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Pain management and symptoms of substance dependence among patients with sickle cell disease

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Abstract

Concerns about dependence on prescribed analgesia may compromise pain management, but there was previously little reliable evidence about substance dependence among patients with sickle cell disease (SCD). We conducted in-depth, semi-structured interviews with SCD patients in London, UK, to assess DSM-IV symptoms of substance dependence and abuse. Criteria were applied to differentiate between pain-related symptoms, which corresponded to the DSM-IV symptoms but involved analgesics used to control pain, and non-pain-related symptoms, which involved analgesic use beyond pain management. Pain-related symptoms are informative about how the pattern of recurrent acute pain in SCD may make patients vulnerable to perceptions of drug dependence. Non-pain-related symptoms are informative about more stringently defined dependence on analgesia in SCD. Inter-rater reliability was high, with mean Kappa coefficients of 0.67–0.88. The criteria could be used to assess analgesic dependence in other painful conditions. Pain-related symptoms were more frequent, accounting for 88% of all symptoms reported. When pain-related symptoms were included in the assessment, 31% of the sample met the DSM-IV criteria for substance dependence, compared with only 2% when the assessment was restricted to non-pain-related symptoms. Qualitative analysis of participants' descriptions of analgesic use showed that active coping attempts (attempts to anticipate pain and avoid hospital admissions) and awareness of dependence were themes in descriptions of both pain-related and non-pain-related symptoms. Seeking a more normal lifestyle and impaired activities were themes associated with pain-related symptoms. Psychological disturbance was a theme associated with non-pain-related symptoms. The implications are for more responsive treatment of pain in SCD and greater awareness of how patients' pain coping may be perceived as analgesic dependence. Further research could examine ways that pain-related and non-pain-related symptoms of dependence may be associated with other pain coping strategies and with the outcomes of treatment for painful episodes in hospital.

Keywords: Sickle cell disease; Pain; Analgesics; Substance dependence; Addiction; UK

Introduction

Sickle cell disease (SCD) is an inherited blood disorder that in Europe and North America mainly affects people with African or Caribbean family origins. The illness causes anaemia, susceptibility to infections, a shortened life expectancy, and recurrent episodes of severe ischaemic pain that occur when 'sickled' red blood cells cause tissue infarction. Painful episodes vary in frequency and severity and many are managed at home with oral analgesics. SCD pain can be as intense as post-operative pain (Walco & Dampier, 1990), and severe painful episodes are treated in hospital with parenteral opiates, usually intramuscular injections or

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intravenous infusions of pethidine, morphine or diamorphine. Patients often report that their pain is poorly managed when they are in hospital, or that staff are not responsive to patients' reports of pain (e.g., Alleyne & Thomas, 1994; Harris, Parker, & Barker, 1998; Maxwell, Streetly, & Bevan, 1999; Shelley, Kramer, & Nash, 1994). Staff–patient interactions, including the ways that staff perceive patients and their pain behaviours, probably have as much influence on the quality of hospital pain management as pharmacological factors like the type of analgesic or mode of administration (Elander & Midence, 1996).

Among the most common complaints by patients is that staff unjustly suspect or accuse patients of drug dependence, and this is borne out to some extent by surveys of hospital staff. In one, 53% of emergency department doctors (23% of haematologists) believed that more than 20% of SCD patients were 'addicted' to analgesics, and 22% (9% of haematologists) thought more than 50% were addicted (Shapiro, Benjamin, Payne, & Heidrich, 1997). In another, the estimated prevalence of opioid dependence was twice as high for patients with SCD compared with patients with other painful conditions (Waldrop & Mandry, 1995).

Staff perceptions of dependence could affect pain management, including premature discharges from hospital, or discharges with inadequate prescribed analgesia for use at home, increasing the risks of further pain. Under-treatment of pain can lead to what Weissman and Haddox (1989) called "pseudo-addiction", where patients whose reports of pain are not accepted have to resort to exaggerated or manipulative pain behaviours that may reinforce staff perceptions of substance dependence. Training staff to be less concerned about drug dependence and more responsive to reports of pain has been shown to increase the effectiveness of pain management in SCD (Brookoff & Polomano, 1992).

Perceptions by staff of substance dependence may affect patients with other painful conditions, but patients with SCD may be at greater risk for several reasons. Firstly, in Europe and North America, SCD patients are almost all members of ethnic minorities, which may adversely affect their treatment in health care settings (Dyson, 1998; Levy, 1985). Race was perceived by SCD patients and their families as the most influential factor affecting health care delivery (Chestnut, 1994), and there is evidence that hospital pain management is poorer for ethnic minorities by comparison with other patients. Among elderly cancer patients, inadequate analgesia was more common for ethnic minority patients (Bernabei et al., 1998), and in hospital emergency departments, ethnic minority patients were twice as likely as other patients to receive no analgesia (Todd, Samaroo, & Hoffman, 1993).

Secondly, the pattern of pain and the importance of active patient coping in SCD are different from other conditions for which comparable analgesics are employed. Parenteral opiates are most commonly used in hospital for the relief of either acute pain, as in fractures or post-operatively, or very severe chronic pain, as in cancer or terminal illness. Those conditions all involve non-recurrent pain associated with verifiable symptoms, and provide little scope for active patient coping. In SCD, by contrast, pain cannot be verified objectively and patients can recover to full health after a painful episode but present again with severe pain several weeks or months later. In one study where doctors made pain ratings for descriptions of fictitious chronic pain patients, the ratings were lower when there was no supporting medical evidence for the pain (Tait & Chibnall, 1997). Hospital staff often have great difficulty dealing with SCD patients who present in great pain and demand analgesia yet appear to recover rapidly once it is administered (Kraemer, 1994).

In SCD, active pain coping is very important outside hospital, and coping strategies that avoid negative thinking about pain and passive pain coping have been shown to predict better outcomes of pain (e.g., Gil, Abrams, Phillips, & Keefe, 1989; Gil, Abrams, Phillips, & Williams, 1992; see Midence & Elander, 1996 for a review). Other strategies used by patients include managing severe pain at home in order to avoid hospital admission (Maxwell et al., 1999) and trading-off pain relief against sedation and other side effects in order to maintain feelings of alertness and control (Forbes, Forbes, & Lee, 1998). In hospital, however, active pain coping strategies may be perceived by staff as drug dependent or drug-seeking behaviour.

Thirdly, patterns of hospital admissions for SCD pain probably reinforce staff perceptions of substance dependence. Relatively small numbers of SCD patients account for the majority of hospital admissions (e.g., Brozovic, Davies, & Brownell, 1987). Clinical audit at one of the centres where the present research was conducted revealed that a group comprising 8% of adult sickle cell patients accounted for over 70% of the emergency inpatient days required for all registered patients (Bevan, pers. comm.). These relatively small groups with frequent hospital admissions are the main contact with SCD patients for many acute frontline staff, and could include disproportionate numbers of patients with substance dependence or problem drug use.

Young adult males are over-represented among SCD patients who attend hospital more frequently. In two large studies, frequency of hospital admissions rose to a peak for male patients in their 20s before falling at about 35 years to the lower and more stable level of that for women (Baum, Dunn, Maude, & Serjeant, 1987; Platt et al., 1991). Those age and sex differences may reflect