

# Self-Care Behavior Assessment of Fragile School-Age Children: An Application of Orem's Self-Care Framework

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## Abstract

**Introduction:** Fragile children who were once called; “terminal cases” nowadays are able to live, due to technical advances; although they are requiring permanent assistance. This study aimed to identify the levels of self-care behavior of school-age medically fragile Jordanian children.

**Methods and Material:** A cross-sectional design using Orem self-care behavior questionnaire to measure the level of self-care behavior of 96 medically fragile children in capital city (Amman), who hospitalized at least once at the affiliated hospitals.

**Result:** 63.3%, n=61 children had high level of self-care behavior with overall mean = 62.3 SD=20. ANOVA and Tukey’s post hoc comparisons of the three groups indicate that the level of self care behavior at the late school age 12-14 years old (mean = 71.56, SD = 4.71) and the early school age 6-9 years (mean = 67.05, SD = 4.73) reported significantly higher than the middle school age 10-12 years old (mean 66.95, SD = 4.37),  $p = .001$ . A round half of the children complaining of respiratory disease 42.7%, n=41.

**Conclusion:** Performing nursing interventions and providing proper discharge plans for school age children and home care for medically fragile children will be based according to the self-care behavior level.

**Keywords:** Fragile medical children, pediatric nursing, school-age population, self-care

## 1. Introduction

Several sick children who frequent hospitalized are those needing for a great deal of caring. Children may need devices for hearing, vision, physical mobility, more caring for survival as breathing: tracheostomies; oxygen therapy devices or feeding: gastrostomies (Cohen et al., 2010). However, caring for children during hospitalization, discharging them from hospital did not show recovery. Definitely, needing for care is continuing after them going home (Spratling, 2013). In general children consist part of a growing population, who, as recently as, could not have survived, due to “life-threatening problems” nowadays are able to live, even though requiring permanent assistance as a result of technical advances. These children are frequently defined as “medically fragile (Cohen et al., 2010; Spratling, 2013).”

Therefore, due to higher costing in hospitalizing of medically fragile children for long-term needs, so hospitalization is not suitable option. The long-term accountability for those children with chronic disease falls as a substitute on families. Thus, it becomes the responsibility of the parents to provide children with guiding self-care actions in order to preserve or improve their nearby wellness, thus cultivating their overall quality of life (Cady, Finkelstein, & Kelly, 2009). Orem (1995) refers to the parents as the dependent care agents, i.e., those who “accept and fulfill the responsibility to know and to meet the therapeutic self-care demand of relevant others who are dependent on them” (p. 457).

Family-centered home care (FCC) of children with chronic disease in Jordan was a newly developed concept, and it has been little investigated or explored. Whereas, nursing literature regarding the care of children with chronic disease exists, limited studies are available about the caring of these children at home. Furthermore, little of these studies utilize Orem’s self-care theory as a framework.

Nurses today could also benefit from the applying of assessment tools grounded in nursing theory. Many of the assessment techniques currently used in practice are focused primarily on the physiological processes of the

patient. Therefore, utilization of theory-based assessment tools will serve as a guide through whom nurses may assess and treat patients in a holistic manner. The study aimed to: assess the level of self-care behavior for fragile children with chronic disease, who's dependent on medically assistive device for survival, in their home by using Orem's Self-Care framework.

### *1.1 Literature Review and Study Conceptual Framework*

The literature reviewed was organized in the following manner: (a). Epidemiology of medically fragile children (b). Applications of Orem's framework in pediatric practice and (c) Pediatric home care and caregivers.

#### *1.1.1 Epidemiology of Medically Fragile Children*

Medically fragile child is known by A New York State Office for People with Developmental Disabilities (OPWDD) (2013) as "an individual who is under 21 years of age and has a chronic devastating condition or conditions, who may or may not be hospitalized or institutionalized, and is: technologically device-dependent for life or health-sustaining functions, and/or requires a complex medication regimen or medical interventions to maintain or to improve their health status, and/or in need of ongoing assessment or intervention to prevent serious deterioration of their health status or medical complications that place their life, health or development at risk". Chronic debilitating medical conditions include, such as, bronchopulmonary dysplasia, cerebral palsy, congenital heart disease, microcephaly, and muscular dystrophy ... etc (Bramlett, Read, Bethell, & Blumberg, 2009). It is challenging to describe a "typical" medically fragile child. The one attribute that most of these children do share is a dependence on technology for everyday functioning. Therefore, medically fragile children are also termed "technology-dependent" (Stutts, 1994, p. 501). The United States Office of Technology Assessment (1987) described a technology dependent child as a person any child with a chronic disability, "who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability" (p. 3). The types of medical technology devices accustomed in care for these children are different, and include devices such as "ventilators, oxygen therapy, cardiorespiratory monitoring, total parenteral nutrition and tube feedings" ... etc (Porth & Bakewell-Sachs, 1995, p. 78).

The Hashemite Kingdom of Jordan witnessed a significant development in the level of awareness on the rights of disabled people following the origination of the international community represented by the United Nation to prepare a draft international agreement to protect and enhance the right of disabled people on 2007. The kingdom was among twenty countries that approved this agreement. At Hashmia Kingdom of Jordan the higher council for disabled people affairs was established the law No (31) on 2007 which is the institutional framework called upon by strategy document. There are many centers provide health services, the number of care centers for disabilities children in Jordan (163) centers distributed in all the country (Ministry of Health Strategy (Jordan) 2013–2017). Regardless of their large number, there is lack of many services in terms of quantity and quality, also fragile children based age group of disabilities in Jordan necessitate for strategic intervention planning.

At Hashmia Kingdom of Jordan the main classification and number of cases accordance to population census on (2004) are: 1. Physical disability: 17299 Cases, 2. Mental disability: 19724 cases, 3. Hearing disability: 9914 cases, 4. Vision disability: 5580 cases, 5. Multidisabilities: 7991 cases and 6. Cerebral palsy: 5076 cases was added to this classification (National Health Strategy 2008- 2012). Nowadays, related to regional wars and political issues in neighbors countries, increase the refugees number in Jordan as well as each category is increased and recent statistics are not available (Ministry of Health Strategy (Jordan) 2013–2017).

#### *1.1.2 Applications of Orem's Framework in Practice*

Orem one of the American foremost nursing theorists developed a conceptual model of self-care, involving three theories: 1) self-care, 2) self-care deficit, 3) and nursing systems. This module has been applied to many different areas of nursing practice. Literature supports the ability of Orem's three theories related to self-care deficit have ability to be both explanatory and predictive of self-care practices. In addition Orem's self-care deficit theory of nursing can be effectively director nursing research. One application of Orem's theory on fragile children was used by (Dashiff McCaleb, & Cull, 2009). This study applied Orem's self care-deficit theory concepts on 152 fragile adolescents with Type 1 diabetes aged between 11 and 15 years such as universal and health deviation self-care. A mean of 27.26 of health deviation self-care indicating more positive self-care behaviors and treatment adherence. 75% of the time representative that these adolescents took care of their self-care needs because the general mean for this sample was 75.37.

Health deviation and universal self-care were significantly and positively related ( $r = .36, p < .001$ ). Dashiff, et al (2009) suggested that age is significant factor to self-care deficit in diabetic children. So, health deviation self-care concept as defined by Orem decreases with age, and early adolescence or late school age is an appropriate time for

interventions to strengthen self-care behaviors.

### 1.1.3 Pediatric Home Care and Caregivers

Children with special health problems previously were called children with disabilities; or medically fragile children now are part of a developing population who are dependent on technology for survival. Many medically fragile children are cared for in their homes; in spite of the rigorous care needs characteristic of these children.

Caregivers for these children are challenged with many responsibilities, including the daily care of their child in addition to the harmonization of dynamic activities. The challenging such as: scarce access to health care, little service accessibility, incomplete insurance and financial restraints may further complicate caring for a medically fragile child in the hospital when medically acceptable and desired by the family, allowing medically fragile children to be cared for at home is best for their health and development (Morawska, Gregory, & Burgess, 2012). Children succeed in both aspect of life psychologically and physical development in the care of a sympathetic family and the hazard of infection is reduced for a child cared for at home (Svavarsdottir, Sigurdardottir, & Tryggvadottir, 2014). Continuous home nursing services empowers medically fragile children to be cared for at home. In many studies, home nursing care and facilities have been shown to be intensely less expensive than hospital care (Dashiff et al., 2009).

## 2. Method

### 2.1 Study Design

The descriptive design was used in this study to interviews 120 children and their families to identify the level of self-care in Jordanian school-age medically fragile children.

### 2.2 Study Sampling, and Setting

Study population was school-age medically fragile children (ages 6 to 14 years) primary followed at the outpatient department by convenience sampling technique from two hospitals in Jordan. Sample size was (88) child, calculated based on Cohen's (1988) method by considering the function of  $\alpha=0.05$ , effect size 0.3 and power 0.80. Children participate if they were in school age, and if they dependent on any technologically device for life or health-sustaining functions, and/or requires a complex medication regimen. Medical information including medical diagnosis, gender, number of hospitalizations, causes of re-hospitalization, duration for disease, type of disease were obtained from medical records.

### 2.3 Study Measurement

The families were interviewed by used Orem's self-care behavior for fragile a self-care questionnaire (*SBFCQ*) to assess self-care practices. It consisted of 50 items, 37 positive and 13 negative items. Answers were in a Likert scale with three levels ranging from "never" to "always." The scores ranged from 0-100 considered interval level data, has three level: the lowest is from (0–33), moderate from (34–66) and the highest from (67–100) of self care (Fan, 2008, Luo, 2003).

(Appendix 1) contains examples of questions used in the questionnaire (Fan, 2008; Luo, 2003).

Considered for testing and developing a valid and reliable the Arabic version of the (*SBFCQ*), a cross-cultural validation was carried out; the internal consistency for the translated (*SBFCQ*) yielded a Cronbach's alpha of 0.77.

### 2.4 Analysis Plan

Data were analyzed using (SPSS, Inc., Chicago, IL, USA version 22). Descriptive and inferential methods of statistical analysis were including in this study. Descriptive statistic was used to organize and summarize the data as calculating mean scores and standard deviation (SD). Inferential statistics as Pearson correlation coefficient ( $r$ ) and Analysis of variance (ANOVA) were used to determine the relationships and differences between selected variables. A  $P$ -value of 0.05 or less was considered to be significant.

### 2.5 Ethical Approval

This study was approved by Institutional Review Board (IRB) ethical committee of research at faculty of Nursing at the Applied Science Private University. As well as, ethical approval was obtained from each hospital setting. There were no identifying information regarding the study participants has been present.

## 3. Results

A total of 94 caregivers of medically fragile children participated in this study with response rate was reached to 80%. Medically fragile children age was ranged from 6 to 14 years with mean ( $M= 9.31$ ,  $SD =1.86$ ). More than half were male 56.2%,  $n=54$ . Most of them in middle school age 45.8%  $n=44$ . The largest part of them (24%  $n=23$ )

had been 3times experience for hospitalization. A round half of the children complaining of respiratory disease 42.7%, n=41 such as chronic bronchial pneumonia and bronchial asthma; thus, their treatment were requiring chest physiotherapy and respiratory nebulizer. Thus, 49% of those children were complaining from chronic diseases since one to two years in their lives, 73.5% of them their mothers were caring for them. Table (1) describes the demographic characteristics of the children participated in the study.

Table 1. The demographic characteristics of the children participated in the study

Items	Frequency	Percentage %
<b>School age</b>		
Early school 6-8	36	37.5
Middle school 9-11	44	45.8
Late school 12-14	16	16.7
<b>Number of previous hospitalization</b>		
1	5	5.2
2	17	17.7
3	23	24.0
4	21	21.9
5	20	20.8
6	9	9.4
7	1	1.0
<b>Gender</b>		
male	54	56.2
female	42	43.8
<b>Duration for disease</b>		
1-24 month	47	49.0
25-48 month	40	41.7
4 years and more	9	9.4
<b>Type of disease</b>		
Renal disease (NS)	10	10.4
Cystic fibrosis (CF)	9	9.4
Cardiovascular (CHD )	24	25.0
Respiratory disease	41	42.7
Gastrointestinal tract disease	7	7.3
OTHER system disease	5	5.2
<b>Caregiver</b>		
Mother of the child	72	73.5
Father of the child	6	6.1
Legal guardian or other relative	18	18.4
<b>Caregiver educational level</b>		
High school	22	22.4
College (diploma)	19	19.4
University (bachelor)	46	46.9
Higher educational	9	9.2

Scores of the self-care behavior ranged from 30 to 84 (mean = 62.3, SD=20). Table 2 presents the level of self-care by the age categories of the children. The majority of children engaged in high levels of self-care behaviors (63,3%,

n=61) having high level such as (76, 77, 82). Moreover a higher percentage of self-care patients are in the middle age-school patients than both other two groups (29.17%, n= 28). In addition, the middle-age groups (9-11years) just 3 children (3.1%) had low levels of self-care, see Table 3.

Table 2. Age of child and self-care levels (n=96)

Child age	Age 6-8 (N=36)	Age 9-11 (N = 44)	Age 12-14 (N= 16)	Total N =96
Self-care level	37.49 %	45.84%	16.67	100%
0-33 (low)	0(0.00)	3 (3.125 )	2.08(2)	5( 5.205)
34-66 (moderate)	14(14.58)	13 (13.54)	3 (3.125)	30(31.245)
67-100 (high)	22(22.91)	28 (29.17)	11(11.46)	61 (63.54)
Total				96(100%)

A one-way ANOVA was used to test for level of self care differences among the three school age grade groups. Self care level differed significantly across the three school age grade,  $F(6, 848.6) = 16.812, p = .001$ . Tukey’s post hoc comparisons of the three groups indicate that the self care at the late school age 12-14 years (mean = 71.56, SD = 4.71) and the early school age 6-9 years (mean = 67.05, SD = 4.73) reported significantly higher than the middle school age 10-12 (mean 66.95, SD = 4.37),  $p = .001$ , see figure 1. Health deviation self-care was a mean of 30.92, SD=2.61, indicating more positive self-care behaviors and developmental self-care behavior (45.0.SD=2.8). Health deviation self-care was significantly and positively related ( $r = .840, p = .000$ ).

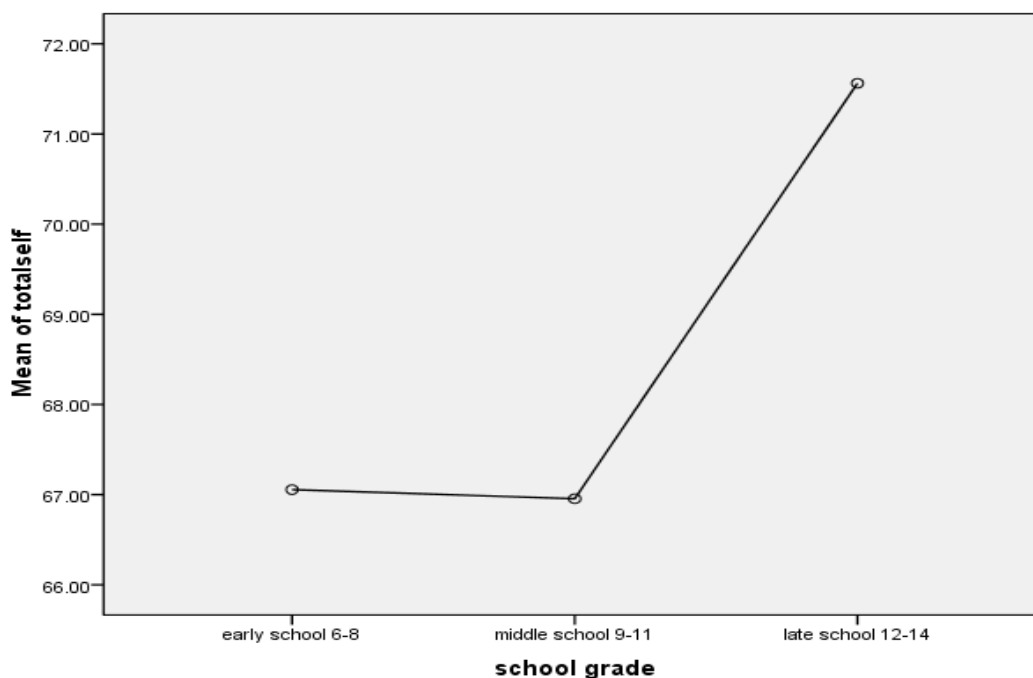


Figure 1. Different mean level of self-care behavior of fragile children with school age grade

#### 4. Discussion

Following nursing services after discharge enable medically fragile children to be cared for at home. The current study showed the high level of self-care in Jordanian fragile school-age children, consistent with the findings of Luo (2003) who studied self-care practices in nephritic syndrome school-age children. Also, this study finding is congruent with Fan, (2008) who used Orem’s self-care theory as the conceptual framework to identify the level of

self-care behaviors of school-age children (6–12 years) with heart disease. Although it is not known accurately why the level of self-care was high in these patients, there are some possible explanations. The first possibility is that these children had enough health education when hospitalized to learn good self-care at home; during hospitalization, nurses educated children and their caregivers about for example respiratory disease such as bronchial Asthma, cystic fibrosis, renal disease, and it is possible that the nurses' education encouraging high levels of self-care to prevent re-infection and re-attacks. As well, a physician routinely sees children with this diagnosis at least once or twice after discharge, and physicians also teach self-care practices. A second clarification relates to family support, which Orem suggests is serious (Orem, 1995).

In Jordanian culture, generally, a child who suffers from a chronic condition such as respiratory disease would be met with a firm concern from the caregiver. Finding of the current study is similar with Bellin et al. (2016) in their qualitative study that they found that their study confirmed the need to improve asthma, control in those fragile population including ongoing child and family education and self-management support. Family responses include physical support (such as getting the chest physiotherapy device to use at home and especial nebulizer buff at any time and any place by the child himself and emotional support. Adequate self-care practices could be promoted by providing the child information about his status and emotional support (Spratling, 2013). Consequently, caregivers and their children need to establish a collaborative relationship with health profession, to be able to offer quality and evidence-based health care services (Svavarsdottir et al., 2014).

Fragile children are need for frequents hospitalization even there is parent-professional collaborations. Fragile children in the current study had frequent hospitalization 24% of them had more than twice admission to hospital and these findings are congruent with (Russell & Simon, 2014) study. Those children were differentiate by extensive health care service needs, one or more severe chronic clinical condition, severe functional boundaries, and high projected use of health devices that may include frequent or extended hospitalization, various surgeries, or the continuing involvement of several subspecialty services and sources (Russell & Simon, 2014).

In the current study around 74% of the caregivers were mothers of fragile children who have strong attachment with children. Around half of caregiver had Bacculreate degree, thus they can teach their medically fragile children how to care for themselves in accurate way, in addition to high-quality caring particularly for early school age 6-9years, and consequently they had high level of self care behavior.

While the dependent caregivers of medically fragile children are often have principle of technically skilled, health care professionals may presume that caregivers are totally familiar with treatment models and rationales. Moderately, caregiver may need the same amount of education that any other them would receive. As a result, nurses should continue to educate caregivers about modern and/or up to dating machinery usage, observation and skills, situation that validate intervention, and carry of growth and development.

The school-age (12-14) year's old fragile children in this study have the highest mean level of self-care behavior might also, be explained by differences in the ability of early, middle, and late school-age children to perform self-care. Late school age or early adolescent are built-up feeling of independence on self-care based on different aspect of growth and development; physical, cognitive, psychological, social, spiritual in personal construction which enhancing healthy self-care behavior (Ostwald et al., 2010; Hockenberry, Rodgers, & Wilson, 2017). Thus, finding of current study is congruent with (Dashiff et al., 2009) suggestion that health deviation self-care is decreased with age development, and early adolescence or late school age is an appropriate time for interventions to strengthen self-care behaviors.

By implementing Orem's Self-Care theory into basic nursing care, pediatric nurses will be able to holistically assess the needs of fragile children in an efficient manner. The self-care requisites defined by Orem (Orem, 1995) are easily applied into the nursing process epically in first step: the assessment. The requisites are considered as to range from the physiological (universal requisites) to the psychological (developmental and health-deviation requisites). Since physiological requisites must be met for survival fragile children and protection of functioning, they are given importance and listed first in the assessment tool. Consequently, by controlling nursing assessments around the given structure of the requisites, more holistic assessments may be completed and children needs with their caregivers prioritized.

## 5. Study Implication

Nurse administrators could be upsurge their awareness related to the importance of self-care education of fragile children to strengthen the quality of their care.

Care planning for fragile children at home is the most important issue that is built on the finding of this study for school age medically fragile children.

Cumulative the technological advances machines and managed care lead to increase numbers of medically fragile children cared for in the home. Consequently, these children will be encountered by nurses in many different areas of practice, including acute care settings, community works, and schools. So, it is vital that nurses be cultivated about the basic children selves-care needs and specialized care delivery methods these children require. Additionally, nurses will also be required to become more and more adapted with home medical equipment, such as respiratory equipment's and feeding tubes ... ets.

## 6. Conclusion

This study is the first over country and population-based review of medically fragile children in Jordan based on our information. Furthermore, an applied reference levels for self-care behavior was derived from a large assembly of Jordanian school-age fragile children. This study adds to the literature importance about self-care practices and behavior for medically self-care theory (universal, developmental and health-deviation requisites).

## 7. Limitation

This study has some limitation such as reduction defined population and small sample size according the accessible one. This study was conducted in teaching hospitals in metropolitan areas, where there is availability of up-to-date technological medical machines and the results cannot be generalized to rural areas. Also, despite similar standards for nursing care for children between hospitals that involved in the study, the quality of health education might have differed. Self-report questioner is considered difficult issues to collect objective data related to its subjectivity, so using it considered one of limitation. Additionally, it would be appealing to conduct a replication study with children in different countries and to compare their reports of self-care activities. Further qualitative cross-cultural studies about caregiver and self-care assessment of fragile children can add to the nursing knowledge of the care of chronically ill children.

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## Competing Interests Statement

The authors declare that there is no competing or potential conflict of interest.

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## Appendix

Some items of Orem's self-care behavior for fragile a self-care questionnaire

Instrument Item	Never 0	Sometimes 1	Always 2
<b>Universal Self-Care Dimension</b>			
Stay in fresh air, no pollution air environment.	0	1	2
There are assistive devices for breathing.	2	1	0
There are barriers or food restrictions	2	1	0
Use assistive devices for elimination (laxatives, ostomies..)	2	1	0
<b>Developmental Self-Care Dimension</b>			
Keep contact with friends when you are sick at home or in hospital.	0	1	2
Do not go to school because of feeling uncomfortable related to body change (cyanosis, ...)	2	1	0
Play sports and games with friends.	0	1	2
Talk about homework or talk with friends.	0	1	2
<b>Health-Deviation Self-Care Dimension</b>			
Eat foods against medical instructions (e.g. high fat roast chicken, animal fat oil, and fried food).	2	1	0
Adherent to regimens: Play sports and games with friends palpitation, dyspnea,( understand the rationale behind care measures)	0	1	2
Choose activities that you can tolerate (sketch, listening to tapes, walking slowly) when you have fatigue. (advocate to treatment)	0	1	2
Not remember to take medication.	2	1	0



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Take medication on time as agreed.	0	1	2
Go to crowded areas.	2	1	0
Tell your caregiver if you have S&S of side effects of medication such as (heart rate less than 80/min).	0	1	2

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