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Cover Page Footnote

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Stigma and patient-controlled analgesia: Trust is the essential ingredient of successful patient education in the patient- doctor relationship

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ABSTRACT A clinical decision report using:

Van Beers EJ, Van Tuijn CFJ, Nieuwkerk PT, et al. Patient-controlled analgesia versus continuous infusion of morphine during vaso-occlusive crisis in sickle cell disease, a randomized controlled trial. *Am J Hematol.* 2007;82(11):955-960.
<https://doi.org/10.1002/ajh.20944>

for a patient with recurrent vaso-occlusive crisis secondary to Sickle Cell Disease.

Keywords: *sickle cell disease, pain management, patient-controlled analgesia, opioids, stigma*

Clinical-Social Context

Felix Marshall [pseudonym] is a middle-aged black man with a PMH of HgbSS Sickle Cell Disease (SCD) who presented to the hospital in a Vaso-occlusive Crisis (VoC). He had been hospitalized numerous times in the past 6 months due to VoCs. Mr. Marshall believed this episode arose due to dehydration following a hard workday noting the pain was worse in his bilateral femur and sternum. Charts from prior admissions stated the patient had “refused” patient-controlled analgesia (PCA) and thus on his last admission required over 500 morphine equivalents of opioid medication daily to combat his pain. Mr. Marshall stated this was common during his VoCs as he tried PCA pumps before and they did not help establish adequate pain control.

Mr. Marshall did mention he had distrust for the medical system, as he felt stigmatized as a “drug seeker” for years, which he stated impacted his quality of care. Prior to an attending shift change, the patient’s hesitance to use the PCA pump was accepted unquestioned. IV opioids were prescribed, which seemed to be providing minimal relief. Little trust was built and often the whole team did not even enter the room as our attending wished to create the least resistance possible. Mr. Marshall was being treated just as he had in the past. Following the shift change, there was a mentality change towards establishing a strong rapport with the patient, spending extra time in his room listening to his story, and building a relationship of trust. This was done while trying various methods of educating the patient on the clinically proven benefits of PCA and proper PCA pump utilization. During this time, I found myself contemplating how many interactions Mr. Marshall had like the initial ones he experienced with our team, and how that played a role in his hesitance to use PCA.

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Learning from Stephen Covey's Seven Habits of Highly Effective People, to effectively enact change in Mr. Marshall, a high-trust, collaborative relationship needed to be established. This was not easy given the years of distrust that had developed due to stigmatization and ineffective medical care. Covey states in habit five that one must first understand before they can be understood. Thus, for us to be understood by Mr. Marshall, would first require us to understand him, his thoughts, feelings and needs. With this newfound understanding of Mr. Marshall, the team approached Mr. Marshall with integrity and maturity, holding firm to our commitment to evidence-based care while also expressing ourselves with consideration for the stigmatization felt by Mr. Marshall. Using these habits were key strategies in the team's development of a better understanding of the stigma felt by Mr. Marshall and establishing a high-trust relationship.¹

Clinical Question

Can patient education regarding the use of a PCA pump help reduce reported pain and length of hospital stay in patients with SCD in acute VoC?

Research Article

Van Beers EJ, Van Tuijn CFJ, Nieuwkerk PT, et al. Patient-controlled analgesia versus continuous infusion of morphine during vaso-occlusive crisis in sickle cell disease, a randomized controlled trial. *Am J Hematol*. 2007;82(11):955-960. <https://doi.org/10.1002/ajh.20944>²

Description of Related Literature

A search of PubMed using the terms "patient controlled analgesia" and "education" yielded 862 results. Filtering of results was conducted selecting for only articles that discussed both PCA use and patient education specifically, reducing the number of remaining studies to 18. Further review of abstracts was conducted to identify those that specifically compared the efficacy of patient education on PCA outcomes. This left 8 potential studies remaining, as they tested the relationship between patient education and efficacy of PCA. All other studies contained parameters that were unrelated to those of the patient in this study.

In a randomized prospective study published by Griffin et al, 85 individuals were placed into to two groups.³ The test group (n=42) received a 20-minute standardized tutorial regarding PCA use, while the control group (n=43) received no additional education other than routine preoperative anesthetic consultation. Results from this study demonstrated that patient pain, satisfaction, and morphine consumption were similar in both groups at 6, 24 and 48 hours. However, it was noted that patients in the test group used antiemetic medication earlier and more effectively.

Shovel et al. completed a randomized controlled trial in which 40 patients all undergoing Total Hip Arthroplasty were divided into two even groups with the test group being provided a typed instructional card immediately post-operatively, and the control group only receiving standard postoperative care.⁴ Pain scores and PCA understanding were assessed. Results indicated that the use of instructional cards explaining PCA usage significantly improved pain scores ($p=0.024$) while improving patient understanding of PCA, suggesting that improved patient outcomes improve overall recovery.

Another randomized controlled trial by Lam et al. investigated the efficacy of preoperative patient education regarding PCA usage, in 60 women undergoing major gynecologic surgery.⁵ Two groups of 30 patients were randomly generated, with the test group receiving a structured preoperative education regarding PCA usage, whereas the control group was given routine preoperative care. Results collected immediately before discharge from recovery, at 24, and 48 hours postoperatively, demonstrated no significant difference in reported pain or recovery times. However patient satisfaction was reported to be improved for the test group, especially in the first 24 hours post-op. Patak et al. published a retrospective study with 350 patients who received postoperative PCA pump for at least 24 hours.⁶ From this study it was also determined that patient satisfaction and self-reported ability to control pain were not affected by patient education about the PCA. However, 92 (26%) of these patients noted difficulty with the PCA pump, 13 (4%) of which were due to not understanding the use of the system.



A study published by Chen et al. assessed the impact of using a preoperative educational video discussing PCA usage and preoperative instructions in a group of 60 surgical patients split into two groups.⁷ The test group received the educational video, and the control group did not. Statistical analysis found that pain understanding, and pain relief were both improved in the test group when compared to the control. Subjects in the test group indicated via survey that the use of the educational video aided in their ability to achieve pain relief with the PCA post operatively. A similar study by Knoerl et al, assessing the impact of a preoperative video for PCA education in 76 patients, determined that patients who received PCA education reported better pain control at both 4 and 8 hours.⁸ Hong SJ and Lee E published an article looking at 79 patients, evaluating the effects of implementing a 40-minute structured preoperative educational program with regards to PCA usage and postoperative pain, using both video and a brochure.⁹ Results demonstrated that there was a significant reduction in pain and adverse reactions, as well as an increase in patient satisfaction and analgesic medication used amongst the test group receiving the preoperative education when compared to the control.

The final article found in this search was a randomized controlled trial by Lin et al. in which 60 patients undergoing TKA were divided into two equal groups.¹⁰ The test group receiving in depth face-to-face education in addition to pamphlets preoperatively whereas the control group received standard training in PACU. Follow-up on post-op day 1 and 2 demonstrated that VAS scores were significantly lower in the test group as compared to the control. Patients in the test group also required nursing help fewer times.

Given the variability amongst reported education methods used and results related to pain control, as well as that all addressed the use of PCA treatment outcomes in the acute postoperative setting not in the setting of SCD, a secondary search of PubMed using the terms “patient-controlled analgesia” and “sickle cell” was conducted to gain better insight into the topic. Filtering of the 77 results was conducted using a “Clinical Trial” and “Randomized Control Trial” filter reducing the studies to 16 potential studies. Of these only 1 study discussed the use of a patient education program. All other studies contained parameters that were unrelated to those of the patient in this study. This study by VanBeers et al, observed the efficacy of PCA pumps in the setting of VoC secondary to SCD, as compared to the prior standard of care, IV morphine boluses.² This helps create a contrast of the two methods of treatment that Mr. Marshall was receiving. Lastly this was the only study found that assessed both the efficacy of PCA in the setting of VoC secondary to SCD, with regards to pain management, and length of treatment, thus it was selected for critical appraisal. This data set included 4 level 1 studies, 4 level 2 studies, with an A level strength of recommendation.¹¹

Critical Appraisal

VanBeers et al. describe a double blinded randomized controlled trial analyzing 19 patients with 25 consecutive episodes of VoC (6 crossover).² All these patients were over the age of 17 with various types of Hgb SSD (HbSC, SS, HbSB) and had confirmed VoC, specified as pain in the extremities, back, abdomen, or head that led to hospital visit and necessitated IV morphine use. In this study patients were randomized into 2 groups, one with PCA morphine, and the other receiving a continuous infusion (CI) of morphine. For those that were administered the PCA pump, there was a period patient education regarding the use of the pump, with specific instructions to push the button whenever experiencing pain. The primary outcomes of measurement were morphine consumption and reported pain levels, with secondary outcomes of length of hospital stay, duration of treatment and quality of life. Patients excluded from the study were those allergic to morphine and those who had already been receiving it for a 24hr period.

Patients in the PCA group received a single 5mg bolus of morphine, and then .02mg/kg q5min lockout was given at a patient-controlled rate. The continuous infusion group was given a 5mg bolus of morphine then given a continuous infusion rate of morphine of .03mg/kg/hr. The pain levels were assessed, and pain medication dosing was adjusted accordingly. Patients also received 50mg diclofenac and tramadol TID and 500mg Acetaminophen q4h. Patient pain was recorded four times daily with a VAS score, to determine perceived pain control and pain intensity. Morphine consumption was recorded hourly.

This study concluded that the morphine consumption of patients was significantly lower in the PCA group, with an average infusion rate of .5mg/hr, and the continuous infusion group had an average rate of 2.4mg/hr. Those that were in the PCA group on average reported a 3 day shorter length of hospital stay and greater pain control with a mean VAS score of 4.2 compared to 5.8 in the CI group. With regards to quality of life, this outcome did not differ significantly between groups, however, lower risk of drug side effects was noted in the PCA group. One of the largest limitations of this study is the small sample size leading to uneven distribution

of confounding factors. Another factor of limitation to this study is that due to the study design, there is a lack of complete blinding potentially introducing bias.² This study was determined to have Level of Evidence of 1.¹¹

Clinical Application

For Mr. Marshall the randomized trial chosen demonstrates that the choice to move to PCA pump was the correct one to control pain most effectively. Patients in this trial are similar to Mr. Marshall in that they were being treated for VoC with PCA and received face-to-face patient education. However, in this case, the patient had utilized PCA pumps in the past and was seemingly unwilling to utilize it during his initial admission, as it had “not worked to control my pain”. A shift in team attendings led to a repetition of detailed interviewing regarding the patient’s experience with pain control in past admissions and uncovered his reason for resisting the use of a PCA pump. The patient was originally of the mindset that he should only push the button when it was available, as he felt then he would be stigmatized as a drug seeker, however his pain was consistently rated at a 9 or 10/10 on the pain scale.

After days of trust building, education and working with Mr. Marshall, he eventually was willing to attempt using the PCA pump, thus leading to more effective pain control over a shorter period. In the period of trust building with Mr. Marshall, the care team was able to break down the barrier to PCA use that had developed due to years of stigmatization. Following this was accepting of education on how the PCA data allowed his physician team to track his medication needs. He was instructed if he was pushing the button more than he was receiving medication the team would be able to have a better sense of his pain control and adjust dosing accordingly. This occurs by tracking the demand to injection correlation. This is a set of data that tells providers the number of times the patient has pushed the PCA button (Demands) and the number of times medication was actually administered via the PCA pump following a lockout period (Injections). If the patient has a much higher ratio of demands to injections, this indicates inadequate pain control, and the PCA dose may need increased, or lockout period shortened.

At first Mr. Marshall had many questions and it was clear he felt anxious regarding this change. He noted again that he did not wish to be stigmatized as a “drug seeker” and was worried about pushing the PCA button too many times. However, after the first detailed education session, the team left the room with a feeling of accomplishment as it seemed we had made a breakthrough, with Mr. Marshall agreeing to try our method of PCA use. Following this, Mr. Marshall had a very high demand to injection correlation as he was pushing the button over 500 times and receiving only 35 injections of his current dosing of Dilaudid. His dose was elevated from 0.8mg Dilaudid at Q5min lockout to 1.7mg Dilaudid at Q5min lockout over the course of the following week. Once this dose was reached, Mr. Marshall reported adequate pain control and was able to start weaning off the PCA pump.

Mr. Marshall, over the course of the following 3 weeks, was weaned slowly from his PCA pump. During this time, conversations regarding his past experiences with PCA revealed that Mr. Marshall had never had a physician team sit down and talk with him regarding PCA use as we had. Mr. Marshall admitted that due to prior stigmatization he felt during past VoC’s regarding his opioid use, he built distrust towards PCA, he was previously unwilling to engage in open discussions with his doctors. An article published in *Clinical Research in Practice: The Journal of Team Hippocrates*, Garcia et al, describe the dramatic impact that stigmatization can have on patient care, and optimal clinical decision making.¹² While this was demonstrated in the case of Tom Williams [pseudonym], a man requiring amputation due to diabetes, this case was similar to Mr. Marshall’s as Mr. Williams was unwilling to accept amputation originally due to fear of stigmatization felt by amputees. It was not until a strong relationship, founded in acceptance and understanding was formed that Mr. William’s physician team was able to successfully remove the barriers to treatment built by fear of stigmatization. This relationship described is nearly identical to the relationship of trust we describe.

These cases are demonstrative that while reasoning for stigmatization can be different (opioid use vs. amputation), its negative impacts on the quality care patients experiencing it receive are the similar in these two settings. Putting together the knowledge learned from these cases, it is likely that had Mr. Marshall’s physician team taken

time build this trust during past admissions, he would have had a much shorter hospital stay, and may not have required as much opioid medication, thus helping control medication tolerance, as demonstrated in this study.²

New Knowledge Related to Clinical Decision Science

In the randomized trial selected, a standardized protocol for educating patients on the use of PCA was utilized in the experimental group, which is not the case for every patient placed on PCA.² While the PCA pump can be a great tool for treating and monitoring patient pain levels, it is only effective in the setting of proper patient education founded in a strong relationship of trust between patient and physician.

As seen in the case of Mr. Marshall, he was not properly educated initially regarding the use of his PCA pump. This lack of prior knowledge led to Mr. Marshall building distrust in the efficacy of PCA, thus adopting the habit of timing his PCA lockout period with his phone or a clock, leading to near perfect demand to injection correlation. Doing so falsely indicated to Mr. Marshall's physicians he was receiving adequate pain control, thus pushing him to distrust the use of PCA. While VanBeers et al. demonstrated that PCA should be the standard of care providing improved pain control and lower hospital outcomes, Mr. Marshall had previously experienced the exact opposite.² It was not until a relationship of trust was established and the fear of stigmatization was removed that this information was uncovered and patient education was successful. Following these patient education sessions, Mr. Marshall was pressing the button much more rapidly, as he was not utilizing a timer but pressing the button with pain requiring further analgesia, thus allowing the physician team to rapidly titrate up his Dilaudid dosing. This led to more rapid pain control, and subsequent weaning from the PCA pump. Prior to this, Mr. Marshall had remained in the hospital for over 2 weeks receiving IV Dilaudid injections, bringing about minimal improvement, with hesitance to even start using the PCA pump, due to prior failed attempts. Had PCA been initiated earlier, Mr. Marshall's hospital stay could have been drastically reduced.

Mr. Marshall's case not only reinforces the use of PCA pumps as the preferred method of pain control in VoC due to SSD but highlights the need for a form of structured education built on a relationship of trust to implement PCA most effectively in patients with SCD. Doing so may help achieve the same positive pain control and length of treatment results as were shown by Van Beers et al.² There is not a set algorithm to best perform this patient education as shown by the many forms detailed in the Related Literature section, however education both before and throughout treatment has shown to be effective. Learning from Mr. Marshall's case, evidence-based education should be initiated early in admission to avoid conflicting treatment plans. Preferably this is done when the patient first requires use of PCA. The change in the care of Mr. Marshall started when there was an attending physician shift change, as the new attending encouraged sitting down and talking with the patient, whereas the previous attending had minimal interest in addressing Mr. Marshall's distrust in PCA use. Without this change towards fostering a doctor-patient relationship of trust, efforts to address Mr. Marshall's distrust in PCA use would have been near futile. This case brings to light trust as a key factor in improving PCA outcomes through patient education, especially in the setting of SCD in which the stigmatization felt by patients is already high. The drastic change in the efficacy of patient education efforts and treatment provided to Mr. Marshall, following the establishment of a relationship of trust, demonstrates this.

Conflict Of Interest Statement

The author declares no conflicts of interest.

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