Viewpoint

Integrating palliative care and emergency medicine for optimal management of sickle cell pain in the wake of the United States opioid epidemic

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Having lost a sibling to sickle cell disease (SCD) related complications, and having heard multiple accounts from a friend with sickle cell about how much she suffers, and how her pain is poorly managed, there is certainly a need to share insights on this topic. My friend claims that in the emergency department (ED), she is consistently prescribed "non-effective" analgesics, instead of morphine, which she deems through experience, as being way more effective for her pain relief. She cites fears of her being potentially addicted to opioids and her socioeconomic status as primary reasons why morphine is withheld from her. Of course there are different sides to a story; my friend has been "noncompliant" in the past, and has toyed with excessive alcohol intake and tobacco use, both of which pose high risk to someone with sickle cell. Thus, from a purely paternalistic standpoint, I understand some of her providers concerns about substance abuse or opioid addiction. Why do more harm by devoting ample time and resources to a deviant patient, whose actions may create liability issues, and perhaps lead to professional censure?

However, as someone who is utterly concerned about her wellbeing, I am inclined to empathize when she tells me that her voice is often silenced, and her concerns about effective pain management routinely dismissed. That she is subject to withholding of opioid treatment even when she currently exhibits no behavior suggesting addiction (1) is an example of unjustified paternalism, and signifies a lack of respect for her autonomy as an individual. In the wake of the United States opioid epidemic, my friend and countless others have become the unrecognized and forgotten victims.

Indeed, management of acute painful episodes in SCD remain suboptimal in spite of advances in the management of acute pain in other clinical contexts (2). Although guidelines for pain management in adults with sickle cell experiencing a vaso-occlusive episode emphasize rapid and successive administration of parenteral opioids (3), people with SCD repeatedly cite their discontent with how their pain is managed in the ED (4).

Geller and O'Connor (5) posit that the pain experienced during an acute SCD vaso-occlusive episode poses a dilemma in pain relief because paradoxically, while people with SCD account for an infinitesimal fraction of those who are addicted to opioids or suffer opioid pain reliever (OPR) related deaths, they are disproportionately and inappropriately labeled as opioid abusers, sicklers, drug addicts or frequent flyers (5). Although there is widespread acceptance of opioid use in the management of SCD acute pain, a very large number of ED clinicians, including physicians, nurses and pharmacists, continue to hold inaccurate preconceptions regarding the prevalence of OPR related deaths, diversion, and opioid addiction among people with SCD (6).

That evidence and practice gaps persist in the appraisal and treatment of SCD pain in the ED suggests that there is a need for improvement. Palliative care can serve as a tool to correct the mismatch between clinician and patient expectations on pain management in the ED. A retrospective review by Ghanem and colleagues (7) revealed that the palliative care needs of people with SCD are comparable to that of people with cancer. In that

study, SCD patients reported experiencing severe social, psychological and spiritual suffering (7). Unlike cancer, however, people with SCD presenting with pain in the ED are particularly stigmatized due to prevailing negative perceptions about abuse in sickle cell.

SCD is unique in that under treatment of pain is often a lifelong phenomenon occurring from infancy to adulthood irrespective of ED setting. Part of the reason why this is the case is because many EDs lack the expertise to appropriately manage sickle cell pain and its complexities.

Ruta and colleagues describe sickle cell pain as being multidimensional and consisting of three types, namely, acute recurrent painful episodes, chronic pain syndromes, and neuropathic pain (8). They go on to state that the acute painful episode is the distinctive feature of the disease and the most common reason for treatment and hospitalization in the ED (8). The acute painful episode transitions through four phases: prodromal, initial, established, and resolving (8). During the prodromal phase, three pathophysiological events (vaso-occlusion, inflammation and nociception) occur simultaneously (8). By managing the acute painful episode at the prodromal phase through hydration, use of anti-inflammatory agents, aggressive analgesia, and anti-sickling combination therapies (e.g., hydroxyurea) patient harm can be mitigated and the acute painful episode halted (8). Thus, management of sickle cell pain should be guided by its own pathophysiologic mechanisms instead of guidelines used for other nonsickle pain syndromes (8).

Granted in the ED setting, care is often very fast paced and fragmented. People with SCD visiting an ED for the first time may not have built quality relationships with clinicians, essential to fostering trust, and making prescription of opioids easier. But better pain management and treatment outcomes may be accomplished by incorporating palliative care and its components tailored specifically towards SCD in the ED service. Also, by recognizing that for people with SCD palliative care approaches should not be limited to end-of-life treatments and decision making but rather applied throughout the trajectory of the disease.

People with SCD are generally very well informed about their illness. A major hallmark of many SCD peer support groups or blogs is discussion of the stereotypes and disparate treatment (covert and overt) received during ED visits. As a result, people with SCD visit EDs with a different or higher set of expectations than most people. Failure to meet those expectations may lead to frustration or conflict. There is no easy way out of this dilemma.

ED clinicians do not have to bear the brunt of the burden. They can partner with palliative care to achieve better outcomes. A fundamental goal of palliative care is to improve quality of life (QoL), not just for the dying, but also the living. Although palliative care pain management principles are inherently different from those of emergency medicine, studies point out that incorporation of palliative care into ED service leads to greater concordance between patient wishes and care received. In addition, it may lead to better patient centered care, improve QoL and reduce costs associated with treatment (9).

Because people with SCD are at high risk of feeling vulnerable and being stigmatized in the ED, where emphasis is often on rapid stabilization and symptom-oriented assessments, rather than shared decision making and holistic care, they are particularly well suited for palliative care. Palliative care brings with it practices and concepts that are particularly hard to implement in a non-integrated ED, e.g., improved care coordination, clinical ethics expertise, effective communication skills, and patient centered care. Granted logistical challenges must be overcome for any successful integration of palliative care into the ED, evidence points to the benefits of doing so outweighing the harms (9).

Finally, for the many people with SCD, who have been unduly labeled as liars, had their dignity violated, voices silenced, called addicts, and had opioids inappropriately withheld, amid severe pain in the ED, now is your time, and you, too, must have your voices heard.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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