

Case Report

Investigating the Application of Orem's Self-care Nursing Theory for Spinal Muscular Atrophy: A Case Study Design



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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. Accordingly, this case study examines the effectiveness of applying Orem's self-care nursing theory to a child with SMA and his parents.

Case Presentation: 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 the patient's lack of self-care and created a tailored plan for self-management training. The initial steps were to understand the patient's needs, organize the implementation, and create the educational system. The final phase entailed implementing the self-care program and assessing its success. The following methods were used to gather the data: Structured interviews and surveys on Orem's theory and self-care ability. A 60-min educational intervention was broken up into four in-person sessions. 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.

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Background

Spinal muscular atrophy (SMA) is one of the most prevalent neuromuscular diseases in children and 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 with a global prevalence of between 1-2 per 100 000 people [3]. The complex condition known as SMA causes muscle weakness, atrophy, and functional impairment due to 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]. On the other hand, the mildest form of SMA (type 4) 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]. To gain control over their well-being and general health through 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 well-being and nurses must assist patients in daily activities until they can do them independently [13-16]. Orem's theory recognizes the importance of parents taking care of and supporting their children to ensure the child's well-being. 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 well-being 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 parent education, encourage favorable 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 boy patient who was monitored in the pediatric intensive care unit and diagnosed with SMA type I (Werdnig Hoffmann disease), which is characterized by delayed motor milestones, progressive muscle weakness, failure to thrive 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 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 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.

The first step was to assess the parents' knowledge and understanding of SMA management and their current self-care practices, including her understanding of the disease process, and awareness of available treatment options, such as medication, physical therapy, respiratory support, and dietary modifications. Tools were used to collect the data, including: 1) A structured interview questionnaire sheet, and 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 the assessment data collected in line with Orem's nurs-

ing 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 (Tables 1 and 2).

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 compromised 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 60-min sessions in-person. The study’s instructional strategies included lectures, question-and-answer sessions, and movie screenings. An informative brochure was given out after the training session (Table 3).

Nursing interventions guided by Orem’s theory were implemented to address the identified nursing diagnoses. Reduced muscle mass, exercise intolerance, mus-

Table 1. Patient’s basic conditioning factors

| No. | Variables | Results |
|-----|---|--|
| 1 | Age | 3 years and 9 months |
| 2 | Gender | Boy |
| 3 | State of development | Pre-school |
| 4 | State of health | SMA type I (Werdnig Hoffmann disease) Cardiac echocardiogram free; Laboratory results; Arterial blood gas test: pH=7.4, pCO ₂ =44, pO ₂ =102, HCO ₃ =38, anion gab=14; complete blood count: Hemoglobin=11, red blood cells=4 M, white blood cells=12000, platelet count=181, mean corpuscular volume=71. Blood urea nitroge=6, creatinine=0.3, serum sodium=132, potassium=3.7, chloride=99, C-reactive protein=45, partial thromboplastin time=32, prothrombin time test=14.3, international normalized ratio=1.1; blood and urine culture was negative. Medications: The patient 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 a poor prognosis (hopeless case). |
| 5 | Social and cultural attitude | He took the medications that 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; the grandfather, grandmother, parents, and brother are living together in the home. |
| 8 | Style of living | The child did not consume alcohol, drugs, or smoke, because the patient was still a child. His father did not take alcohol or drugs, he is a smoker and his mother did not smoke. The child cannot perform any activity due to her medical condition. |
| 9 | Environmental variables | He resided in an apartment complex on the 1 st floor. The building was in a crowded area because he lives in the city center. |
| 10 | Availability and sufficiency of resources | He experienced a lot of financial problems because his father was obligated to buy a portable mechanical ventilator and suction machine. In addition, the child needs frequent admission to the pediatric intensive care unit, which needs considerable money; however, those cases are financially supported by the Palestinian government, they support him through medications and supplies he needs for 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

| No. | | Universal Self-care Need |
|-----|----------------------|---|
| 1 | Air | A tracheostomy was available. Respiratory machine support (mechanical ventilator) via tracheostomy, on synchronized mandatory ventilation mode, respiratory rate was 30 breath/min, FiO ₂ 40%, tidal volume 70 and peep 5. |
| 2 | Water | A gastrostomy was available. Water and daily fluids were given to him through a gastrostomy tube according to the dietitian's order and her requirements. |
| 3 | Food | Gastrostomy was available, and dietitians were calculated. He needed around 1200 kilocalories per day, these calories were given as matched food, milk or Pediasure and they were divided into 6 meals per day. We fed the child every 4 hours. |
| 4 | Excretion procedures | The baby had a Foley catheter and urine was calculated daily, he urinated from 2.5-4 mL/kg/h. About the defecation, he passes stool, moderate to good amount 2-3 times a day, and diapers were used. |
| 5 | Activity-rest | The patient could not do any activity since he was immobilized. His mother did not frequently adjust his 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. |
| 8 | Support for normalcy | Communication with the patient could not be established. |

Self-care Deficit and Developmental Self-care Requirements

| | | |
|---|---|--|
| 1 | Preserving and protecting the environment for development | He went in for a checkup every year To prevent further cases and decrease the risk factor. |
|---|---|--|

Health Disturbance Self-care Needs and the Self-care Gap

| | | |
|---|---|--|
| 1 | Locating and securing suitable medical help | For therapy and testing, he went to facilities with internal medicine or specialists when he was ill, no problem. |
| 2 | Understanding sick illnesses' effects and consequences and being prepared for them | No contact could be made with the patient. His mother was unaware of the problems caused by safe feeding practices and signs of aspiration, motor function, nutrition, and respiratory status. Self-care deficit: Insufficient information on the impacts and outcomes of a disease condition. |
| 3 | Putting into practice the diagnostic, therapeutic and rehabilitative procedures that have been medically prescribed | His parents were aware of the following items: Every 2 hours, a position change was made; lung sounds, breathing depth and rate, breathing noises, saturation levels, and skin tone were checked. Self-care deficit: Insufficiently effective handling of medical treatments and rehabilitative interventions due to lack of knowledge of parents. Self-care deficit: Ineffectiveness in airway pattern due to SMA. Self-care deficit: Nutrition less than body requirements. Self-care deficit: Fluid volume imbalance. Self-care deficit: Due to disease-related skin, ulcerations, PEG, and sore tracheostomy (tissue integrity deterioration). Self-care deficit: Depending 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 | No 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 had no problems with it. |
| 6 | Learning to cope with harmful effects | No problem. |

Table 3. Session activities and topics

| Session | Topic | Activities |
|---------|--|---|
| 1 | 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 | Understanding SMA Expressing research and defining SMA Explaining the cause, types, symptoms, and diagnosis of SMA Discussing complications of SMA |
| 2 | 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 | Managing daily life with SMA Answering past questions Providing an overview of SMA Discussing better control of SMA |
| 3 | 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 | Nutrition and SMA Discussing important issues regarding nutrition and exercise for SMA |
| 4 | 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 SMA patients to voice their needs and concerns Introduction to support groups and resources for SMA patients and their caregivers Exploring adaptive hobbies and activities that promote mental well-being. | Psychological and emotional well-being |
| 5 | Understanding the benefits of exercise for SMA patients Tailoring exercise programs to individual abilities and limitations Introduction to adaptive exercises and techniques for maintaining muscle strength and flexibility Collaboration with a physical therapist for personalized exercise plans Discussion on the importance of regular physical therapy sessions | Adaptive exercise and physical therapy Answering past questions |
| 6 | Exploring assistive technology options for communication, mobility and daily living tasks Introduction to accessibility features in the environment, home modifications, and adaptive equipment Collaboration with occupational therapists to assess and optimize the living environment for accessibility and independence Addressing financial resources and assistance programs for acquiring assistive technology | Assistive technology and accessibility Summarizing the contents of the sessions Presenting a pamphlet |

SMA: Spinal muscular atrophy.

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culoskeletal impairment, and reduced physical mobility were demonstrated 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. Swallowing and chewing abilities were tested in addition to the assessment of dietary consumption for adequate nutrition. A therapist evaluated the child's swallowing abilities and advised 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. The patient's respiratory pattern was not 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. 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. In terms of 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 health-care 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 is 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 presented a comprehensive exploration of the effectiveness of applying Dorothea Orem's self-care deficit nursing theory in managing a child diagnosed with 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 parent's 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 demonstrated 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 anemia 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. [19] and Si et al. [20] 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, a study by Irshad Ali [14] showed that the usability of theory in practice resulted in drastic changes in practice and patient's early recovery.

Conclusion

In conclusion, this study provides valuable insights into applying nursing theories in pediatric nursing practice, particularly in managing SMA. By leveraging theoretical frameworks like Orem's self-care deficit nursing theory, nurses can play a pivotal role in promoting self-care independence and improving outcomes for children with SMA and their families.

Study limitations

This study's limitation is that only one patient was used in it. The findings would be improved by more research in the form of a longitudinal study with more participants.

Ethical Considerations

Compliance with ethical guidelines

Written and verbal consent was obtained from the patient who participated in the study.

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Authors contributions

All authors equally contributed to preparing this article.

Conflicts of interest

The authors declared no conflict of interest.

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