

Satisfaction with and Perception of Pain Management among Palliative Patients with Breakthrough Pain: A Qualitative Study

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■ ABSTRACT:

Breakthrough pain is a significant contributor to much suffering by patients. The experience of intense pain may interfere with, and affect, daily life functioning and has major consequences on patients' well-being if it is not well managed. The area of breakthrough pain has not been fully understood. This study thus aimed to explore the experiences of breakthrough pain among palliative patients. A qualitative study based on a series of open-ended interviews among 21 palliative patients suffering from pain at an urban tertiary hospital in Malaysia was conducted. Five themes were generated: (i) pain viewed as an unbearable experience causing misery in the lives of patients, (ii) deterioration of body function and no hope of recovery, (iii) receiving of inadequate pain management for pain, (iv) insensitivity of healthcare providers toward patients' pain experience, and (v) pain coping experiences of patients. The findings revealed that nonpharmacologic approaches such as psychosocial support should be introduced to the patients. Proper guidance and information should be given to healthcare providers to improve the quality of patient care. Healthcare providers should adopt a sensitive approach in caring for patients' needs. The aim is to meet the needs of the patients who want to be pain free or to attain adequate relief of their pain for breakthrough pain.

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Pain is one of the most distressing symptoms experienced by cancer patients (Deandrea et al., 2014; Mercadante, 2011). Patients with cancer suffer from moderate to severe pain (van den Beuken-van Everdingen et al., 2007). Pain is estimated to affect 50%-80% of patients receiving active cancer treatment and 60%-90% of those with advanced cancer (Bradley, Davis, & Chow, 2005; Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Hwang, Chang, & Kasimis, 2003). Patients with cancer are at risk of acute and persistent pain (Mishra, Bhatnagar, Chaudhary, & Rana, 2009). The pain is caused by common diagnostic and therapeutic interventions related to the cancer. Cancer patients usually do not have well-controlled pain symptoms and are prone to having transitory "breakthrough" pain.

Overall, more than 1 in 2 cancer patients (59.2%) experience breakthrough pain, with the highest prevalence (80.5%) reported among those patients in hospice (Deandrea et al., 2014). Breakthrough pain is "a transient exacerbation of pain that occurs either spontaneously, or in relation to a specific predictable or unpredictable trigger, despite relatively stable and adequately controlled background pain" (Davies, Dickman, Reid, Stevens, & Zeppetella, 2009). Breakthrough pain is an important contributor to suffering in these patients (Hwang et al., 2003; Lai et al., 2011). Breakthrough pain may affect physical and psychological well-being of patients and their caregivers (Bunn & Griffiths, 2011). The experience of intense pain may interfere with, and affect, daily functioning such as ordinary daily activities, sleeping, walking, working, mood, and enjoyment of life. Breakthrough pain can also disrupt disease treatment schedules and can have significant consequences for patients' well-being if it is not well managed (Vissers, Stam, Nolte, Lenre, & Jansen, 2010).

Although cancer pain has been well studied, the area of breakthrough pain has not been fully understood. There is a dearth of information and only a small number of studies have explored in-depth understanding of breakthrough pain (Soden et al., 2010; Webber, Davies, & Cowie, 2011). The aim of this study was thus to explore the pain experiences of Malaysian palliative care patients with breakthrough pain as well as their perceptions and expectations regarding their pain experience.

METHODS

This study used a descriptive interpretive design with a purposive heterogeneous sample to reflect the range of the pain experience of palliative patients with breakthrough pain. The design was selected in order to understand the world as it is from the subjective experience of the individuals. This was aimed at

guiding the researchers in capturing information on patients' experiences that could not be obtained through quantitative designs. Purposive sampling was used to capture the reality of the patients' lives within that context. Various cancer patients at the end of their lives who were still undergoing active treatment, such as pain control, were approached for the in-depth interview. The respondents came from various units such as palliative, surgical, and oncology. To ensure all the respondents had pain experiences, their medical notes were reviewed before they were invited to participate in the study. All the participants had breakthrough pain and the pain scores varied from moderate to severe. All eligible respondents approached by the researcher agreed to participate in the interview session. Data were collected over a period of 6 months and all interviews were carried out by one author (PS). In addition to the interviews, information related to pain management was also obtained from field notes and medical notes. The interview schedule guide was developed based on key issues from the literature (Table 1). Questions addressed issues pertaining to pain experiences, the strengths and limitations of current approaches to pain control, and their expectations of pain control (Haozous & Knobf, 2013; Rustøen, Gaardsrud, Leegaard, & Wahl, 2009; Rustøen et al., 2013). A total of 8 male and 13 female palliative patients aged 23-75 years took part in this study. Twenty-one interviews were conducted, with all participants consenting to their interviews being recorded with a digital audio recorder. Each interview lasted 45-60 minutes. All the interviews were conducted in a quiet room in the wards. Data collection was continued to a point until data saturation of emerging themes.

A total of 21 interviews were audio-recorded and transcribed verbatim for analysis. All interview data were analyzed using the constant comparative method. Open coding was carried out on the raw data to develop the code and categories. The second step was the constant comparative method where the initial coding was linked and finally the main coding was generated. The constant comparative method involves breaking down the data into discrete "incidents" and coding them into categories (Glaser & Strauss, 1967). The common themes were then identified and agreed on by the second author. The data were analyzed with the aid of the QSR NVivo 10 software program. During the study, a journal was kept to note the content and the process of interaction in order to increase self-awareness. The journal served as a guide to keep track of the relationships and provided material from reflection. By detailing decisions taken in the research process, a clear audit trail can be

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