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Title: Application of Orem's Self-Care Nursing Theory for Spinal Muscular Atrophy: A Case Study Design

Running title: Orem's Nursing Theory

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Abstract

Background: Spinal muscular atrophy (SMA) is a neuromuscular disorder that is highly frequent in children. This leads to serious health challenges for children of different severity levels. Orem's Self-Care Deficit Nursing Theory helps parents get involved in their child's care, leading to better outcomes and healthcare experiences. So, this case study examines the effectiveness of applying Orem's self-care nursing philosophy to a child with SMA and his parents.

Methods: This study used Orem's Self-Care Deficit Nursing Theory to treat particular self-care deficiencies relating to mobility, eating, swallowing, and respiratory function in a 3-year-old child with SMA Type I. The researcher recognized patient's lack of self-care and created a tailored plan for self-management training. Understanding the needs of the patient, organizing the implementation, and creating the educational system were the initial steps. The final phase entailed putting the self-care program into action and assessing its success. Two methods were used to gather data: structured interviews and surveys on Orem and self-care ability. A 60-minute educational intervention was broken up into four in-person sessions.

Results: This study illustrates the useful application of theories in illness management. This theory was used to identify deficiencies in movement, feeding, swallowing, and respiratory function. Nursing interventions focused on neuromuscular deficits, while educational interventions enhanced parents' awareness.

Conclusions: This case study investigates the usefulness of Orem's theory in controlling SMA, empowering parents, emphasizing patient-centered care, and the possible advantages of nursing theories in treating chronic diseases.

Key words: Nursing education, Spinal Muscular Atrophy, Nursing theories, Children, Neuromuscular disorders

1. Introduction

One of the most prevalent neuromuscular diseases in children, spinal muscular atrophy has a high morbidity and mortality rate (1), (2). Infant mortality due to genetics is the most common, accounting for 1 in 10,000 live births. and having a global prevalence of between 1-2 per 100,000 people (3). The complex condition known as spinal muscular atrophy (SMA) causes muscle weakness, atrophy, and functional impairment due to the degeneration and spinal cord motor neuron loss. SMA can range greatly in severity; Type 1 SMA, which typically manifests in the first few months of life, is the most severe (4). Untreated SMA type 1 has a classic clinical presentation of flaccid weakness, motor regression, muscle atrophy, dysphagia, respiratory failure, and untimely death in the first six months of life(5), (6). The mildest form of SMA, Type 4, on the other hand, manifests symptoms in adults (7). The child's ability to move around, breathe, and swallow are all significantly impacted by the SMA-related progressive muscle weakness and functional limitations(8). SMA also puts a significant burden on parents, who are crucial to the upbringing and welfare of their children(9),(10). In order to gain control over their wellbeing and general health by a variety of disease-related activities, children with disabilities who self-care engage in a dynamic, regular, and adaptable process in which responsibility and decision-making are shared by them and their parents (11), (12). The Self-Care Deficit Nursing Theory by Dorothea Orem emphasizes the role of nursing in helping people meet their self-care needs. The definition of self-care is actions taken regularly to uphold one's health and wellbeing, and nurses must assist patients in daily activities until they are able to do so on their own (13), (14), (15), (16). Orem's theory recognizes the importance of parents taking care of and supporting their children in order to ensure the child's wellbeing. It recognizes the value of educating and assisting parents so they can actively take part in the care of the child and increase their

confidence in handling the condition (10). Informed decision-making and efficient management of the difficulties caused by SMA are skills that nurses can teach parents to use in their active involvement in their child's care. This entails instruction on medication administration, observation of the child's respiratory condition, identification of deterioration signs, and seeking the proper medical attention. Orem's Self-Care Deficit Nursing Theory offers nurses a useful framework for evaluating, organizing, and putting into practice interventions that support independent self-care and maximize the wellbeing of the child (5). Additionally, by encouraging parents to actively participate in their child's care, nurses can recognize and support the crucial role that parents play in improving outcomes and improving the healthcare experience for everyone(17). The case study demonstrates how nursing theories can direct efficient patient and parents' education, encourage favourable outcomes, and emphasize the theory's practical use in SMA treatment

Case presentation

In this case report, According to Orem's self-care deficiency theory, data on a 3 years and 9 months old boy patient who was monitored in the pediatric intensive care unit and diagnosed with Spinal Muscular Atrophy (SMA) Type I (Werdnig Hoffmann Disease), which is characterized by delayed motor milestones, progressive muscle weakness, failure to thrive (FTT) and compromised respiratory function, poor feeding, difficult swallowing, poor reflex and risk for aspiration. The child's parents, are actively involved in their son's care and are seeking guidance to improve their understanding of SMA management and enhance their self-care abilities.

According to Orem's theory, people may practice self-care to preserve their health and wellness. However, when a person is unable to meet their needs, a self-care deficit arises, which results in health problems. In the case of a 3-year and 9-month-old boy diagnosed with

Spinal Muscular Atrophy (SMA) Type I (Werdnig Hoffmann Disease), Orem's Self-Care Deficit Nursing Theory was applied to guide nursing interventions that promoted self-care independence for the child and empowered the parents in their caregiving role. The first step is to know the client and parent's needs in order to determine what kind of nursing care the person needs. The second stage is the design of the supporting educational system and planning for the implementation of care. The implementation of the self-care program and evaluation of that program's implementation make up the third step.

Assessment: The first step was to assess parents' knowledge and understanding of SMA management and their current self-care practices, including her understanding of the disease process, awareness of available treatment options, such as medication, physical therapy, and respiratory support and dietary modifications. Tool were used to collect the data including: 1. Structured interview questionnaire sheet, 2. Examine and recognize the conceptual structure of the Orem. This questionnaire was used to determine the nursing diagnoses for any self-care-related flaws or weaknesses. Based on assessment data collected in line with Orem's nursing theory of self-care insufficiency. The right strategy was developed to fulfill the needs of the patient. The researcher evaluated the limitations, deficiencies, disabilities, and abilities, as well as the study objectives and discovered flaws based on the type of patient needs (Table 1, 2).

 Table 1. Patient's Basic Conditioning Factors

1	Age	3 years and 9 months	
2	Gender	Boy	
3	State of Development	Preschool	
4	State of Health	 Spinal Muscular Atrophy (SMA) Type I (Werdnig Hoffmann Disease) cardiac ECHO free. laboratory results ABGS: PH 7.4, PCO2 44, PO2 102, HCO3 38, Anion gab 14. CBC: HGB 11, RBC 4 M, WBC 12000, PLT 181, MCV 71. BUN 6, creatinine 0.3, serum sodium 132, potassium 3.7, chloride 99, CRP 45, PTT 32, PT 14.3, INR 1.1, Blood and urine culture was negative. Drug: Was given antibiotics Meropenem and Vancomycin according to weight. Epanutin, Baclofen, and Phenobarbital Albuterol, Ipratropium and Budesonide nebulizer. Oxytetracycline HCl, and Blink Tears Lubricating Eye Drops Health impression: The health situation was rated as low with poor prognosis (hopeless case). 	
5	Social and Cultural Attitude	He took his medications the doctor had given.	
6	Factors in the healthcare system	A member of the social security organization. He claimed that for health checkups, he utilized state and university hospitals.	
7	Family system variables	The family is extended family, grandfather, grandmother, parents, and brother are living together in the home	
8	Style of Living	The child did not consume alcohol, drugs or smokes, because he is still a child. her father didn't take alcohol or drugs, he is smoker and the mother didn't smoke. The child can't perform any activity due to her medical condition.	
9	environmental variables	he resided in an apartment complex on the first floor. The building was in a crowded are, because he lives in city center.	
10	Availability and sufficiency of resources	He experiencing a lot of financial problem, because her father obligated to bay a portable mechanical ventilator, and suction machine. In addition, the child needs frequent admission to PICU, which need a lot of money. But those case are financially supported from the Palestinian government, they support him through medications and supplies he needed for her treatment (suction catheter, suction connection, dressing equipment's, pediasure, needles, etc.).	

Table 2. Medical Self-Care Requirements, Patient Self-Care Deficiencies, and Universal Self-Care Requirements

	Uni	versal self-care need
		Tracheostomy was available. Respiratory machine
		support (mechanical ventilator) via tracheostomy, on
1	Air	synchronized mandatory ventilation mode, Respiratory
		rate was 30 breath/min, FIO2 40%, tidal volume 70,
		and peep 5.
		Gastrostomy (PEG) was available. Water gave him
2	Water	daily fluids through gastrostomy tube according
		dietitians order and her requirements.
		Gastrostomy (PEG) was available, dietitians were
		calculated, he need around 1200 kilocalories per day,
3	Food	these calories given ether matched food, milk, or
		pediasure, and its divided into 6 meals pear day, that
		mean we fide the child every 4 hours.
		Baby has a foleys catheter and urine calculated daily, he
		urinated from 2.5-4 ml/kg/hour. About the defecation,
4	excretion procedures	he passes stool, moderate to good amount 2-3 times a
		day, and diapers were used.
		The patient could not do any activity since he was
		immobilized. His mother did not frequently adjust his
5	activity-rest	posture in bed. He was mute and slept for around eight
		to nine hours every day.
6	social interaction	No contact could be made with the patient
7	Hazards reduction	Trauma was a possibility.
		Communication with the patient could not be
8	support for normalcy	established.
	Self-Care Deficit and I	Developmental Self-Care Requirements
		•
1	Preserving and protecting the	He went in for a checkup every year. In order to preven
	environment for development	farther cases and decrease the risk factor.
	Health Disturbance S	elf-Care Needs and the Self-Care Gap
	locating and securing suitable	For therapy and testing, he went to facilities with
1	medical help	internal medicine or specialists when he was ill. No
	medicai heip	problem.
		No contact could be made with the patient.
		His mother was unaware of the problems caused by safe
	understanding sick illnesses'	feeding practices and signs of aspiration, motor
2	understanding sick illnesses' effects and consequences and	feeding practices and signs of aspiration, motor function, nutrition, and respiratory status
2	_	
2	effects and consequences and	

		His parents didn't aware about: Every 2 hours, a position change was made. Lung sounds, breathing
3	Putting into practice the diagnostic, therapeutic, and rehabilitative procedures that have been medically prescribed	depth and rate, breathing noises, saturation levels, and skin tone. Self-care deficit: Insufficiently effective handling of medical treatments and rehabilitative interventions due to lack of knowledge parents, Self-care deficit: Ineffectiveness in airway pattern due to SMA Self-care deficit: Nutrition less than body requirements Self-care deficit: Pluid volume imbalance Self-care deficit: Due to disease-related skin, ulcerations, PEG, and sore tracheostomy "Tissue integrity deterioration" Self-care deficit: Depends on oral intake "Risk of changes in the oral mucous membrane" Self-care deficit: A lack of knowledge about the effects of medical therapy brought on by illiteracy. Self-care deficit: Reduced muscle mass, exercise intolerance, musculoskeletal impairment, and reduced physical mobility as seen by the child's inability to walk, which are all symptoms of neuromuscular impairment.
4	recognizing and planning for the effects of medical care	Not a problem.
5	modifying one's conception of and perception of oneself in a certain condition of health	His parents tried to manipulate his SMA and having no problems with it.
6	Learning to cope with harmful effects	No problem.

Diagnosis: Based on the assessment, nursing diagnoses were formulated, focusing on the child's self-care deficits and the parents' need for education and support. Some of the identified nursing diagnoses included impaired physical mobility related to muscle weakness, compromised nutrition and swallowing difficulties related to poor feeding and difficult swallowing, impaired respiratory function related to compromise respiratory function, and deficient knowledge related to SMA management.

Planning: A care plan was developed based on the identified nursing diagnoses. The plan

prioritized enhancing self-care abilities, improving the child's overall well-being, and empowering the parents to effectively manage the child's condition. Collaboration with a multidisciplinary team, including physicians, physical therapists, respiratory therapists, and nutritionists, was incorporated into the plan. An educational intervention was divided into four in-person sessions of 60 minutes each. The study's instructional strategies included ere given

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Accepted Marti lectures, Q&A sessions, and movie screenings. An informative brochure were given out at

 Table 3. Session Activities and Topics

Торіс	Activities
• Introduction to SMA: defining the disease, its causes, and types	Understanding Spinal Muscular Atrophy (SMA)
 Overview of SMA symptoms and their impact on daily life 	Expressing research and defining SMA
• Discussion on the genetic inheritance pattern of SMA	Explaining the cause, types, symptoms, diagnosis SMA
• Exploring available treatment options and ongoing research for SMA	Discussing complications of SMA
• Addressing emotional and psychological aspects of living with SMA	
 Adaptive strategies for mobility and 	Managing Daily Life with SMA
independence in daily activitiesAssistive devices and technologies for SMA	Answering past questions
patients	Providing an overview of SMA
 Techniques for maintaining good posture and preventing muscle contractures 	Discussing better control of SMA
Discussion on respiratory care, including	
breathing exercises and the use of respiratory	
× ·	
	NT4242 I CINT A
	Nutrition and SMA
	Discussing important issues regarding
	nutrition and exercise for SMA
2/	
• Collaboration with a nutritionist or dietitian for	
personalized dietary plans	
Coping strategies for dealing with emotional	Psychological and Emotional Well-being
challenges associated with SMA	
•	
SMA patients to voice their needs and concerns	
•	
• Introduction to support groups and resources for	
•	
	 Introduction to SMA: defining the disease, its causes, and types Overview of SMA symptoms and their impact on daily life Discussion on the genetic inheritance pattern of SMA Exploring available treatment options and ongoing research for SMA Addressing emotional and psychological aspects of living with SMA Adaptive strategies for mobility and independence in daily activities Assistive devices and technologies for SMA patients Techniques for maintaining good posture and preventing muscle contractures Discussion on respiratory care, including breathing exercises and the use of respiratory devices Tips for optimizing energy conservation and managing fatigue Nutritional considerations for individuals with SMA, including maintaining a healthy weight and managing swallowing difficulties Addressing specific dietary needs and adaptations for individuals with SMA Discussing the importance of proper hydration and managing constipation Collaboration with a nutritionist or dietitian for personalized dietary plans Coping strategies for dealing with emotional challenges associated with SMA Addressing social and psychological support systems for SMA patients and their families Encouraging self-advocacy and empowering

	• Understanding the benefits of exercise for	Adaptive Exercise and Physical Therapy
		_
	SMA patients	Answering past questions
	 Tailoring exercise programs to individual 	
	abilities and limitations	
5	• Introduction to adaptive exercises and techniques	
3	for maintaining muscle strength and flexibility	
	 collaboration with a physical therapist for 	
	personalized exercise plans	
	• Discussion on the importance of regular physical	
	therapy sessions	
	 Exploring assistive technology options for 	Assistive Technology and Accessibility
	communication, mobility, and daily living tasks	Summarizing the contents of the sessions
	 Introduction to accessibility features in the 	Presenting a pamphlet
	environment, home modifications, and adaptive	X
6	equipment	
O	 Collaboration with occupational therapists to 	X 6
	assess and optimize the living environment for	
	accessibility and independence	
	Addressing financial resources and assistance	~~

programs for acquiring assistive technology

1. Nursing interventions guided by Orem's theory were implemented to address the identified nursing diagnoses. Reduced muscle mass, exercise intolerance, musculoskeletal impairment, and reduced physical mobility as seen by the child's inability to walk, which are all symptoms of neuromuscular impairment. For impaired physical mobility, physical therapy interventions were introduced to promote motor development, muscle strength, and mobility. Adaptive devices such as braces, walkers, or wheelchairs were recommended to facilitate mobility. 2. Swallowing and chewing abilities are tested. The assessment of dietary consumption for adequate nutrition. A therapist evaluated the child's swallowing abilities and gave advice on suitable feeding approaches, such as placement and texture changes, to address the child's poor nutrition and swallowing issues. The parents got instruction on proper feeding techniques and aspiration warning signals, as well as help locating any necessary feeding devices. 3. Patient's respiratory pattern wasn't efficient. To manage the child's impaired respiratory function, nurses educated the parents on respiratory support techniques, including

chest physiotherapy and airway clearance methods. The parents were trained in recognizing signs of respiratory distress. 4. To increase awareness and comprehension of the variables affecting one's need for and capacity for self-care. Education and support were also provided to the parents regarding SMA management. This included understanding the disease process, medication administration, monitoring of respiratory function, recognizing signs of deterioration, and accessing appropriate medical interventions. The parents were involved in care planning and decision-making, allowing them to actively participate in their child's care. 5. Support from family and caregivers: As the severity of their child's SMA worsens, parents of SMA patients report feeling more and more stressed. The palliative care team's involvement soon after diagnosis may be the best way to meet the parents and siblings of SMA patients' needs for long-term support. Family-wide psychological support reduces healthcare use and improves quality of life. As a result, one of our main responsibilities is to mentally support and educate parents. Families frequently describe shock, anticipatory anguish, and a sense of helplessness when faced with a lethal form of SMA, especially after cardiac arrest. SMA are fatal, and her child's case seems bleak. Therefore, my social worker and I have frequent contact with his parents and we support him in receiving end-of-life care.

Evaluation: Regular evaluation of the care plan and interventions was conducted to determine their effectiveness and make necessary adjustments. The child's progress in achieving self-care independence, improvements in motor function, nutrition, and respiratory status, as well as the parents' confidence in managing the child's care, were assessed. Orem's Nursing Theory may assist nurses in many disciplines in dynamically and meticulously evaluating patients' capacity for self-care and implementing appropriate nursing interventions according to their needs, interests, and issues. By applying Orem's Self-Care Deficit Nursing Theory, nurses provided tailored care and support to the child with SMA and empowered the parents to actively participate in their child's care. This approach promoted self-care

independence, improved the child's overall well-being, and enhanced the parents' ability to effectively manage the challenges posed by SMA.

Discussion

This case study presents a comprehensive exploration of the effectiveness of applying Dorothea Orem's Self-Care Deficit Nursing Theory in managing a child diagnosed with Spinal Muscular Atrophy (SMA) Type I. By integrating Orem's theoretical framework into nursing practice, this study aimed to promote self-care independence for the child while empowering the parents in their caregiving role. According to this study, the application of Orem's theory facilitated a systematic approach to assessing the child's and parents' needs, formulating nursing diagnoses, and designing tailored interventions to address identified deficits. Through structured educational sessions and collaborative care planning, nurses equipped the parents with the knowledge and skills necessary to effectively manage the challenges associated with SMA.

The results of this study demonstrate the positive impact of nursing interventions guided by Orem's theory on the child's overall well-being and the parents' confidence in managing their child's care. By focusing on enhancing self-care abilities and promoting parental involvement, nurses contributed to improved outcomes for the child with SMA. Similarly, The findings of a study conducted by Awaliyah et al. in 2018 showed that the application of self-care theory is suitable for multiparous pregnant women with anaemia as it helps them to be independent patients (18). Moreover, the interdisciplinary collaboration involved in this study underscores the importance of a holistic approach to SMA management, involving healthcare professionals from various disciplines to address the multifaceted needs of the patient and family. Our findings are supported by research conducted by Hermalia et al. (18), Si et al. (19) nursing care with the theory of an effective

self-care model will shape the ability of patients and families to perform self-care and

improve the quality of life of patients with chronic diseases.

The findings of this study highlight the practical relevance of nursing theories in pediatric

care and the value of patient-centered approaches in managing complex conditions like SMA.

By emphasizing the importance of patient education, empowerment, and collaboration, this

study underscores the potential of nursing theories to inform evidence-based practice and

enhance patient outcomes. Similarly, study by Ali (14) showed that the usability of theory

into practice that resulted in drastic change in practice and patient's early recovery.

This study's limitation is that just one patient was used in it. The findings would be improved

by more research in the form of a longitudinal study with a larger number of participants.

Conclusion

In conclusion, this study provides valuable insights into the application of nursing theories in

pediatric nursing practice, particularly in the management of SMA. By leveraging theoretical

frameworks like Orem's Self-Care Deficit Nursing Theory, nurses can play a pivotal role in

promoting self-care independence, improving outcomes for children with SMA and their

families.

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Ethics approval

Informed Consent: Written and verbal consent was obtained from the patient who

participated in the study.

Authors' contributions: All authors contributed in designing, running, and writing all parts.

Conflicts of interest: The authors declared no conflicts of interest.

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