

Understanding the world of children and adolescents with chronic disease through esthetic knowing: A qualitative study from a university hospital, Turkey

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ABSTRACT

Aim: Chronic diseases that lead to continuous monitoring, treatment, and repeated hospitalizations could affect development (mental, psychomotor, and language development) of children. These negative experiences undergone by children and adolescents may affect disease management negatively. This study was conducted qualitatively with intern nurses to understand what chronic disease means to children and adolescents with chronic diseases using esthetic knowing method. **Methods:** Intern nurses (n=25) caring for children and adolescents with chronic diseases between 9 and 18 years of age participated in the study. Intern nurses requested children and adolescents to express what it meant to have chronic diseases through drawing, writing, poetry, etc. Focus group interviews were carried out to find out and record the experiences of the intern nurses. Ethical approval and consent from students, children, and adolescents and their parents were obtained. **Results:** Intern students noticed differences in the reactions of the children and adolescents. They described how esthetic knowing was used as a coping method by the children, comforted them psychologically. Intern nurses stated that they entered the internal world of the child with esthetic knowing, meant that having chronic disease was a punishment, a family burden, dependent and different for children. They established a trust relationship and saw the children's own weak points. Intern nurses recommended that esthetic knowing should be included in training syllabuses, used by intern students in practice, placed on in-service training, maybe applied to the families and used in other clinics. **Conclusion:** Esthetic knowing is recommended focusing in nursing education and practice.

Key words: Adolescents, esthetics, children, chronic disease, intern nurses, nursing

INTRODUCTION

Chronic diseases are commonly seen during childhood, and their incidence has been increasing more and more. Since these diseases require continuous examinations, treatments and monitoring and cause frequent hospitalization, children and adolescents with chronic diseases experience social, psychological, developmental and relational problems, and these problems may be painful.^[1,2] Children may not exactly express the problems from which they suffer, due to their developmental (mental, psychomotor, and language development) characteristics.^[3] Chronic diseases, which threaten body integrity and self-confidence, may cause loss of independence and auto control, affect the adolescents' coping skills negatively and may produce such negative feelings as anxiety, fear, worry, and reluctance among these children.^[4] These negative experiences undergone by children and adolescents may affect disease management negatively. In the management of chronic diseases, it is very important to explore the meaning the children and adolescents attribute to the chronic diseases, the problems they suffer and the solutions they have found and to enter their inner worlds. With quantitative approaches, experiences the

individuals undergo cannot be discovered exactly and correctly.^[5] To determine these dimensions, qualitative data are necessary. With esthetic knowing, which is the aspect of art reflected on care in the name of "understanding human and human life," these dimensions may be handled.^[6,7] Thanks to qualitative studies conducted with esthetic knowing, including artistic practices, health-care personnel can obtain information about the problems children undergo and the solutions they have found, can enter their inner worlds, can guide their practices and can be successful in disease management by providing holistic care.^[1-3,6-9] In esthetic knowing, different techniques (drawing, painting, poetry, stories, dramas, and music) based on art are used to help people express themselves.^[6,7,10-14] People are enabled "to see," "to hear" and "to feel" what is perceived, felt and thought about the present time.^[9,11,13-15] Esthetic knowing is based on such approaches as empathy, intuition, interpretations, and ethical understanding and is considered a self-learning/teaching experience.^[6-8,11,16] Esthetic knowing and art should be included in educational curriculums so that health-care workers can understand what is happening in the patients' worlds and guide treatment and care. Health-care personnel trained in this manner can understand patients,

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provide them emotional support and shape care and treatments in this direction.^[17,18] The studies conducted report that esthetics knowing and using art-based methods have increased nurses' awareness, consolidated confidence between patient and nurse and helped nurses understand individuals' reactions and thoughts about health/disease. Besides, esthetics knowing has improved nurses' ability to provide multiple care.^[6,7,9,10,15,19,20] Particularly, nurses and nursing students who work with children with chronic diseases should use esthetic knowing while they plan, implement and assess care.^[7,13,14,20,21] The current study aimed to make intern student nurses understand what diseases mean for children with chronic diseases through esthetics knowing.

MATERIALS AND METHODS

This is a qualitative study conducted with intern nurses who continue their bachelor degrees in the 4th grade, using a focus group method to define the effects on the lives of children and adolescents with chronic diseases and to understand their worlds using the esthetic knowing method. Qualitative studies are guides in the understanding of people's lifestyles, behavior and reactions and the meaning they assign to events.^[3,5] This study has attempted to define how intern nurses perceive the diseases of children and adolescents with chronic diseases. The purposeful sampling method has been used in the study, and it was carried out in the pediatric clinics of a university hospital in the Cappadocia Region of Turkey, using 25 intern nurses providing care to children and adolescents with chronic diseases in the 9-18 age groups. Before the study, the intern nurses were provided with training related to knowing methods and esthetic knowing in nursing, and during practice, while providing care, they were required to use esthetic knowing to understand what having a chronic disease meant for the children and adolescents. The intern nurses in the study provided care for children and adolescents with diabetes mellitus (8), epilepsy (5), chronic renal failure (4), and other various chronic diseases (8). The children and adolescents with chronic diseases who were receiving care from the intern nurses chose one of three different esthetic knowing methods (picture, writing, and poetry) to express themselves. The majority chose the writing (13) and picture/drawing (8) methods. The children and adolescents who drew a picture were required to explain what had been expressed in the picture, and then the intern nurses' later described their experiences using the focus group method. A researcher using five groups of five intern nurses carried out the focus group interviews, each in a relaxed and appropriate environment. Each interview was recorded on sound recording equipment, and the intern nurses gave consent. The length of the interviews varied between 30 and 50 min, and they continued until the data saturation was obtained. Data were collected using a semi-structured interview form composed of questions about the efficacy of esthetic knowing in patient care and how they directed the care they provided. Qualitative content analysis was used to analyze the data. First, a researcher carried out the raw breakdown of all the interviews, and then another researcher checked the data, which had been broken down, by making random selections from the sound recordings. Three researchers, independent of each other, analyzed the data. At the first stage of analysis, the interviews were read line by line, and the data were encoded within the framework of the questions prepared at the beginning. The encoded data were separated

into categories, according to their content and meanings. Two themes were created by establishing connections between the categories. These were: (1) Intern nurses' gains (giving meaning to the child's and adolescent's reaction, understanding what the disease means for the child and adolescent and reflecting this in the care) and (2) intern nurses' recommendations relating to the use of esthetic knowing in nursing. All the data were interpreted and put into the form of a report.

Ethical Considerations

In order for this study to be carried out, permission had to be obtained from the university academic committee, the Ethics Committee and the institution concerned. In order for them to take part in the study, written and verbal consent was obtained from the intern nurses, the children and adolescents with chronic diseases and their parents.

RESULTS

The data obtained from the study were placed into two themes in the form of suggestions related to the intern nurses' gains (understanding the reactions of the children and adolescents, understanding what the disease means for the child and adolescent, and how this was reflected in the care provided) and the intern nurses' use of esthetic knowing in nursing.

Intern nurses' Gains

Understanding the reactions of the children and adolescents

The intern nurses took notice of the reactions of the children and adolescents with chronic diseases through the use of esthetic knowing, particularly any expressions of blaming themselves for the disease, anger, inability to express their feelings, shame, weeping, fear, anxiety, introversion, disregard, discomfort, contradiction, or not accepting the disease. Some of these reactions were expressed by the intern nurses in the interviews as follows:

Because my patient was quiet, I thought they had perhaps accepted the disease and was now used to it, but they he still wanted to live like a normal person, they were imagining that. I got the impression that they still hadn't actually accepted the disease (An intern nurse taking care of a child with Hemophilia, using writing method).

When I first approached the patient, I didn't pay any attention to that at all. I had more tried to get something particular to the disease; I was directing my approach at that.... I didn't notice that the patient had fears related to the disease (An intern nurse taking care of a child with epilepsy, using writing method).

It gave me awareness, because I had seen while reading the letter at which points there may have been something missing. She had also discussed in the letter how the time she paid no notice to had affected her life negatively, how stays in hospital had disrupted their schooling. She mentioned how this in itself had created stress and how it was constantly difficult to cope with the disease (an intern nurse taking care of a child with type 1 diabetes mellitus (T1DM), using writing method).

The patient felt a little guilty. She had thoughts like "If I had been a bit careful, I wouldn't have got this disease." I don't know if they

had other kinds of thoughts like this, but I saw that she expressed this more comfortably in writing (an intern nurse taking care of a child with chronic renal failure [CRF], using writing method).

After the intern nurses had used esthetic knowing, they noticed differences in the reactions of the children and adolescents. The students described how esthetic knowing was used as a coping method by the children and adolescents, that it had decreased their anxieties, comforted them psychologically and helped them to express themselves better. Furthermore, the students stated that using esthetic knowing had made them feel more attentive to the children and adolescents, helped them to establish and continue communication and facilitate communication between the children and adolescents and the health professionals, particularly the intern nurses and their families, and to take part in their treatment.

It contributed toward the children's development. They are able to express themselves in some way. She thinks you understand them and she can communicate with you more comfortably (A student taking care of a child with epilepsy, using writing method).

This was a child who found it really difficult to communicate. After she expressed herself, it became easier to communicate, and I saw that she had more trust. It is definitely a very good method when it comes to communication (a student taking care of a child with juvenile rheumatoid arthritis [JRA], using writing method).

I think they felt she was more important. That is, she thought that we regarded what she thought more highly (a student taking care of a child with T1DM, using writing method).

The patient was uncomfortable because she had to stay in hospital, and she was angry with her mother. When it was happening bad, she behaved to her mother badly. She preferred to painting, well, after she had done painting, she was so glad. I felt that the anxiety of the patient had decreased. Her communication with her mother improved. In fact, I saw them making pictures together. His mother kept asking "what did you do?" (a student taking care of a child with tuberous sclerosis, using drawing method).

Understanding what the disease means for the child and adolescent

The intern students in the study described what it meant having a chronic disease, that it was a punishment, a family burden, dependent and different for children and adolescents. The intern students stated that they entered the internal world of the children and adolescents with esthetic knowing, understood through their eyes what the diseases meant and analyzed the reasons why they could not adhere to them because children with chronic diseases define the meanings assigned to diseases.

They felt guilty because they were ill. Even when the nurses touched them they perceived it as a punishment (an intern student caring for a child with JRA, using writing method).

My patient thought that her polyclinic control was a family burden. But they couldn't bear the pain. On the one hand, she was in a dilemma, but on the other, she did not want to be a burden on their family, and she also has to treat. She thought they had put her family in a bad situation. Because of this, she felt sad

(an intern student caring for a child with Crohn's disease, using writing method).

My patient said things like "because of my illness I can't play football or basketball at school as they are scared I'll have an accident," "when will I live like a normal person?," "I want to see what it's like to live like a normal person. I want to experience that feeling" (an intern student caring for a child with hemophilia, using writing method).

I realized that we didn't understand children. I thought I had entered their internal world. They have other lives outside the hospital, not like the ones we saw there. They have to adjust to other things (An intern student caring for a child with epilepsy, using writing method).

I had her draw a picture, because it's a real guide for us. They depict their minds and as they describe it, I understand. What are they thinking? What are they doing? But they have different worlds in their subconscious minds. I think I understand her with esthetic knowing (an intern student caring for a child with epilepsy, drawing method).

Its reflection in the care provided

Using esthetic knowing methods had an effect on the aspect of care provided by the intern students. Using esthetic knowing helped the students to define the children's and adolescents' informational needs, to notice aspects that are not normally noticed by nurses, to establish a relationship of trust and to see the children's own weak points. The students stated that using esthetic knowing gave them the opportunity to make a connection between the theory and the practice, to take part in care of the family and to guide for social support. Furthermore, the intern students emphasized that esthetic knowing helped them in training, in providing awareness and in the planning and directing of treatment, and it gave them more time and provided job satisfaction:

But when there's a trust relationship, you take part in the patients to planning their treatment; they want to join in themselves. It is helpful in this. I think it also makes our work easier, when establish vascular accessor in other interventions ... (an intern student caring for a child with T1DM, using poetry method).

I think it increases the quality of the care. Nursing is not just taking vital signs or applying a treatment. When it is handled in this way, our and the other people's perspectives on nursing will change, so the care will develop (An intern student caring for a child with T1DM, using writing method).

For me, this study has been extremely helpful in the aspect of the parents taking part in the care. After this study, I have tried to include the parents in the care a lot more. I have tried to give more information about treatment procedures ... one of the biggest reasons of upset experienced in relation to their condition of their child is not knowing what has been done and what will be done ... (an intern student caring for a child with epilepsy, using writing method).

It provides a really important addition to indicate the child's priorities and needs ... because the environment and experiences they live, their families, and their perceptions are different, it is

an extremely positive method in terms of how we approach them and define their priorities (an intern student caring for a child with mitral deficiency, using writing method).

The Students' Recommendations Regarding the Use of Esthetic Knowing in Nursing

The students who used esthetic knowing recommended that it should be included in training syllabuses and used by intern students in practice for nurses; students should be trained in esthetic knowing and should use this method in their working lives. The students also stated that this method may be applied to the families and used in other clinics:

Esthetic knowing should be used for understanding what children in the pediatric department are feeling, because they can explain nicely what they are feeling in a letter or a picture. But ... they may not be able to express themselves in words. However, with this method, we might be able to understand what they are feeling (an intern student caring for a child with T1DM, using writing method).

I think it should also be used for the families. They really have a need for this. The families have to be here just as much as the patients (an intern student caring for a child with CRF, using writing method).

... nurses should have training about esthetic knowing. I think that it should be put into in the clinics (an intern student caring for a child with CRF, using drawing method).

It could also be included in the training syllabus. If we start it while at college, it will not be difficult to do it after graduation ... (an intern student caring for a child with T1DM, using writing method).

DISCUSSION

Children and adolescents with chronic diseases may display emotional reactions to their diseases, such as shock, denial, anger, depression, blaming themselves, and tears. As the disease progresses and hospitalization increases, the child's or adolescent's fears related to the disease and death also increased.^[1,2,22-24] In Michael's study, esthetic knowing was an aid to students in understanding the patients' fears, beliefs and thoughts about disease and death.^[7] Beytut *et al.*, through getting them to draw pictures, recognized the anxiety and anger experienced by hospitalized children.^[22] The intern nurses in this study also recognized that the children and adolescents with chronic diseases also showed similar reactions through using esthetic knowing. For this reason, esthetic knowing should be given a place in nursing training syllabuses. At the same time, esthetic knowing should also be included in-service training for nurses in their clinics.

Esthetic knowing can help to bring out the perceptions, thoughts and feelings of children and adolescents with chronic diseases and help them to enter their inner world, because children and adolescents have difficulty understanding themselves.^[3] In this study, it was determined that having chronic disease was like a punishment, a family burden, dependent and different for children and adolescents with esthetic knowing. In other studies, children

with asthma were able to describe through their pictures that their disease was like a hand cutting off their breath, a weight on their chests or a monster inhibiting their breathing.^[23]

Esthetic knowing, which can be a unique and unforgettable learning experience for nurses, can help nurses to share the experience and to understand the perspectives of children with chronic diseases.^[7,8,11,13-15] In Northington's study, using esthetic knowing through books and films helped students to understand how the patients and their families perceive disease, abuse, disability, or death.^[13] In Pardeu's study, the students noticed that esthetic knowing was provided to pay attention to the patient's emotions and to understand their perspectives.^[14] In this study, the intern students stated that they entered the inner world of the children and adolescents, understood what the diseases meant through their eyes and analyzed the reasons why they could not adhere to esthetic knowing. In conclusion, it may be said that esthetic knowing has helped intern students to understand the experiences of children and adolescents with chronic diseases and to improve self-consciousness. Esthetic knowing, which is used as both an aim and a tool, is an effective learning and teaching method in nursing education and in practices. It may present a learning opportunity for the patient as much as for the nurse.^[7,13,14] In Michael's study, esthetic knowing helped to give patients hope, was used by patients as a coping method, played a role in the reduction of stress and enabled them to express themselves.^[7] In this study, the intern students reported that the methods used for esthetic knowing enabled the children and adolescents to express themselves, comforted them psychologically and helped them to cope. Furthermore, the students stated that esthetic knowing made the children and adolescents feel more highly regarded, helped them to initiate and continue communication and adhere to therapy. From this aspect, esthetic knowing can be an effective method to help children and adolescents between the ages of 9 and 18 with chronic diseases to communication with those around them and to cope with anxiety and stress. Thus, it can provide holistic nursing care by handling the psycho-social dimension of the patient. Esthetic knowing is an aid to students, both in recognizing children's and adolescents' reactions and assigned meaning about chronic diseases and in choosing appropriate nursing interventions and directing care.^[6,7,9,13,14] In Pardeu's study, the students reported that esthetic knowing was an interesting learning strategy that integrated amusement with thought, provided a humanistic, patient-centered approach in care and helped them to discover empathy.^[14] In a different study, students who used esthetic knowing reported that it increased their awareness of the child and the family, and the students realized their own clinical skills and understood the importance of hope for the families.^[13] Michael *et al.* detected that students who used esthetic knowing made changes to their care plans and care aspects. In this study, using esthetic knowing had an effect on the aspect of care provided by intern students.^[7] Using esthetic knowing helped the students in defining the informational needs of the children and adolescents, in noticing aspects that cannot be noticed by nurses, in establishing trust relationships and in seeing their own weaknesses. The students stated that using esthetic knowing gave them the opportunity to make a connection between the theory and the practice, to take part in care for the family and to guide social support. Furthermore, the intern students emphasized that esthetic knowing helped them in training, in providing awareness, and in the planning and directing

of treatment, and it gave them more time and provided on-the-job satisfaction. In the study of Wilson *et al.*, too, it is emphasized that art has reinforced the interaction between personnel and patients, increased work performance of health-care personnel and decreased burnout.^[25]

CONCLUSION

According to the results of this study, esthetic knowing enabled students to recognize the needs of children and adolescents with chronic diseases and recognize the meaning of the diseases for them. Furthermore, esthetic knowing helped the students to establish therapeutic communication and empathy with the patients and to provide family-centered and holistic care.

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