2010; Mouratidi, Nonoti, & Leondari, 2015).

Recommendations

Qualitative research provides important insights into adolescents' representations of the disease, and deserves to be continued and supplemented with younger populations. In practice, we recommend specialists to provide information to adolescents about the psychosocial factors involved in the onset of the disease, the importance of emotional state and the functioning of the body, as they demonstrate the ability and need to understand these issues. Adolescents are concerned with the emotional feelings caused by the disease, associating it with sadness. As a result, intervention programs should include a component of strategies to allow young people to manage the emotional feelings associated with the disease in a healthy way.

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