

Paediatric nurses' perception of the child-family dyad's autonomy in managing a chronic disease situation: the experience of an Italian Paediatric Department

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Key words

Paediatric chronic disease • Adherence • Autonomy

Summary

Introduction. Chronically ill patients have to take several medications and non-adherence to treatment can lead to severe and negative outcomes. Therefore, several interventions are suggested in literature to improve adherence rates in clinical practice. Adherence to treatment can be particularly troublesome in adolescents, who strive for autonomy and self-care independence. Literature suggests that improving adherence is useful to guarantee positive outcomes and reduce costs.

Aim. To explore how nurses perceived autonomy in parents, adolescents, and children related to the management of chronic disease.

Materials and methods. A qualitative study including 1 focus group and 7 semi-structured interviews conducted between Sep-

tember 2011 and October 2011. The qualitative data were analysed with the thematic analysis method. The sample included 12 paediatric nurses working in a Children's Cystic Fibrosis Unit and Neuromuscular Disease Unit.

Results. The 5 main categories that emerged from this qualitative study after the process of categorization were: 'Changes in daily lifestyle', 'Nurses' attitude towards educating the dyad', 'Adolescence and transition', 'Parents' attitudes towards chronic disease', and 'Availability of information'.

Discussion. Correct information and education is crucial for families who have a chronically ill child. Internet can be a misleading source of information and provide wrong information also in relation to prevention.

Introduction

Chronically ill patients are obliged to take several medications and the success of the therapy depends on patient's ability and willingness to engage in and maintain beneficial health behaviours such as taking medications correctly. However, it is also strongly influenced by the supportiveness of the patient's and family's environment, healthcare providers' practices, and by the quality of the healthcare system [1].

Literature suggests that improving adherence can be useful to ensure positive outcomes and reduce costs. On the contrary, the consequences of non-adherence to treatment can be disastrous for patients [2] and depend on forgiveness of the drug regimen (i.e. how much deviation from the dosing schedule is tolerated before an adverse event occurs).

K.K. Marciel [3] suggests various interventions to improve adherence in clinical practice in chronically ill children, such as the use of technological devices including automated reminders (e.g. text messages, alarms) and use of videos, which were well accepted by especially by adolescents. However, adherence can be particularly difficult during adolescence. In two large, multicentre studies, adolescents scored 55-60% on a knowledge measure focusing on Cystic Fibrosis (CF) care management, showing a significant knowledge

gap. However, Marciel did not evaluate the relationship between knowledge [4, 5] of disease management and adherence to treatment, the positive association between knowledge of prescribed treatments and treatment-related behaviours was described in other populations [6]. Despite the effectiveness of psychological interventions in improving adherence in chronically ill children [7], few behavioural interventions to improve adherence in CF patients have actually been developed and studied. Recently, an educational intervention utilizing a CD-ROM for children with CF was planned to fill gaps in knowledge and improve coping skills, but this study unfortunately did not evaluate changes in adherence behaviours [8].

Different previous research has consistently shown that education alone is not sufficient to change behaviour [9]. Behavioural interventions conducted in a group format, including the dyad, successfully increased adherence to prescribed caloric intake in young children with CF [10]. Some of the success of this program may be due in part to the much-needed peer support between parents, which has been related to improved adherence [11]. However, programs including interactive group sessions are no longer considered to be safe because of the potential for patient-to-patient transmission of respiratory tract pathogens [12, 13]. Thus, elimination of group-based activities and minimizing contact between patients has led to a

loss of peer support. Although studies have not evaluated the impact of the current infection control guidelines on patients' social and emotional functioning [2, 13, 14], social support has been shown to play a major role in facilitating adaptation to chronic diseases, including CF, and adherence to daily medical regimens [14, 15].

Although adherence to treatment and autonomy in self-care can prevent possible complications [16], to date, there is a paucity of studies in the Italian context regarding the correlation between adherence to treatment and self-care autonomy in the field of paediatric chronic diseases. To improve future quality improvement interventions it is crucial to have a better understanding of the context [17] and determine what is the nurses' perception regarding the autonomy of the dyads (parents, children and adolescents) in the management of chronic disease in an Italian Paediatric Department.

Autonomy refers to 'the parent's, child's or adolescent's freedom of choice, self-sufficiency and independence, the extent to which the child/adolescent feels able to shape his/her own life, as well as being able to make decisions about day-to-day activities' [18].

Materials and methods

DESIGN

This is a descriptive study with a qualitative approach including one focus group and semi-structured interviews [19]. Since the aim of the study was to investigate the healthcare professionals' perceptions of the autonomy of the dyad (parents and sons) in the management of a chronic disease, the qualitative approach was the most appropriate choice, so that participants could describe their personal experiences, feelings and thoughts.

In addition, literature suggests that qualitative data can contribute to provide answers to specific research questions also in epidemiological studies, by focusing on the understanding of meanings, beliefs, and attitudes from the point of view of the participants [20-23], allowing the analysis of human behaviour.

SETTING

The present study was conducted at the 'Giannina Gaslini' Children's Hospital in Genoa (Italy) and it involved paediatric nurses working in the two units of Cystic Fibrosis and Neuromuscular Diseases. The study was carried out from September 2011 to October 2011 and was approved by the Hospital Direction.

PARTICIPANTS

A total of 12 paediatric nurses agreed to participate in this study: 5 paediatric nurses took part in a focus group and 7 answered to a semi-structured interview.

The focus group participants were: 5 paediatric nurses; 1 experienced moderator, and 1 person taking notes and the participants were all full-time staff nurses working in the Neuromuscular Disease Unit.

Seven nurses working in the Cystic Fibrosis Unit were individually interviewed. We personally contacted the participants to explain the objective of our study and if they agreed to take part in our study we fixed an appointment with our interviewers.

Since the semi-structured interviews would have been audiotaped, a priori written consent was obtained from the participants.

The participants were all females aged between 25-37 years and their experience in the Unit ranged between 2-15 years. All participants were enrolled on a voluntary basis.

DATA COLLECTION

To define the questions, the research team met several times and additional demographic data were included (age, gender, years of experience in the Unit, education). The semi-structured in-depth interviews were administered to 3 nurses working in the Diabetes Outpatients Clinic to test acceptability and comprehensibility.

All the interviews were conducted in rooms inside the Units, in a relaxed atmosphere and no interruptions. Notes were taken at the end of each interview.

The first question was of a general nature to investigate how nurses perceived the autonomy of the dyad facing the chronic disease. The other questions aimed at identifying the major factors influencing the field accordingly to the evidence cited in the introduction.

DATA ANALYSIS

The second, third, and fourth authors listened to and verbatim transcribed the recordings, analysed and coded the transcriptions 'line by line' according to the 'thematic analysis' [22]. The three researchers analysed them independently, and then compared the codes they had identified to reach an agreement on the emerging categories.

VALIDITY AND RELIABILITY

To ensure the trustworthiness of the present study we adopted Lincoln and Guba's "Four criteria" [24]: credibility, confirmability, transferability and dependability. Credibility was demonstrated by the length of the interviews, data saturation, and independent analysis of the three researchers [23]. At the end of the interviews and after the data analysis, the researchers gave nurses the possibility to review the emerging themes.

Variation in sampling ensured the confirmability of the conclusions.

Reliability was confirmed by the negotiation of the codes done by the three researchers. Finally, the results were discussed with another 2 colleagues to confirm the transferability of the results who were not on duty during the interviews

Results

The results include the following 5 main categories, considered to be important factors influencing the nurse's

perception of the dyad's autonomy in managing a chronic disease in Paediatric Cystic Fibrosis Unit and Neuro-muscular Disease Unit:

- Changes in everyday life.
- Attitude of nurses in educating the dyad.
- Adolescence and transition.
- Attitudes of parents in facing the chronic disease.
- Availability of information.

CHANGES IN EVERYDAY LIFE

The majority of the nurses said that the chronic disease totally changed the family's everyday life. This change is triggered by the diagnosis that generates a strong sense of guilt, stress and anxiety in parents. Parents felt overwhelmed by a strong sense of disorganization, anger, fear, and often struggled with depression: they felt guilty for their child's condition. Initially, *"there are difficulties related to the lack of knowledge about the disease and its management practices, especially at home."*

However, nurses reported that it was a *"fleeting moment"*, because in a short time they became very skilled and autonomous in managing their child's disease, and sometimes were even *"better than the health workers themselves"*.

In addition, *"The parents recognize all types of symptoms and they understand if their child needs the application of non invasive ventilation, during the night"*.

The required changes regard not only the parents' and their ill child's personal behaviours, but also the house they live in has to be adapted to facilitate the autonomous management of the disease.

ATTITUDE OF NURSES TOWARDS EDUCATING THE DYAD

All nurses stated that they play a crucial role in helping parents and their children to increase the level autonomy and safety. *"Our job is to educate parents to help them increase both their self-esteem and their confidence in our competences and in nursing techniques"*.

The nurses pointed out that another key element is their ability to communicate. Nurses declared that it is possible to learn *"communication skills"* by attending special courses and with their own professional experience.

In addition, all nurses stated that it is instrumental to assess the different types of parenthood. In fact, some parents are totally alienated by their child's disease, whereas others *"serenely accept their child's disease"*. The nurses' ability to communicate with the parents and the children can improve the parents' and children's participation in the care plan to achieve their autonomy with the chronic disease.

ADOLESCENCE AND TRANSITION

All nurses are aware that adolescence is considered the most critical period of the individual's life, because it entails a series of changes that mark the transition to adulthood. Chronic diseases are challenging at any age, but even more in childhood and adolescence.

"In our practice, we meet adolescents who underestimate the disease, and refuse therapies".

Despite their condition, however, nurses reported that the social life of these patients continues, thanks to the steady progress of technology that provides them with innovative devices:

"They go out, have a pizza with friends, go to the cinema...".

It should be emphasized that their parents, who can be more or less permissive according to their health conditions, always influence their social life. It seems that the parents' age influences the adolescent's life:

"The degree of anxiety and fear makes parents more open-minded and permissive or more prohibitive"

"Attitude also changes depending on the age of the parents"

All nurses reported that, at least in the hospital, they tend to give greater independence to boys, and reduce the role of the parents.

Admission is the first step to win their trust:

"You have to communicate with him/her as if he/she wasn't ill, for example, you have to ask simple questions related to his/her hobbies, favourite movies / books. This relationship based on mutual trust helps us to make fun of the disease"

The interviewed nurses unanimously reported that in adolescents another critical moment concerning the chronic disease is the transition to the *"adult hospital"*.

"The "adult hospital" is another world."

Indeed, the first element of destabilization in this *"Transition"* is the *"change"* of the nurses, when the adolescents lose their relationship made of friendship with their former caregivers.

The fact that they have to take on all the responsibilities that used to be shared with the family and nurses, is the second element of destabilization. *"They want to grow up but they refuse responsibilities"*

PARENTS' ATTITUDE IN FACING THE CHRONIC DISEASE

All nurses reported that children are less rebellious than adolescents. Their life is influenced by their parent's perspective and knowledge

"The child's knowledge about the disease comes from his parents"

"The acceptance or denial of the disease of the child are related to the parents' perspective and ideas"

"If the parent does not accept the disease, it will be more difficult to educate the child."

In the long term, chronic illness can interfere with the child's habits, conditions, and it can affect them.

The interviews show that, in very young children, the burden of the disease is mitigated by the reassuring presence of an adult.

"The children face the disease as their parents do."

Subsequently, the patient acquires a sharper awareness of his status.

The patient gets to understand the explanations about the treatments, received from the nurses.

The ability to explain the disease to the child, and to make him/her more aware using simple words or play is very important. Not being honest could lead to confusion and mistrust.

All nurses pointed out the importance of helping them lead a life as normal as possible, and to encourage their participation in various activities.

AVAILABILITY OF INFORMATION

Nurses pointed out that Internet is accessible to everyone, including ill children, adolescents, and parents.

Nurses stated that *“Patients and parents already know everything about the disease when they meet us for the first time”*.

Nurses had the perception that information provided by the hospital is not considered as important as the one taken from the Internet. Certainly Internet can be dangerous and misleading, *“A guy asked me when he would have been transplanted, but he did not need it. He read it on the Internet”*

“The Internet is the most consulted tool for the resolution of their cares, although in some cases, it is a source of misunderstanding”. Nurses believed that any material used to educate patients must be selected by *“experts”*, such as physicians and senior nurses. One senior nurse suggested *“Educational material should be evidence-based”*

All nurses agreed on the definition of the parent as *“one of the figures for the patient’s development of autonomy.”*

Discussion

The following 5 categories emerged from our qualitative study after categorization of the verbatim transcriptions:

- Changes in every day life.
- Nurses’ attitude towards educating the dyad.
- Adolescents and transition.
- Parents’ attitudes.
- Availability of information.

This study confirmed and extended previous findings regarding the factors influencing the autonomy of the dyad.

Living with a chronic disease can profoundly affect the life of all the family members in terms of the everyday biological and psychosocial functions. Literature shows that comparing the Quality of Life (QoL) of a chronically ill child with that of a healthy child can be useful to assess the impact of a chronic disease. Health-Related Quality of Life (HRQoL) [25] can be conceptualized as a multidimensional construct which describes physical, psychological and social functioning. Impaired HRQoL was found in children and adolescents with several chronic conditions, e.g. diabetes, gastrointestinal diseases, cardiac conditions, asthma, obesity, end-stage renal disease, psychiatric disorders, cancer, rheumatologic conditions, and cerebral palsy [26].

Nurses perceived that parents played an important role in the life of the children and adolescents included in our study. Literature points out that parents play a key role in ensuring that their child’s treatment plan properly implemented and in preventing complications.

Overanxious parents may attempt to further restrict their children’s autonomy. These children could be inadvertently isolated from their peers and siblings due to concerns related to their illness, the fear of pain and the need for constant monitoring [27].

Nurses agreed that parents sometimes override their child’s decisions. This overstepping attitude probably derives from a situation of stress, and generally dictated by fear of the disease and the consequences it may entail. Nurses underlined the impossibility, especially for the mothers, to lead a normal life, due to their child’s disease. For this reason, it is very important to support parents and give them the help they need. For instance, it is instrumental to inform parents that the hospital offers them the possibility to speak to a psychologist.

The state of anxiety can *“be transmitted to their children”*. Nurses try to facilitate the adherence of the child and the family to treatment to both improve their health status and gain their confidence through high quality personalized care and constant evaluation. Constant evaluation prevents misunderstandings related to treatment, can improve adherence and facilitates the achievement of a more autonomous lifestyle.

In relation to this, nurses’ communication skills play a key role in the way they handle their relationship with these families.

Literature identifies two different types of adolescents with chronic diseases: a) those who are autonomous in spite of the disease; and b) those who are totally dependent on their caregivers [28].

These 2 types of adolescents require different approaches to build a strong sense trust with health professionals [28]. Nurses should firstly focus on the acceptability of the disease, then move on to encourage autonomy and adherence to treatment so that complications are prevented and a good quality of life is ensured.

Some adolescents instead have an excessive feeling of autonomy and tend to be indifferent towards the disease, because their unconscious desire to be autonomous prevails. On the contrary, adolescents forced to sit in a wheelchair are fully aware of the disease and their autonomy is limited by the constant presence of their parent. Obviously, it is necessary to negotiate the objectives of the care plan to be sure that personal preferences are respected. From this perspective, the education provided to parents and their chronically ill children also has a preventive purpose.

Transition to the adult hospital is another critical point, because they are never keen to leave the paediatric hospital even if they have grown up to be young adults. This could be an interesting point that would deserve to be investigated to prevent conflict between adult and paediatric unit/staff and rethink paediatric nurses’ education so that they may also deal with adolescent patients [29-33]. Our study showed that patients often use Internet to search for medical information but they do not share this information with physicians and nurses [34]. Adolescents in particular seem to be receptive to online health information and often use this information for their deci-

sion-making processes. Yet, online health information is often incomplete, inaccurate, or unreliable [35].

As reported in literature, the role of the patient has shifted from being a passive recipient of care to that of an active consumer of health information [36].

Health professionals are reacting to more 'Internet-informed' patients in the following ways: a) health professionals feel threatened by the information patients have and respond defensively by asserting their 'expert opinion' (health professional-centred relationship); b) Health professionals and patients collect and analyse the information together (patient-centred relationship); c) Health professionals guide patients so that they may retrieve health information from reliable websites (Internet prescription). In our study, nurses feared the Internet because they found that patients often did not share the information they had found with them. Our findings highlighted the need to establish quality standards for health website content, adequately train health care providers to help their patients retrieve reliable health information from the Internet, and maybe strengthen e-health literacy skills among online-information seekers, including health professionals themselves.

STUDY LIMITATIONS

The major limitation of this study is that it was conducted only in one centre. In addition, only nurses were

included in the survey, excluding the different perspectives of physicians and other healthcare workers, which could have provided further interesting data.

Conclusions

This is a first study to explore the factors that could affect autonomy management practice patterns in paediatric chronic patients of Cystic Fibrosis and Neuromuscular Diseases units. According to our findings, we would suggest to plan educational interventions so that nurses gain a better understanding on how to facilitate the integration of more effective strategies into daily practice (e.g. multi-level behavioural and psychological/affective interventions).

A Family Centred Care approach [37] could enhance the involvement of the child-family dyad in the care plan. Although nurses are often aware of this concept they sometimes have great difficulty in putting it into practice.

Our study confirmed that nurses play an important role in terms of providing education/information, because they stay with the patient on a 24/7 basis.

This study would benefit from further research to explore the views of the child-family dyad concerning the disease.

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