



## Adherence to treatment in patient with severe cancer pain: A qualitative enquiry through illness narratives



Maria Marina Torresan <sup>a,1</sup>, Lorenza Garrino <sup>b,1</sup>, Alberto Borraccino <sup>b,\*</sup>, Giorgia Macchi <sup>a</sup>,  
Anna De Luca <sup>a</sup>, Valerio Dimonte <sup>b</sup>

<sup>a</sup> Pain Management and Palliative Care Unit, City Hospital Health and Science of the City of Turin, Corso Dogliotti 14, 10126 Torino, Italy

<sup>b</sup> Department of Public Health and Paediatrics, University of Turin, Via Santena 5 bis, 10126 Torino (TO), Italy

### A B S T R A C T

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**Purpose:** Pain is a common symptom in cancer patients and often the most tangible sign of disease they and their families perceive. Despite currently available treatments, cancer pain frequently remains underrated and undertreated because of lack of adherence to the prescribed drug regimen. With this study we sought to identify elements that could facilitate pain management by exploring through narrative interviews the lived experiences of patients with severe chronic cancer pain in relation to their adherence to pain therapy.

**Method:** A purposive sample of 18 cancer patients, treated at the Centre for Oncology and Haematology (COES), City Hospital for Health and Science, Turin, were interviewed. The interview contents were analysed using a qualitative phenomenological methodology as described by Giorgi.

**Results:** Three themes emerged from analysis of the interview transcripts: the significance of pain in subjective experience; the experience of being a patient pursuing a care pathway and the importance attributed to pain therapy. Factors facilitating adherence included the perception of the physical and psychological benefits of having and following a pain medications plan, subjective self-efficacy in pain control, and trust in the healthcare team. Barriers to adherence were negative attitudes toward opioid analgesic therapy, debilitating drug side effects, and denial of pain as a tangible sign of disease.

**Conclusion:** Probing into the significance of the pain experience and its treatment through these narrative interviews revealed several core constituents of adherence. Healthcare providers can use this better understanding to build a trusting relationship with patients and foster adherence to treatment throughout the care pathway.

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### Introduction

An estimated 1.8 million Italians live with cancer (Crocetti and Buzzoni, 2009). With the currently available treatments, the overall survival rate at 5 years after diagnosis is now 55% (ISTAT, 2005). As cancer has evolved into a chronic illness, pain symptoms have become an essential part of the disease itself (Graziottin et al., 2011). During the course of treatment, 70% of cancer patients report experiencing pain, in 20–34% of which pain is acute (Bruera and Portenoy, 2009).

Chronic cancer pain, both disease- and treatment-related, is often seen as a personal and subjective experience. The psychosocial and physical burden of cancer pain adversely affects a patient's quality of life (Butow and Sharpe, 2013; Deandrea et al., 2008) and compliance with a therapeutic regimen: less than half of patients fail to comply with the prescribed treatment, either under using their medications or not taking them at all, making pain difficult to measure, control, and treat (Butow and Sharpe, 2013; Miaskowski et al., 2001; Valeberg et al., 2008; Ward et al., 1993). Among the barriers to cancer pain management there are: i) patient-related factors, e.g., non-adherence to the prescribed pain medications plan; ii) healthcare provider-related factors, such as poor understanding or minimization of patients' complaints; and iii) healthcare system-related factors, i.e., a lack of pain management services (Butow and Sharpe, 2013; Jacox et al., 1994; Miaskowski et al., 2001; Ripamonti et al., 2011). Understanding the patient-related factors is

\* Corresponding author. Tel.: +39 011 6705836.

E-mail address: [alberto.borraccino@unito.it](mailto:alberto.borraccino@unito.it) (A. Borraccino).

<sup>1</sup> These authors contributed equally.

crucial to overcoming the obstacles patients are likely to encounter when they cope with pain. Patients' behaviours reflect the shift in the doctor–patient relationship from the concept of “compliance”, defined as a patient's propensity to follow physicians' recommendations, to the notion of “adherence” which involves an informed decision to accept the treatment and to take an active role in the therapeutic process (Aronson, 2007; van der Peet et al., 2009).

In 2003, the World Health Organization (Sabaté, 2003) defined adherence to long-term treatment as “the measure in which a person's behaviour in taking medication, following a diet and/or changing lifestyle adheres to recommendations by clinicians or health care providers”. Healthcare provider-related factors that promote adherence include good communication, emotional support, regularly scheduled assessment of pain intensity, and verifying that the patient understands that the prescribed treatment is effective. In addition, patient-related factors that can enhance adherence include a basic knowledge of the disease, motivation to start and continue with the treatment, self-efficacy in managing the proposed regimen, and realistic expectations of its efficacy (Sabaté, 2003).

Among the factors that can reduce adherence there are: denial of the disease, lack of trust in doctors and/or healthcare services, anxiety, high levels of emotional and psychosocial stress, economic problems, religious or cultural convictions (Ballantyne, 2007; Sabaté, 2003), lack of perceived personal benefit (Graziottin et al., 2011), and the underrating of pain due to fear of treatment, such as side effects on the central nervous or the gastrointestinal systems (Potter et al., 2003). Among the latter, the fear of opioid dependence, sustained also by apprehensive family members and friends, can influence a patient's decision to accept or refuse opioid therapy, leading to inadequate adherence or discontinuation of treatment (Haynes et al., 2008; Schumacher et al., 2002). The inevitable consequences are exacerbation of pain, increased anxiety and depression, repeated hospitalizations and urgent examinations, personal and familial conflicts, and frustrating helplessness in coping with pain. Therefore, patients and their families play an essential role in pain management and need to be informed about the various options and educated through appropriate interventions that can enhance their adherence to therapy (Ganz, 2001; Horne and Weinman, 1999; Zepetella, 1999).

Adequate adherence hinges on perceivable physical and psychological benefits, enhancing adherence itself and continuation of therapy (Graziottin et al., 2011; Horne and Weinman, 1999; Potter et al., 2003). Adherence to therapy can be maximized when doctors, patients and their family agree on goals of pain treatment and the medication plan (Haynes et al., 2008) that foster the patient's self-responsibility, identity, active collaboration and empowerment (Aujoulat et al., 2007, 2008; Lin et al., 2006; van der Peet et al., 2009). The few studies that, to date, have examined the issue from the patient's perspective have described the role that uncertainty and personal identity concerns can have on patients' self-care behaviours and self-management capacity (Miaskowski et al., 2001; Schumacher et al., 2002).

The aim of this study was to explore, through narrative interviews, the lived experiences of patients with severe chronic cancer pain in relation to adherence to the medication plan and to describe the elements that could facilitate pain management in cancer patients with severe chronic pain.

## Methods

### Study design

The need to better describe the experience of patients living with chronic cancer pain sustained this study. We employed a qualitative phenomenological approach through narrative

interviews (Atkinson, 1998; Garrino, 2010) to reveal the factors constituting adherence to cancer pain therapy. In accordance with the Giorgi method (Giorgi and Giorgi, 2008), patients' expectation, trust, and personal experience in coping with cancer pain and treatment were the criteria that oriented the study. The goal of the descriptive phenomenological approach is to explore the essence of human experiences as they are lived as freely as possible from the researchers' presuppositions about the phenomenon under study. The approach entails the careful portrayal of ordinary conscious experience of “things” as people experience them. These “things” include hearing, seeing, believing, feeling, remembering, deciding, and evaluating (Polit and Beck, 2013).

### Setting and subjects

The study was carried out at the Centre for Oncology and Haematology (COES), City Hospital for Health and Science, Turin, the largest cancer centre day hospital in Italy and a European reference centre for cancer treatment. On average, more than 50 patients are seen daily and more than 15,000 are admitted annually.

The inclusion criteria for participating in the study were: age  $\geq 18$  years, diagnosis of a solid tumour; severe intensity of perceived pain, 7 to 10 on the numerical pain-intensity rating scale; in treatment with opioid therapy for chronic cancer pain, in accordance with EAPC/WHO recommendations (Caraceni et al., 2012). Exclusion criteria were: inability to understand or to speak Italian language and cognitive impairment.

### Data collection

A registered nurse, involved in palliative care and pain management activities and with an extensive experience in qualitative research enquiry, conducted in-depth semi-structured one-to-one narrative interviews to explore the factors influencing the level of adherence to pain treatment. A list of questions and themes to be addressed during the narrative interviews, both generated through literature and involved health care providers audit, had been prepared as an interview guide before the recruitment phase (Box 1). Purposive sampling was employed. Sample size was based on the point at which data saturation was reached and information redundancy was achieved (Polit and Beck, 2013). Potential participants were chosen after review of the case records of oncology department inpatients and were screened for eligibility based on

### Box 1

Interview guide: list of questions and themes addressed during the narrative interviews.

- Thinking about your experience of disease, and of pain in particular, how would you describe pain?
- How would you define pain therapy?
- Have you always taken your medications as prescribed?
- Thinking about the pain therapy you receive, which factors help you continue with therapy? Which factors do not?
- Thinking about your health care providers (doctors, nurses, psychologist, etc.), what kind of relationship do you have with them as concerns your pain and its management?
- Besides drugs, what other ways are there to treat pain?
- What kinds of resources, personal and/or of other kind, help you to adhere to therapy?

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