AUCTORES
Globalize your Research

Journal of General Medicine and Clinical Practice
Deirdre Hawkins *

Open Access

Review Article

Concept Analysis: Sickle Cell Pain Clinic

Deirdre Hawkins [1]*, Ali M. Al Yasien [2], Muhammad Yasir [3], Shini Cherian [4], and Najla Al Shehri [5]

[1,2, 4 & 5] General Nursing Administration, Security Forces Hospital Program, Riyadh

[3] Pain Consultant Security Forces Hospital Program, Riyadh.

[5] Pain Nurse

***Corresponding Author:** Deirdre Hawkins, General Nursing Administration.

Received date: October 25, 2023; Accepted date: November 06, 2023; Published date: November 13, 2023

Citation: Deirdre Hawkins, Ali M. Al Yasien, Muhammad Yasir, Shini Cherian, Najla Al Shehri, (2023), Concept Analysis: Sickle Cell Pain Clinic, *J. General Medicine and Clinical Practice*, 6(6); **DOI:10.31579/2639-4162/121**

Abstract

The number of people living with sickle cell disease globally is on the increase. Sickle cell pain crises often results in emergency department visits, with delays in receiving pain relief. Pain from sickle cell disease accounts for 90% of hospital admissions. While sickle cell pain clinics have been established successfully in the US there is limited evidence of the establishment of sickle cell pain clinics in the Middle East. The basis of theoretical thinking in nursing lies in delineation of the concepts that are relevant to the discipline. By using Walker and Avant's (2011) concept analysis method, the author reviewed the literature to better understand sickle cell pain clinics as a concept. In conducting this concept analysis, Walker and Avant's framework was applied to examine the nature of the findings selected for the advancement of the concept. After identifying the concept, a hospital in Riyadh implemented a Sickle Cell Pain Clinic. Donabedian model was used for the implementation of the concept. The clinic allowed patients to receive pain management treatment without any delay, helping to reduce emergency department visits in an already overcrowded Emergency Department and it also helped to reduce hospital readmissions.

Kew Words: sickle cell disease; sickle cell pain management clinic; vaso-occlusive crisis; concept analysis; sickle cell pain

Introduction

Sickle cell disease (SCD) is a multisystem disorder and the most common genetic disease in the United States. Prevalence of the disease is highest among the people of Sub-Saharan Africa, South Asia, the Middle East, and the Mediterranean. Knowledge of the phenotypic expression of the disease is still limited although environmental factors such as cold weather and air quality, infections, fetal hemoglobin level, and genetic subtypes play a role in the manifestations of the disease [1].SCD affects approximately 100,000 individuals in the United States and more than 3 million worldwide [2]. The number of people living with SCD globally increased by 41.4%, from 5.46 million in 2000 to 7.74 million in 2021. In children under 5 years, there were 81,100 deaths ranking SCD mortality as 12th across all causes estimated by the Global Burden of Disease in 2021 [3].

There is a clear economic burden of sickle cell related hospitalization. A study reported that there were about 113,000 hospitalizations for sickle cell related illnesses in the United States, 75% occurring in adults [4]. Orle institute reported success with a dedicated outpatient facility for the treatment of uncomplicated painful crises, which reduced the time to pain relief, increased the number of patients discharged home, decreased the hospitalization rate and reduced the use of the emergency department. Over five years studied, average savings amounted to more than USD1.7 million due to fewer hospital admissions and shorter length of stay [5].

The pain of living with sickle cell crisis is excruciating and in global terms is a major health problem. Unpredictable, recurrent, and excruciating episodes of acute pain—often referred to as "pain crises"—and the various consequences of chronic pain are responsible for most of the psychosocial devastation of the disease and are also the primary reason for the use of healthcare [6]. However, despite its importance, pain is perhaps the least understood complication of SCD. In SCD increased pain has been shown to correlate directly with death [5].

There is evidence of successful outpatient facilities in the management of sickle cell pain in the United States. In one study patients with frequent episodes of moderate-to-severe pain from SCD were seen in an outpatient clinic. Visits included group music therapy and individual medical care,

including comprehensive blood work and scheduling of medical tests when appropriate. Between visits, the pain and palliative care physicians followed patients on an as-needed basis. Emergency department (ED) visits and hospital admissions were dramatically reduced in the three patients whose pain was managed in the pain clinic. For each patient, hospital admissions were reduced to < or = 1 visit per year. These reduced levels of ED visits and hospital admissions remained constant for more than three years [5]. Using the intranasal or sublingual approach to administering analgesia to SCD patients with VOC offers a fast, safe, noninvasive, non-traumatic, and easily accessible route of administration which could reduce the time to first dose of analgesia [7].

Walker and Avant's [8] Concept Analysis consists of 8 steps. These iterative steps include as follows: 1) selecting a concept; 2) determining the aims of the analysis; 3) identifying all possible uses of the concept in nursing; 4) defining concept attributes; 5) constructing a model case; 6) constructing related and contrary cases; 7) identifying antecedents and consequences of the concept; and 8) defining empirical referents of the model. Careful examination of the implications of this concept provides an understanding of the phenomena [9].

1. Selecting a Concept

The concept selected was Sickle Cell Pain Clinic. There is no clear definition in the literature for Sickle Cell Pain Clinic. There were inconsistencies in the definition of Pain Clinics where definition varied depending on whether they were provider-based, treatment based or outcome based. Examples of definitions include "integrate multiple (or single) approaches of pain treatments through co-ordinated teams" [10]. The simplest definition of Sickle Cell Disease itself is an inherited blood disorder marked by defective hemoglobin. It inhibits the ability of hemoglobin in red blood cells to carry oxygen. Sickle cells tend to stick together (forming the shape of a sickle), blocking small blood vessels causing painful and damaging complications [11,12]. Medical clinicians need to view Sickle Cell not just as a hematological disorder but as a biopsychosocial model. The biopsychosocial model affirms that in addition to biological elements, psychological and social elements also play a role in managing pain [13]. A biopsychosocial model Sickle Cell Pain Clinic was implemented in a hospital in Riyadh.

2. Determining the aims of the analysis

The objective of the concept analysis was to synthesis the literature to formulate the defining attributes, antecedents and consequences of a sickle cell pain clinic. The researcher did an in-depth analysis of the literature regarding the concept of a Sickle Cell Pain Clinic. A comprehensive search for the term sickle cell pain clinic was entered into online databases for articles published in the last 20 years. The main aim of the Sickle Cell Pain Clinic was to help improve the care and management of sickle cell patients (12 years and above) by minimizing complications, thus minimizing visits to the emergency room and hospital readmissions.

3. Identification of possible use of concept in nursing

The conceptual framework used to evaluate the quality of care provided in the clinic was the Donabedian Model. The Donabedian model is a conceptual model that provides a framework for evaluating quality from three categories: "structure," "process," and "outcomes." Structure describes the context in which care is delivered, including hospital buildings, staff, financing, and equipment. Process denotes the transactions between patients and providers throughout the delivery of healthcare. Outcome refers to the effects of healthcare on the health status of patients [14]. In this case the structure was the setting up of the clinic, including the provision of staff (a pain physician, pain nurses, hematologist, psychologist and social worker) and resources (including availability a of clinic room with equipment, a clinical guideline etc.). Process included firstly, the assessment (involving patient self-appraisal of attitude and readiness in determining the type of sickle cell disease, the nature of the pain and the assessment of its significance for the patient) and secondly, the treatment (concerned with the planning and execution of an assessment-based management of the illness and pain) and finally, the evaluation of the effectiveness of the treatment executed. The processing system included feedback loops or regimen-adjustment strategies (titration, maintenance, rescue and taper-dosing) so that if the treatment was not deemed to be effective, the healthcare provider may alter after original and/or subsequent treatment based upon assessment of the sickle cell disease or pain, or both. Outcome included the benefits gained for both the sickle cell patients and the hospital, such as improved quality of life with faster pain relief, reduced emergency visits, hospital admissions and reduction in economic costs.

Pathway to Implement the Concept

Stage 1

Patients come to the clinic as a walk-in or as a referral from the emergency department.

Stage 2

Initial Assessment including patient identification, allergies, and vital signs (blood pressure, heart rate, oxygen saturations, temperature and pain score recorded as per the Numerical Pain Rating Scale) are completed. The assessment must occur within 15-20 minutes of the patient's arrival to the clinic [16].

Stage 3

Patient to be seen by the Pain Nurse who will assess the patient's pain using the Pain Assessment Tool. The patient will have complete pain assessments at half hour intervals. The nurse will differentiate whether the patient will need urgent care (for example, acute chest pain, aplastic crisis-pulmonary or abdominal on the basis of temperature >38 degrees, respiratory signs/symptoms, low saturations, tachycardia or hypotension. If required, nurses will make necessary arrangements to move the patient to the emergency department. Full blood count, reticulytes, urea and electrolytes will be determined on all patients attending with severe pain.

Stage 4

Once it is decided to manage the patient in the clinic, the patient will be seen by the physician. The physician will treat the pain aggressively and promptly. The 1st dose analgesia will be administered within 30 minutes of arrival and the 2nd dose will be administered if there is a delay in transfer to an alternate care site. Opioids will be administered as per patient specific protocol --- subcutaneous, intramuscular, intranasal or sublingual when intravenous is not available. Pain sedation will be reassessed every 15-30 minutes and analgesic doses will be administered until pain relief is obtained (pain score 2 or less). Also non-pharmacological approaches such as heat pads will be provided as necessary. Pain will be managed for 6-8 hours. If unable to control pain, admission to short term observation unit will be considered.

Patient can be categorised into 2 categories: The first category are infusion

visits used to treat patients with acute vaso-occlusive crisis who need extended, parenteral analgesic and hydration. The second category is acute follow up visit who usually do not require extended analgesics and hydration [16].

Time to 1st Dose

Analgesic Therapy should be initiated with a goal of having patients receive their 1st dose of opioid within 30 minutes of assessment.

Evaluate, record and treat adverse effects:

Assess and record for occurrence of nausea, vomiting, pruritus, respiratory depression and sedation when indicated.

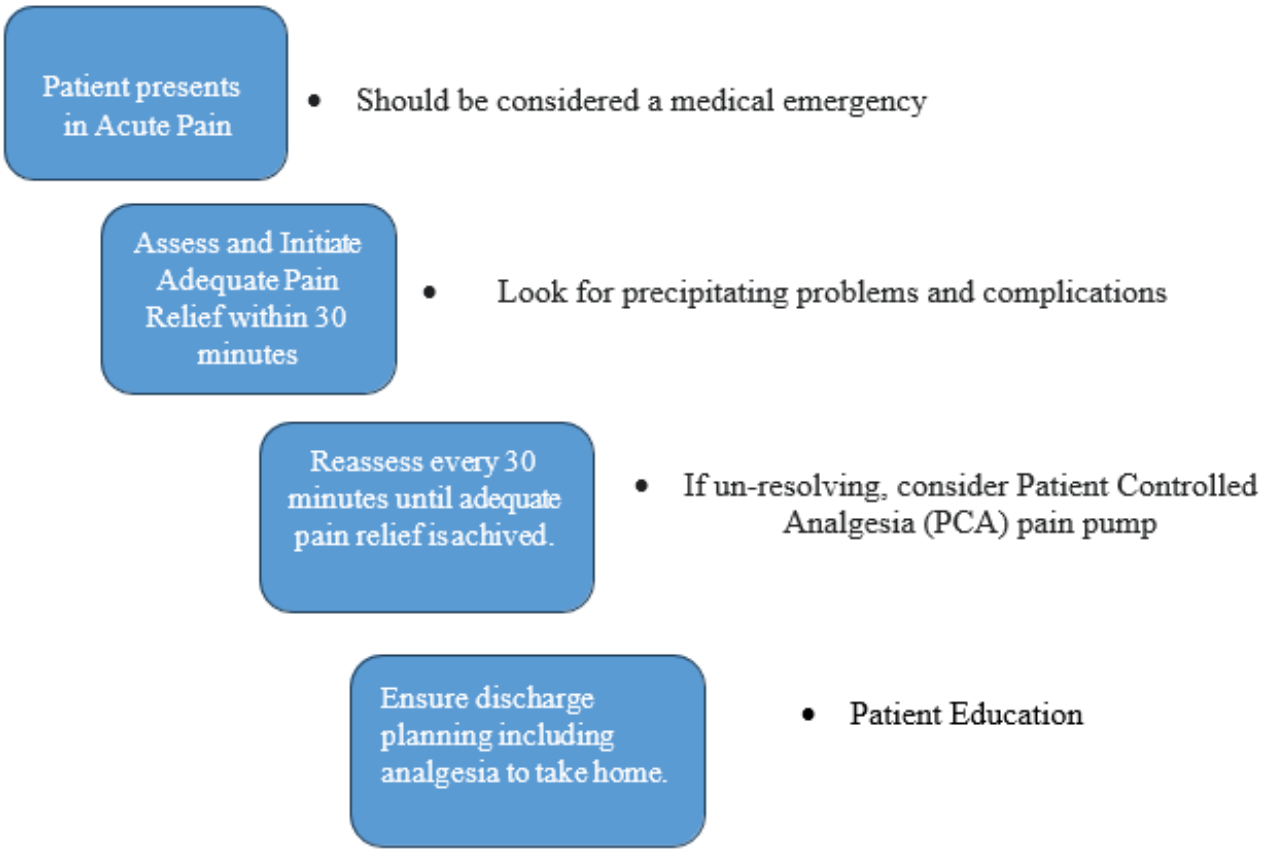
Identify and treat precipitating factors:

Precipitating and propagating events, such as dehydration, acidosis, hypoxia, infection and stress also need to be treated.

If a pain pump needs to be started follow the hospital policy and procedures.

Stage 5

After intervention reassessment will be done by the pain nurse and communicated to the physician.



If pain remains untreated then physician will decide to prolong the stay by either referring the patient to the ED or admitting the patient [16].

Stage 6

•The pain nurse will assess the patient and communicate readiness for discharge. Once the pain is settled to the extent that it can be managed by oral medication at home, then the patient can be discharged and pain education to be given by nurse.

•The pain nurse will provide the patient advice in relation to discharge instructions, for example no driving and he/she will also explain the prescription along with the discharge form.

•At discharge, titrate off the parenteral opioids before conversion to oral opioids and adjust the home dose of long and short-acting opioids to prevent withdrawal.

•The pain nurse will arrange a follow up appointment as per the instructions of the physician. If the patient does a repeat visit to the ED or clinic within the next 7 days this visit will be considered part of the same crisis.

•If the patient needs to see a psychologist or social worker the physician will make an arrangement for that.

•On discharge the patient should have sufficient medication until their next appointment [17].

1. Defining Concept Attributes

Pain is the most common characteristic of the sickle cell patient. Not all patients experience pain with the same frequency or intensity and degree of disability associated with sickle cell disease crisis are highly variable. Patients with sickle cell presented to the clinic with mild, moderate or severe episodes of acute pain. Acute pain is caused by recurrent and unpredictable episodes of vaso-occlusive crises (VOC) [18]. VOC is when a sickle cell

patient experiences acute painful episode caused by deformed sickle shaped red blood cells which can lead to tissue infarction. Anemia and Infection are the other attributes of patients with Sickle Cell who need to be referred to the Sickle Cell Pain Clinic.

2.Constructing A Model Case

Walker and Avant [8] defined a model case as one that demonstrates all of the concept's defining characteristics. In other words, the model case should be a pure case of the concept, a paradigmatic example, or a pure exemplar. The following is an example of a model case that is consistent with the concept. A 28-year woman with a diagnosis of sickle cell disease since birth has had 3 episodes of VOC in the past three months. She is now experiencing pain in her chest, arms, back and legs. She is desaturation. She is currently experiencing a VOC and her pain score is 10 out of 10. She attends the clinic and is seen by the Hematologist, Pain Physician, Psychologist and Nurse. The patient is immediately put on high- flow oxygen to maintain her saturations above 95%. Hydroxyurea is administered and a blood transfusion is commenced. The patient receives intravenous morphine within 30 minutes of arrival to the clinic. The nurse has reassessed her pain score which is now 5. She receives an additional dose of morphine and a further reassessment of her pain. Her pain score is now 2. Her blood transfusion is completed within a couple of hours of arrival at the clinic. Her saturations are within normal parameters. The psychologist has reviewed the patient and has recommended breathing techniques. [19] The patient is now settling. If she continues to settle she can be discharged home today with home pain medications. Education will be given on discharge by the pain nurse.

3.Constructing Related and Contrary Cases

A contrary case is a clear example of when the concept is absent. A 19-year old sickle cell patient diagnosed since birth arrives at the sickle cell pain clinic. She has being experiencing sickle cell crises since birth. She is very anxious and demanding pain relief. The nurse assesses her pain score which is reported by the patient as 10 out of 10 but the nurse doesn't believe the patient and documents the pain score as 3. She believes the patient is an addict. Based on the pain score of 3 recorded, the doctor doesn't prescribe strong painkillers. The patient remains in pain. No pain reassessment is done as no intervention has been given. After 1 hour the doctor is asked to review the patient again. This time he realizes that the patient is in pain. However, the doctor is reluctant to prescribe opioids for fear of addiction to the patient. The patient continues to remain in pain. The patient starts to desaturate because of her ongoing crisis which is not being managed. The patient starts to clinically deteriorate and has to be admitted to the Intensive Care Unit for closer observation and proper management.

4. Identifying Antecedents and Consequences of The Concept

Antecedents are events or incidents that must be present before a concept can occur. Prior to admission to the clinic the patients had to have experienced 3 or more vaso-occlusive episodes in the past 3 months where they previously visited the emergency department or were previously admitted to the hospital as a result of their vaso-occlusive crisis. Stress, poor diet, infection can all lead to vaso-occlusive crises but also the cause can be unknown. Antecedent included a patient self -assessment of their pain and attitude towards their pain.

Consequences are those incidents that occur as a result of the interpretation of the concept. With the establishment of a Sickle Cell Pain Clinic sickle cell patients are provided with safe and timely treatment to patients in pain, reducing emergency visits and hospital readmissions and resulting in improved quality of life for patients who suffer from this excruciating pain.

5. Defining Empirical Referents of The Model

The measurement of sickle cell pain involved the use of a validated Pain Assessment Tool. Both the patient and the pain nurse completed the validated Pain Assessment Form.

Conclusion

Emergency department visits and hospital readmissions were reduced for the patients who were seen in the Sickle Cell Pain Clinic. Patients with SCD need effective management in the outpatient setting in the hope to receive more efficient pain relief, reduce ED visits, prevent readmissions, and ultimately decrease the economic burden to the healthcare system.

Implications

The implications of better understanding the concept of a Sickle Cell Pain Clinic in the Middle East and its implementation in hospitals will lead to improved quality of life for sickle cell patients by providing faster pain relief, less emergency visits and hospital readmission, not to mention reduced economic burden in an already overstretched healthcare service, particularly in a time of economic crisis.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Author Contributions

The author contributed substantially to the conception and design of this work and revised and drafted the manuscript. The author approved the final version to be published and is accountable for all aspects of this work.

Conflict of Interest Statement

None declared.

References

1. Sedrak, A., & Kondamudi, N. P. (2023, August 12). In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Retrieved October 1, 2023, from Available from: https://www.ncbi.nlm.nih.gov/books/NBK482384/
2. Brandow, A.M., & Liem, R.I. (2022). Advances in the diagnosis and treatment of sickle cell disease. J Hematol Oncol. Mar 3; 15(1):20. doi: 10.1186/s13045-022-01237-z. PMID: 35241123; PMCID: PMC8895633.
3. GBD (2021) Sickle Cell Disease Collaborators. Global, regional, and national prevalence and mortality burden of sickle cell disease, 2000-2021: a systematic analysis from the Global Burden of Disease Study 2021. Lancet Haematol. 2023 Aug;10(8):e585-e599. doi: 10.1016/S2352- 3026(23)00118-7. Epub 2023 Jun 15. Erratum in: Lancet Haematol.2023 Aug;10(8):e574. PMID: 37331373; PMCID: PMC10390339.

4. Singh, R., Jordan, R., & Hanlon, C. (2014). Economic Impact of Sickle Cell Hospitalization. Blood, 124(21). https://doi.org/10.1182/blood.V124.21.5971.5971.
5. Shaiova, L. & Wallenstein, D. (2004) Outpatient management of sickle cell pain with chronic opioid pharmacotherapy. J Natl Med Assoc. Jul;96(7):984-6. PMID: 15253332; PMCID: PMC2568430.
6. Martinez, R. M., Osei-Anto, H. A., & McCormick, M. (2020). Complications of Sickle Cell Disease and Current Management Approaches. In www.ncbi.nlm.nih.gov. National Academies Press (US). https://www.ncbi.nlm.nih.gov/books/NBK566466/
7. Ojo, A. S., Odipe, O. G., & Owoseni, O. (2023). Improving the Emergency Department Management of Sickle Cell Vaso-Occlusive Pain Crisis: The Role and Options of Sublingual and Intranasally Administered Analgesia. Journal of Clinical Medicine Research, 15(1), 10–22. https://doi.org/10.14740/jocmr.v15i1.4841
8. Walker, L.O. and Avant, K.C. (2011) Strategies for Theory Construction in Nursing. 5th Edition, Prentice Hall, New York. - References - Scientific Research Publishing. (n.d.). Scirp.org. https://scirp.org/reference/referencespapers.aspx?referenceid=1813212
9. Martínez N, Connelly CD, Pérez A, Calero P. (2021) Self-care: A concept analysis. Int J Nurs Sci. Sep 5;8(4):418-425. doi: 10.1016/j.ijnss.2021.08.007. PMID: 34631992; PMCID: PMC8488814.
10. Andraka-Christou, B. Rager, J.B., Brown-Podgorski, B., Silverman, R.D. & Watson, D.P. (2018) Pain clinic definitions in the medical literature and U.S. state laws: an integrative systematic review and comparison. Subst Abuse Treat Prev Policy. May 22;13(1):17. doi: 10.1186/s13011-018-0153- 6. PMID: 29789018; PMCID: PMC5964673.
11. John Hopkins Medicine. (2023). Sickle Cell Disease. Johns Hopkins Medicine Health Library. https://www.hopkinsmedicine.org/health/conditions-and-diseases/sickle-cell-disease.
12. Sickle cell treatment | Johns Hopkins Aramco Healthcare. (n.d.). www.jhah.com. Retrieved October 2, 2023, from https://www.jhah.com/en/news-events/news-articles/sickle-cell- program
13. Childerhose, J. E., Cronin, R. M., Klatt, M. D., & Schamess, A. (2023). Treating Chronic Pain in Sickle Cell Disease — The Need for a Biopsychosocial Model. https://doi.org/10.1056/nejmp2301143.
14. Berwick, D., & Fox, D. M. (2016). Evaluating the quality of medical care: Donabedian's classic article 50 years later. The Milbank Quarterly, 94(2), 237–241. https://doi.org/10.1111/1468-0009.12189
15. Binder, C., Torres, R. E., & Elwell, D. (2020). Use of the Donabedian model as a framework for COVID-19 response at a hospital in suburban Westchester county, New York: A facility-level case report. Journal of Emergency Nursing, 47(2). https://doi.org/10.1016/j.jen.2020.10.008.
16. Brandow, A. M., Carroll, C. P., Creary, S., Edwards-Elliott, R., Glassberg, J., Hurley, R. W., Kutlar, A., Seisa, M., Stinson, J., Strouse, J. J., Yusuf, F., Zempsky, W., & Lang, E. (2020). American Society of Hematology 2020 guidelines for sickle cell disease: management of acute and chronic pain. Blood Advances, 4(12), 2656–2701. https://doi.org/10.1182/bloodadvances.2020001851
17. Glaros, A., & Brandow, A. M. (2020). Neuropathic pain in sickle cell disease: measurement and management. Hematology, 2020(1), 553–561. https://doi.org/10.1182/hematology.2020000142
18. Sagi V, Mittal A, Tran H, Gupta K. (2021) Pain in sickle cell disease: current and potential translational therapies. Transl Res. Aug; 234:141-158. doi: 10.1016/j.trsl.2021.03.007. Epub 2021 Mar 9. PMID: 33711512; PMCID: PMC8217144.
19. Myrick, R., Pernell, B., Madan-Swain, A., Howard, T. H., Hilliard, L., & Lebensburger, J. D. (2019). Impact of a Pediatric Sickle Cell Outpatient Pain Clinic on Health Outcomes. Blood, 134(Supplement_1), 4691–4691. https://doi.org/10.1182/blood-2019- 131059.

DOI:10.31579/2639-4162/121