



Research Article

COMPREHENSIVE NURSING STRATEGIES FOR COPING WITH CHRONIC ILLNESS IN CHILDREN

Kavitha K^{1*} and Padmaja A²

¹B.L.D.E.A's Shri B.M.Patil Institute of Nursing Sciences, Vijayapur

²SVIMS College of Nursing Tirupati

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ABSTRACT

Illness in childhood may vary from non acute condition to acute and chronic conditions. Children with chronic conditions need long term care and continued attention in every stage of life. The care burden can lead to stress among children suffering with those conditions as well as their parents and family. Normally children and parents adapt to some kind of coping mechanisms to overcome the stress. These coping mechanisms may be positive or negative. As nurses are playing vital role in caring of children with chronic illness, they can help the children, parents and family to successfully cope with the demanding situations. The nursing care should be embedded with developmental needs of children. The future hopes for enhancing coping mechanism include active consumerism, inter disciplinary care, use of technology.

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INTRODUCTION

The degree of illness in sick children may vary from non acute illness which can be cared at home or admitted to hospital for observation and diagnosis (ex. Mild aching discomfort in ears); it may be acute where the children must be admitted to hospital and treated immediately (ex. pneumonia) or the illness may be long term and not self limiting in nature. These conditions are called as chronic illness¹. Chronic illness is medically defined as an illness lasting longer than 3 months². In general, chronic illnesses are characterized by at least three important features: prolonged duration, no spontaneous resolution, and minimal chances of complete cure³. In other words, chronic illness is “any physical, emotional, or mental conditions that prevent child or an adolescent from attending school regularly, doing school work, or doing usual childhood activities or that require frequent care by health care provider, regular use of any medication or special equipment⁴. It is a comprehensive term and includes congenital and acquired diseases as well as disabilities of somatic and mental nature⁵. It is estimated that up to 20% of the school age population have a long-term condition⁴.

Prolonged illness during the glooming stages of childhood tends to interfere with the normal growth and development. They may have difficulties in developing confidence in their own abilities and a sense of acceptability of their peer group.

Children respond to chronic illness primarily in one of three ways:

1. Increased dependency on care givers and fear interacting with others outside the home which may leads to over protection and vice versa.
2. Believing themselves as defective persons and may direct their anger to others.
3. Rebellng against their guilt ridden care givers when they reach older childhood and adolescence and become very independent, taking risks or indulging in forbidden activities that endanger their health still further⁶.

On the other hand, the parents also may feel sorrow, guilt, anxiety and anger. They feel sorrow or grief because their child can never be the well child of their dreams. Guilty is due to negative feelings that they have contributed to the child's illness in some way. They become anxious, confused, disorganized and overwhelmed by a feeling of helplessness, leading to an inability to take minor decisions concerning their child's care. Parents feel anger, and may express their anger to each other.⁷

The child's condition may also have impact on family relationships. How a family responds is based on the age and developmental stage of the ill individual, the strength and coping mechanisms of the family, and the family life-cycle stage.

In general, pediatric chronic conditions have two levels of consequences: (i) those experienced by the child or individual family members (school absence, activity limitation,

**Corresponding author: Kavitha K*

B.L.D.E.A's Shri B.M.Patil Institute of Nursing Sciences, Vijayapur

psychosocial and behavioral problems) and (ii) those experienced by the family system (disruption of usual routine, alteration of role and relationships) and other outcomes related to the family interactions with the child's health care providers⁸. Since chronic disease is a family affair, life and daily routines have to be arranged around the illness⁹.

Overview of Chronic Illness

Causes

Chronic conditions may develop from multiple causes:

1. Genetic conditions Ex. hemophilia, sickle cell disease, Thalassemia or Cystic fibrosis.
2. Congenital defects or insult during intra uterine development Ex. neural tube defect.
3. Insult or injury associated with birth and care following birth. Ex. Sepsis, prematurity.
4. acquired as complication of other diseases or injury Ex. brain injury, mental illness⁷

Prevalence

The prevalence of children suffering from a chronic illness varies globally, but the overall rate is estimated to be between 10% to 20%¹⁰. As many as 1 out of 4 children in the U.S suffer from a chronic health problem. The prevalence of specific diseases and conditions ranges widely.¹¹

Characteristics of children with chronic illness

Chronically ill children may be

- Handicap or disability that interferes with their ability to fully participate in society. This can be related to one of the following: medical impairment (chronic condition itself), functional limitation (mobility, self care, communication or learning behavior impairment) and difficulty maintaining social role in school or play.
- Medically fragile, technologically assisted and depend on medical device to sustain life (Ex. Mechanical ventilation, Intravenous nutrition or drugs, tracheostomy, etc.)
- Depend on medical device that compensate for vital body Ex. renal dialysis^{12,13}

Diagnosis of chronic illness

The conditions with chronic nature can be:

1. Detected at the time of birth or early infancy, Ex. Neural tube defect,
2. Parents may suspect that their child has a problem when she/he does not achieve expected developmental milestones and seek diagnosis Ex. cerebral palsy.
3. Recurrent illness may actually be related to a chronic condition (ex. Asthma).
4. Learning or behavioral problems can be identified during schooling⁷

Stressors associated with diagnosis of a child having chronic illness

A range of stressors that children with chronic diseases face were categorized into seven domains: medical complications, treatment and side effects, disruption in daily routines and activities, emotional reactions, communication issues, social

challenges, and concerns about future. The stresses can be classified into four types:

Day- to-day stresses: a) Constant attention required by the child b) Reaction of other children and the community c) Social relations d) Effect on siblings and e) Marital relations

Life maintenance stresses: a) Financial stress, insurance b) Housing c) Transportation d) Clothing and appliances e) Worries about the future f) Future children g) Schooling, vocational training and h) Residential care

Anticipated parental stress: a) Developmental milestones may be or may not be attained b) Entry into school- appropriate learning may not take place in a regular classroom c) Adolescence- must address issues such as sexuality and independence d) Future placement-must decide about placement when the child become an adult or when parent can no longer care for the child and e) Death of the child

Anticipated sibling stress: a) may react to the birth of the affected sibling b) Diagnosis of the condition- times of remission and exacerbations b) Entry into school- may experience particular stress if friends reject the child with special needs c) Adolescence- may be embarrassed to bring peer home d) Future placement- may worry about responsibility for the affected sibling especially if the parents are ill or die.¹⁴

Factors affecting adjustment of child and family to chronic illness

1. Available support system: marital relationship of parent, communication network
2. Perception of the illness or disability: previous knowledge of disorder, influence of religion and culture, beliefs about the cause of disorder
3. Coping mechanisms, available resources and concurrent stresses¹⁵

Coping Mechanisms of Chronically Ill Child & Their Families

Coping mechanisms are those behaviors directed at reducing the tension elicited by a crisis. There are two types of coping mechanisms identified:

Approach behaviors: movement toward adjustment and resolution of the crisis.

Some of the approach behaviors are:

- Asks for information regarding diagnosis and present condition; anticipates future problems; actively seeks guidance and answers
- Seeks help and support; shares burden of disorder with significant others
- Acknowledges and accepts child's awareness of diagnosis and prognosis
- Expresses feelings, such as sorrow, depression, and anger, and realize reason for the emotional reaction
- Realistically perceives child's condition; adjusts to changes and plan realistically for the future
- Recognizes own growth through passage of time

Avoidance behaviors: non adjustment or mal-adaptation to the crisis.

Approaches to avoidance behaviors are:

- Fails to recognize seriousness of the child's condition: may refuse to agree for treatment and showing anger and behaving hostile to staff. They may not be able to accept or adjust a change in progression of disease. They Intellectualizes about illness, but in areas unrelated to child's condition
- Use magical thinking and fantasy: Withdraw from outside world, refuse help and places complete faith in religion. They refuse to acknowledge the child's understanding of disease and prognosis rather continually look for new cures with no perspective toward possible benefit
- Punishes self: they feel guilt or blame and verbalizes suicidal intention. They will not try to make changes in lifestyle to meet the needs of family members. At many times they may resort to excessive use of alcohol or drugs to avoid problems. They may also experience inability to discuss possible loss of child or previous experience with death¹⁶

Avoidant coping tend to have a direct adverse effect on anxiety and depression. This kind of style appears to influence emotional distress and low sense of control over the illness²³.

Coping Strategies Adapted By Child with Chronic Illness

Coping strategies are mainly classified into three types

Appraisal focused: strategies are directed towards challenging one's own assumptions and modifying the way one think. This may include distancing self from the problem or challenge, altering goals and values, or identifying the humor in the situation to bring a positive spin

Problem focused: strategies are directed towards reducing or eliminating the cause of a problem. This includes finding out more information about the issue, learning new skills to manage it, or evaluating the pros and cons of the alternatives.

Emotion focused: strategies are directed towards reducing or preventing our own emotional reaction. This includes managing feelings by finding methods of release or distraction such as seeking social support or using relaxation techniques. Often chronically ill children tend to use appraisal and problem focused strategies.²⁵

Developing resilience among children with Chronic Illness

Children with more accepting and positive attitudes about their condition use a more adaptive coping style, characterized by competence, optimism and compliance. They display fewer behavior problems at school and at home. They use the following measures to develop resilience:

- **Connect:** with others, including family, friends, and social support organizations
- **Avoid:** seeing the challenges as insurmountable and act when faced with adverse situations
- **Nurture:** positive self-image and pay attention to oneself²⁷
- **Accept:** the chronic illness as a part of living and develop realistic goals
- **Look:** for opportunities that promote self-discovery, establish perspective and maintain hope

Resilience building is influenced by factors such as self efficacy; self perceived confidence in pursuit of goals, positive life attitude and a willingness to fight against the disease.²⁸

Stages of Coping with Chronic Illness

Stage 1: Shock, disbelief and denial

The diagnosis of a chronic illness is often met with intense emotion characterized by shock, disbelief and denial. It can last from days to months or even longer. They look for other physicians; attribute the symptoms of actual illness to minor conditions; refuse to believe the diagnostic test results; delay agreeing to treatment; refuse to tell or talk to anyone about the condition and deny the reason for hospital admission.

In children, denial has repeatedly been demonstrated as an important factor in their positive coping with diagnosis. Denial allows the child to maintain hope in the face overwhelming odds and to function adaptively and productively. Denial becomes maladaptive only when it impedes recognition of treatment or rehabilitative goals essential for the child's optimum development or survival.

Stage 2: Adjustment

The type of parental reactions to the child can affect the child's eventual adjustment to the condition. (1) overprotection: parents fear allowing the child to achieve any new skill, avoid all discipline and cater to every desire to impede frustration; (2) rejection: the parents detach themselves emotionally from the child but constantly nag and scold the child and provide adequate physical care; (3) denial: the parents act as if the condition does not exist (4) gradual acceptance: parents place realistic and necessary limitations on the child, foster reasonable social and physical activities and promote self-care.

Stage 3: Reintegration and Acknowledgement

The individuals and family take stock of what remains and begin to establish new goals for their lives. They are motivated to learn about the restrictions imposed by the child's illness and to decide how they want to function within those confines²⁰.

Role of Nurse in Coping of Child with Chronic Illness & Their Families

The nurse can help child in the following ways to cope with chronic illness

Normalization

Assist parents in strengthening the child's image by emphasizing the normal. The children can be encouraged to use clothing according to their likes, cosmetics, wigs, or changing hair style etc^{7,8}. Acknowledge the strengths and weaknesses of the family unit, by being supportive and open about the child's condition and treatment and providing family centered care³⁰. Educate the public regarding persons with special care needs and helping normalize experience for the child, family and community.

Hopefulness

Children especially adolescents are sensitive to the presence or absence of hope³¹. It helps protect the adolescent from incapacitating despair and assists in coping with unmet personal needs. It can result in increased participation in health seeking behaviors and an improved sense of well being.

Hopefulness can enhance quality of life and improves self-esteem of these children. Persons reporting higher levels of hope find multiple routes to goals, view setbacks as challenges, and better manage psychological symptoms.³²

Nurses can be instrumental in fostering hopefulness through environmental and interpersonal means.

- Converse with the child on neutral, non-disease related topics such as sports
- Be honest and consider the developmental stage while reporting about health condition
- Demonstrate competence and gentleness when delivering care
- Encourage and participate with the child in physical activities like going for walk
- Encourage the child to think ahead and discuss activities planned for the future

Realistic future goals

For children with severe disabilities, preparing for the future should be gradual process. Throughout the childhood, the parents should consider realistic vocational options. Advance financial planning should be considered. Help the adolescent prepare for the transition from pediatric health set up to adult health care setup. These include: presenting idea of transfer; assessing the readiness of the adolescent and parent.

Coping with ongoing crisis

Encourage the parents to establish support system. Spirituality plays a major role in effectively coping with the crisis. The parents should focus on child's strengths and encourage independence^{7,8,20}

Components of nursing care of children with chronic illness

Nurses should have a broad range of knowledge and skills in providing comprehensive care like pathophysiology and anticipated progress of the diseases. Family assessment skills are needed to identify the child's and family's strength, reactions to the stress and coping mechanisms in order to provide developmentally appropriate, cultural sensitive care. They also must know about resources such as community agencies, tertiary care centers, specialty professionals appropriate for the child and family with chronic conditions. The ability to communicate effectively and work collaboratively with other health professionals is also essential¹⁷.

Home care teaching and discharge planning

Provide condition specific education to help prepare the family for care at home (Ex. medication administration). Identify peer support group for supportive care interaction specific to the condition.^{8,20}

Coordination of care

Gain access to and integrate services and resources on behalf of child and family. Facilitate inter disciplinary communication network among professionals to prevent duplication of services and unnecessary cost. Suggest the family to maintain log of health care team members, their roles, when the child was shown to health facilities and any interventions done, the results of interventions, future planned interventions or treatments. This can be used to communicate

with the health care providers, particularly in case of emergency situations.²⁰

Respite care and other supportive services

These services may include home health services and parent support group²⁰

Supportive care for a child

Provide opportunities to express concerns about the condition and its effects on quality of life. Collaborate with the child and family to involve the child in self care management and decision making process considering cognitive and developmental level like self administration of medications, monitoring glucose level etc. Support for transition of adolescent to adult health services by introducing the adolescent to adult health care team⁸.

Health promotion

Review the next stage of expected development with parents and provide suggestions and strategies to help the child achieve developmental milestones. Remind parents of routine health promotion activities like immunization, dental check up etc. Assist the family as needed in providing a nurturing environment and offering praise for achievement⁸

Facilitation of education service planning

Chronic illness in young children may lead to decreased school readiness.³⁶ The nurse can assist the family with school entry of the child. Communicate with school personnel regarding modification in class room arrangement required by a child. Educate the teachers and school authorities about the medical/assistive device used by child. Nurse can act as liaison officer between school authorities, family and the health team.^{20,21}

Support for family's psychosocial adjustment

Provide opportunities to discuss how the child's conditions affect family daily lives. They can get help from social network like friends, relatives or neighbors in performing day to day activities like picking up children from school. Counseling may be helpful for parent's marital stress due to child's condition. Provide instructional materials, videos, books, pamphlets etc. for gaining information regarding child care. Allow siblings to express their feelings and concerns. Discuss with family members in sharing the responsibilities.^{8,20}

Emergency preparedness

Ensure that medical service needed for children who need technology for survival is available in home setup. Parents need to arrange for durable power of attorney so that consent for emergency medical care can be provided without any delay⁸.

Developmental care for children with chronic illness

Infant

Promote parent infant bonding by encouraging face to face interaction and spending time with the infant. Involve parents in caring of infant. Provide sensory stimuli such as soft music, using different textures for the infant to touch etc.

Toddler

Offer choices when possible based on likes and dislikes of child such as preference for dress, food etc. Help parents to recognize the toddler capabilities and allow him/her to take the time to practice and learn particular skill.

Preschooler

Explain the child about the purpose of therapeutic procedures and emphasize treatments are not punishment for any wrong doing. Incorporate play therapy as possible so that child can learn self-care, perform activity and feel sense of accomplishment. Encourage social interaction with peer group. Appreciate the child for efforts and success in performing activities.

School age children

Link the child to peer support group with same kind of chronic illness to promote social interaction and help to recognize that others also have same condition. Encourage contact from school peers, and friends during the absence of school through phones or other means to complete the school assignments. They can be sent to special camps for children with chronic conditions (if available) to promote recreation, social interaction and self care skills.

Adolescents

Adolescent should be educated about illness, the care needed to manage or control the condition and problem solving skills for self care. Teach regarding transitional care, sexual maturation and the importance of protective sexual activity. Discourage risk behaviors such as alcohol, smoking etc. Provide opportunities to express concern regarding self management, vocational planning and future independent living^{7, 8,20,21}.

Complementary therapy

Music therapy: used to induce positive behavioral changes, reduce pain stress, or various other positive effects³⁸

Pet therapy or animal assisted therapy: has been found to be beneficial in ease the stress of the child and family. Pets enable family members to express pleasure and affection, and family may spend more time together around pet related activities³⁹

Hippo therapy or horseback riding for the handicapped or equine-facilitated psychotherapy: the unique movement of the horse and the child helps to achieve flexibility, balance and muscle strength among children with physical defect. Children with mental or emotional disorders may experience increased self-esteem, confidence and patience as a result of unique relationship with the horse⁴⁰.

Massage and aroma therapy: The essential oils derived from medicinal or aromatic plants (ex. neroli, juniper, eucalyptus and lavender) are applied externally by massaging them into skin. Aroma therapy has been found to help relaxation, calmness and general comfort among cancer patients⁴¹.
Homeopathic and herbal therapy

Reflexology or zone therapy: application of pressure to the feet and hands with specific thumb, finger, and hand techniques without the use of oil or lotion.⁴²

Relaxation techniques: which include guided imagery, muscle tension relaxation

Psychotherapy

There are four types of Psychotherapies found to be effective in coping with chronic conditions among children and families. They are:

Cognitive behavioural therapy (CBT): focus on modifying social/environmental and behavioural factors as well as maladaptive thoughts that may exacerbate or cause symptoms, and prevent relapse.

Family therapy (FT): interventions typically focus on altering patterns of interactions between family members. It includes structural family therapy, strategic family therapy and behavioural systems family therapy.

Problem-solving therapy (PST): include didactic instruction in problem-solving skills, followed by in-session modelling, behavioural rehearsal and performance feedback, as well as homework assignments.

Multisystemic therapy (MST): incorporates a wide range of evidence-based interventions based on the individual needs of the child and family, including cognitive- behavior approaches, parent training and family therapies. It targets broader systems such as the child's school, work or medical team as needed⁴².

Psychological therapies have two beneficial effects: (i) improved adaptive parenting behavior and (ii) improved parent mental health⁴³.

Existing Shortcomings in Evidence Related To Coping among Chronically Ill Children

At present, the incidence and prevalence of chronic diseases in pediatric age group in different geographical region is not available, hence there is no proper mechanism in implementing care for effective coping strategies. Follow up studies are needed for assessing the impact of interventions on coping. Relatively little research has been done to examine age and developmental patterns in children's coping with chronic illness. Minimal or lack of support groups related to specific conditions for better management of self care.

Future Strategies for Better Coping Mechanisms among Children with Chronic Illness and Their Families

Active consumers

Patients and their care givers may take many active steps to manage their own care like recognizing and acting on warning signs and symptoms, diet, exercise etc.

Better tools to manage chronic disease: in the future, people with chronic illness will have access to information to manage their disease. Some chronic care management program organizational group meetings among people with the same chronic disease to share information provide motivation and support in maintaining healthy behaviors.

The development and evaluation of interventions to enhance children's abilities to cope with the stress of chronic illness need to be developed.

Technology: using the internet can be helpful in managing chronic illness.

Care coordination: linking people with special health care needs and their families to services and resources in a

coordinated effort to maximize the potential of the client and provide optimal health care.

Inter-disciplinary care: integrating baccalaureate and masters-prepared nurses into interdisciplinary treatment teams along with clinician and other health team members such as physiotherapist, occupational therapist as part of disease management program is a way to reduce the cost of health care as well as providing holistic care^{20,7,8}.

CONCLUSION

Children with chronic illness are more vulnerable as compared to the normal children of their same age group because of their nature of illness, and more importantly their limited understanding of, and lack of control over what happening and what will happen to them. Moreover, frequent visit to the health care set up also has negative impact on emotional wellbeing of those children. In the past, most of the children suffering with chronic conditions had a short life span. But, with lot of treatment modalities and other therapies available at present, many children live up to adulthood. Even though the life expectancy increased among these people, the quality of life is not satisfactory. The contributing factors include various stressors associated with the long term –illness and poor coping mechanisms. Hence it is the responsibility of the health care providers in general and pediatric nurses in particular to assist the children with chronic illness and their families to effectively cope up with the condition and adapting to the modified lifestyle.

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