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

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**Title Page****Adherence to treatment for chronic pain: a qualitative study through illness narratives**

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## **Adherence to treatment for chronic pain: a qualitative enquire through illness narratives**

### **ABSTRACT**

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. Fully grasping the uniqueness of how patients cope with pain can allow healthcare teams to engage them in a trusting relationship and generate treatment adherence.

With this study we sought to identify elements that could facilitate pain management by exploring through narrative interviews the lived experiences of patients with chronic cancer pain in relation to their adherence to pain therapy. 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. 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. 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.

## **Adherence to treatment for chronic pain: a qualitative enquire through illness narratives**

### **INTRODUCTION**

An estimated 1.8 million Italians live with cancer {Crocetti, 2009 #1}. With the currently available treatments, the overall survival rate at 5 years after diagnosis is now 55% {ISTAT, 2005 #2}. As cancer has evolved into a chronic illness, pain symptoms have become an essential part of the disease itself {Graziottin, 2011 #4}. During the course of treatment, 70% of cancer patients report experiencing pain, in 20 to 34% of which pain is acute {Bruera, 2009 #6}.

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 {Deandrea, 2008 #3;Butow, 2013 #8} and compliance with a therapeutic regimen: less than half of patients do not comply with prescribed treatment, either underusing their medications or not taking them at all, making pain difficult to measure, control, and treat {Miaskowski, 2001 #7;Ward, 1993 #9;Valeberg, 2008 #10;Butow, 2013 #8}. Numbering among the barriers to cancer pain management 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 {Jacox A, 1994 #12;Ripamonti, 2011 #11;Miaskowski, 2001 #7;Butow, 2013 #8}. Understanding the patient-related factors is crucial to overcoming the obstacles patients are likely to encounter when they cope with pain. Patients' behaviors, 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 #13;van der Peet, 2009 #14}.

In 2003, the World Health Organization {Sabaté, 2003 #15} 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 #15}.

Among the factors that can reduce adherence 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 {Sabaté, 2003 #15;Ballantyne, 2007 #16}, lack of perceived personal benefit {Graziottin, 2011 #4}, and the underrating of pain due to fear of treatment, such as side effects on the central nervous or the gastrointestinal systems {Potter, 2003 #17}. 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,

2008 #18;Schumacher, 2002 #19}. 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 be educated through appropriate interventions that can enhance their adherence to therapy {Ganz, 2001 #5;Zeppetella, 1999 #21;Horne, 1999 #22}.

Adequate adherence hinges on perceivable physical and psychological benefits, enhancing adherence itself and continuation of therapy {Horne, 1999 #22;Potter, 2003 #17;Graziottin, 2011 #4}. Adherence to therapy can be maximized when doctors, patients and their family agree on goals of pain treatment and the medication plan {Haynes, 2008 #18} that foster the patient's self-responsibility, identity, and active collaboration {Lin, 2006 #24;van der Peet, 2009 #14}. 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 {Aujoulat, 2007 #25;Aujoulat, 2008 #26}.

The aim of this study was to explore, through narrative interviews, the lived experiences of patients with 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 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 #27;Garrino, 2010 #29} to reveal the factors constituting adherence to cancer pain therapy. In accordance with the Giorgi method {Giorgi, 2008 #33}, 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, 2013 #30}.

### **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: diagnosis of a solid tumour, active treatment with opioid therapy for chronic cancer pain, and age  $\geq 18$  years. 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 a long course 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 (Box1). Purposive sampling was employed. Sample size was based on the point at which data saturation was reached and information redundancy was achieved {Polit, 2013 #30}. Potential participants were chosen after review of the case records of oncology department inpatients and were screened for eligibility based on inclusion and exclusion criteria. Selected patients received a written explanation of the purpose and the methodology of the study and data collection at the first contact. Participation was voluntary, and written informed consent to participate was obtained before the interview took place.

Permission for conducting the study was sought from the director of the Centre and the head of nursing services. **The Hospital Review Board approved the study design and methods**. Prior to joining the study, prospective participants were informed of the following: participation was voluntary, the aims and means of data collection, their participation would involve completing a conversational interview that would be recorded, and that confidentiality of the recorded material would be **assured**. **In case of acceptance written consent was then collected**. In accordance with the topic requirements and following the participants' wishes {Holloway, 2009 #32} the length of interview did not exceed 2 hours. The interviews were audio-recorded and transcribed verbatim. Member checking was allowed. Four participants reviewed the transcriptions of their narratives to confirm content accuracy and validated the researcher's interpretations {Polit, 2013 #30}. No external funding was requested.

## **Data analysis**

Giorgi's qualitative phenomenological analysis method was used {Giorgi, 2008 #33}. Data were analysed following a four-step method: i) reading the entire set of protocols to get a sense of the whole; ii) discriminating units from participants' descriptions of the phenomenon being studied; iii) articulating the psychological insight in each of the discriminated units; iv) synthesizing the transformed meaning units into statements regarding the participants' experiences of adherence to pain treatment {Polit, 2013 #30}.

In keeping with the tenets of the method, the quality of the study was ensured using the Lincoln & Guba framework (credibility, dependability, confirmability, transferability and authenticity) as described by Polit {Polit, 2013 #30}. Credibility and dependability were ensured through the use of an audit trail, verbatim transcription and member checking. All phases of the analyses were conducted by the researchers (the registered nurse and a psychologist experienced in supporting patients with advanced-stage diseases and in psychotherapy for chronic pain patients), and an independent auditor. The auditor was an assistant professor of nursing sciences not directly involved in the study but expert in the methodology. During the analysis, the researchers reflected on their own values and suspended judgment, knowledge, and ideas

about the phenomenon under study (so-called bracketing). Confirmability and authenticity were achieved through member checking as described above. To strengthen accuracy, the study participants were invited to review their transcript, to review the categories and themes developed, and to give their comments. Because of the participants' clinical conditions, only four of them were able to contribute feedback. Transferability was addressed by describing the settings and the conditions in which the study took place. Several themes emerged from the analysis, each of which exemplified below by one or more excerpts from the interviews.

## **RESULTS**

The interviews were conducted between December 2011 and January 2012 and were 45 minutes in duration on average. Table 1 lists the demographic characteristics of the participants (n = 18) based on the data obtained during eligibility screening. Seventeen participants were Italian and one Rumanian, the mean age was 59 years (range, 34-81). The mean duration of pain therapy was 14 months (range, 1 month – 4 years).

[Table 1. Patient characteristics.]

All interviewees reported taking their prescribed medications without questioning or having doubts about the treatment regimen, indicating that their adherence to treatment was adequate. Four patients stated they were initially hesitant about taking drugs.

Three major themes emerged from the analysis of the interviews that describe the patients' perceptions about adherence to treatment: a) subjective meaning of pain in one's personal experience; b) perceptions of being a patient in a care pathway; and c) perceived value of pain therapy. The following sections describe each themes investigating the unit of meaning and providing relevant quotations (table 2).

[Table 2. Themes and unit meanings.]

### **Theme 1. Subjective meaning of pain in one's personal experience**

All interviewees reported that they experience pain as a highly stressful condition that adversely affects all aspects of their life. In the patients' experience, pain is identified as a detectable sign of their disease. Among the unit meanings were the difficulties associated with pain; the negative thoughts generated by the presence of pain; and the pain-coping behaviours they adopted.

#### *Perception of the difficulties associated with the experience of pain*

In their narrations, all interviewees clearly described how deeply pain has influenced their emotional states, intruding their thoughts with stressful feelings and making life unpleasant.

“Besides making everyday life difficult, pain makes it difficult to think, and that creates fear and anger.” [P4]

#### *Negative thoughts generated by the presence of pain*

Thoughts, images, beliefs and convictions accompanying the presence of pain referred mainly to the idea of pain as an obstacle. Pain hampers thinking about the future of getting over the disease.

“Pain makes you think negative thoughts, because you’re in the dark and you’ll never get out of it. You will never be able to cope with the pain and everything else.” [P4]

The patients perceived limitations in all aspects of their daily life, with adverse effects on their family, social and workplace activities, ultimately resulting in a considerable drop in their quality of life.

“When you wake up with pain in the morning, it ruins your entire day. You don’t feel like eating, doing anything, going out or seeing friends or family.” [P7]

### Behaviors depending upon the presence of pain

When describing the limitations associated with the presence of pain, the interviewees emphasized the subjectivity in reacting to pain. Each patient reacts to pain with pro- or anti-social behaviours. Some patients stated they preferred staying close to the persons in their inner circle.

“Because of my character, I feel edgy around people. I don’t want to let them see I’m in pain, so I have to hide it.” [P14]

Other patients reported that the experience of pain brought about a radical change in their social life, enabling them to make new acquaintances and develop the capacity to better understanding others.

“[...] my character changed. If someone needs help, even in something small, I’m there to help. I’ve widened my circle of acquaintances. This helps me to move forward in life and not go it alone. You can fight pain in this way, too.” [P5]

Oftentimes, pain is seen as a tangible sign of illness. In their narratives, the patients who were better able to accept the disease and its consequences, such as pain, were more likely able to adapt positive strategies to control and manage it.

“One thing that can ease pain is inner serenity; the disease and the pain become part of you, so you have to somehow learn to accept it.” P14

## **Theme 2. The experience of being a patient in the care pathway**

The narratives revealed that the quality of relationships and communication with the healthcare providers the interviewees met along their care pathway is of particular importance for the management of pain. Several factors contribute to increasing treatment adherence, facilitating a patient’s propensity to take analgesic medications. Among these emerged the value of their relationship with and the trust in physicians; the importance that information, communication and collaboration between patients and clinicians can have in choosing the therapy.

### Value of relationship and trust with the physician and other healthcare providers

Patients need to be reassured they will meet expert professionals to trust in. The physician’s professional approach is key factor. When patients recognize in the physician a professional, they are more likely to develop a trusting relationship and to collaborate with the treatment regimen.

“I trusted the professionalism of the doctors, from my primary care provider to all the others involved in treating the disease and the pain. When I looked them in the face, I immediately saw they were professionals, and that was what helped me start taking the medications [...] The relationship is important, because you feel doctors and nurses understand your problems and that they’re concerned about a person’s wellbeing. One of the reasons why I followed the therapy was because I could trust them.” P4

A trusting relationship with the entire healthcare team, characterized by humanity, friendliness, trust and hospitality with a mutual understanding of the patient’s suffering, enhances adherence to therapy. **Patients reporting negative relationships were more apt to question the treatment plan and, in other circumstances, the efficacy of prescribed drugs.**

“[...] the way he told me to take those pills, even my daughter did not understand so well what they were and how I should take them. Almost I did not take them ...I took those pills because I was very bad, and I wanted to try. If I had just a little less bad I would not have just taken, at all [...]” P12

Patients see healthcare team members as a whole, independently of their role, all working with the same commitment. Some interviewees stated that, although drugs are the basis for analgesic treatment, other interventions like psychotherapy and massages can help to reduce the anxiety and fear that can increase pain intensity.

“My psychologist helps me to see things differently; this reduces my anxieties and worries about the disease and the family.” P15

“[...] the drugs are at the base. The other things, such as massage, for example, are an aid to overcome the anxiety, tension [...]” P13

#### Importance of communication, information and collaboration

The interviewees highlighted the importance of receiving clear, detailed and reassuring explanations with regard to their specific needs, the drug regimen, its side effects, and the expected results. The importance of receiving thorough information is witnessed by the statements some patients made about their use of the Internet as a source of more in-depth information.

“It’s important that doctors and nurses explain and then check whether the patient has really understood what they have said. If that happens, then the relationship also works. But you can’t always expect them to take the time to explain and make sure you’ve understood. In which case, you have a double problem to deal with.” P6

Patients revealed that it is significant for them to share the decisions on the analgesic therapy prescription. It clearly emerged how discussing the available options, agreeing on its rationale and the objectives can influence adherence. Adherence was found to be a dynamic, interactive process that engages the healthcare team members, the patients, and their families altogether.

“[...] at the end, along with the doctor and the nurse, I decided that it was better for me to put the patch on. So we just chose the most suitable time for me to change it.” P9

“Patients have to ask, patients have to know. There must be interaction between patients and the healthcare team, because if the patient does not cooperate, he threatens to nullify the

results and therapy won't work, and in the end it's the patient who suffers. And this is the opposite of what we all wanted." P18

#### Fostering patient's collaboration and responsibility

Pain is experienced not only by the patient, it also involves the entire family. Both the patient and their family members need to be educated in managing pain therapies. Some of the interviewees stated that when their family received educational interventions, they helped facilitate adherence to treatment, managing pain flare-ups, dealing with side effects, and checking that the drug-delivery devices worked properly.

"The nurses taught me and my husband how to give a subcutaneous injection, so that when I feel acute pain I take morphine before the pain becomes unbearable. Before that, when I didn't know what to do, I was afraid of the pain." P15

The patients agreed that adherence to therapy increases when personal and familiar resources are tapped, when they feel there is support around them

"..trust in myself, my care providers, and my husband's support, and that of my son. And I also found comfort and strength in faith; praying for myself and others helps me a lot." P4

"Sometimes I feel discouraged. Then for the sake of my family, I regain hope and willingness." P18

"The family counts a lot because they help and encourage you, but you feel guilty when you see they feel bad for you. Disease also changes the lives of those around you." P7

Some of the interviewees also stated that, besides personal and family resources, the attitude of the healthcare team is important for feeling satisfied about achieving treatment objectives. Gratification increases patients' self-efficacy in managing the pain autonomously.

"Their availability, the calm they convey or their friendliness during control visits, the way they make you feel special all help to instil trust in following the therapy." P2

"..People always want to be gratified, trusted, told they're good, that they can make it and have the strength to so." P4

### **Theme 3. The importance patients attribute to pain therapy**

Adherence to pain therapy strongly depends on the importance patients attribute to therapy as a means to alleviate the symptoms of the disease and maintain an acceptable quality of life. The perception patients have not only of the drug's effects but, more generally, of the outcomes associated with the treatment play an important role in fostering collaboration between the patient and the healthcare team. Among the units of meaning gleaned from the interviews emerged the value patients associate with pain therapy; the objective benefits gained by taking the drugs; the perception that therapy efficacy also somehow influences the healthcare team's attitudes; the reassuring effect of having a plan to fight the pain and the consequences of the therapy side effects.

#### Recognition of the value of pain therapy

All patients recognized that pain therapy was essential for them, for carrying out activities of daily living and for making the disease bearable.

“The therapy is a basis for living.” P14

“[...] for me, the drugs are at the base. [...]. Pain is pain, it doesn't go away with other things.” P10

Taking opioid analgesics, though sometimes viewed with fear and apprehension, is recognized as essential for adequate pain management, which facilitates adherence to therapy.

“I used to take anti-inflammatory drugs, but then the pain came back. Now I take morphine and feel better and know what to do when I feel the pain coming on. I couldn't live without it.” P8

#### Benefit of taking the drug

The benefit of taking an analgesic was found to be a key factor in adequate adherence to therapy, even when the pain intensity was reduced to a bearable level, without disappearing completely. This effect occurred also when the patient was initially sceptical, reluctant or hesitant about starting therapy.

“..If you're in pain, only drugs can relieve it. It's the relief of pain that makes you want to continue with therapy.” P6

“[...] the pain has never gone away completely, never really relented, but the painkillers allow me to have a real life.” P5

“I initially resisted the pain because I'm not inclined to take drugs. But when I took them, the pain went away a bit and life was different. Now I take medications whenever I need to.” P16

In contrast, difficulty in achieving short-term pain relief increases anxiety and influences whatever trusting attitude or propensity patients may have toward taking their medication.

“At the beginning, the biggest problem was finding the right mix of drugs for the pain. This went on for about 2 to 3 excruciating months until we found one that worked for me. This meant the end of that spasmodic nerve-wracking search.” P3

#### Perception of the importance that therapy also has for healthcare providers

Some patients stated that observing and perceiving that fighting the pain is also important for the healthcare team helped them adhere to treatment.

“It helped me to notice that good pain control was a priority for the healthcare team. Their shared interest in controlling pain is a big part of care, so that you can't help but trust them.” P6

#### Reassuring effect of prescribed pain therapy

The narratives indicated that adherence is also linked to the reassuring effect of having a prescribed pain medications plan.

“Pain therapy creates a certain sense of calm; it helps the person to fight the disease and focus on that.” P6

Not only does having a pain therapy plan reassure the patient, but also knowing what to do in case of flare-ups and the occurrence of predictable side effects.

“I’m so afraid of pain. Being able to self-medicate when the pain worsens is reassuring because I know what to do.” P15

### Undesired side effects of pain therapy

Side effects are important because patients are concerned as much about side effects as they are about pain. Some prefer enduring a bearable amount of pain rather than increase the therapeutic dose which for them was associated with potentially undesirable side effects.

“I’d rather deal with the pain when walking than with the nausea and drowsiness from the drug.” P8

“[...] the constant drowsiness during the day slows down my thinking and affects my work, so I can’t work as efficiently as my employer expects me to [...]” P3

The patients stated that at ultimately, even if afraid, they tacitly accept even bothersome side effects if they can get the relief they need.

“Dry mouth scares me; sometimes it makes me think of dying by suffocation. If I have to increase my dosage, I’ll do it because I know that I’ll have to do it anyway, because this is a disease that does not go away.” P5

Just as worrisome as drug side effects are using the drug-delivery devices and the availability of medications. Some interviewees stated that the practical difficulties with obtaining their medications and the size of the drug devices made adherence to treatment more troublesome.

“..carrying this unwelcome guest around – this elastomeric pump – with all the medical advances, you’d think they could’ve invented something more comfortable, less bulky.” P3

“[...] the pharmacy wouldn’t give me the drug even though I had a prescription. It was summer and my substitute doctor didn’t have the right prescription booklet. I was desperate and couldn’t deal with the situation.”P2

## **DISCUSSION**

This study is the result of a qualitative inquiry approach conducted through the use of narrative interviews {Polit, 2013 #30} with a view to gain a deeper understanding of experienced elements that can influence adherence to pain treatment in cancer patients, **whatever therapeutic strategy is adopted.**

Three main interrelated themes emerged as elements influencing adherence. The patient’s lived and subjective experience within the care process was depicted as a cardinal point for understanding and accepting the therapy. Common to all the narratives were the awareness of and worries about pain and the influence that the experience of pain has on their quality of life: pain is a limit of every day activities; generates disruptive thoughts; and affects social behaviours {Deandrea, 2008 #3; Bruera, 2009 #6}. The majority of the interviewees described pain as an unwieldy obstacle, an indelible mark of their disease. Its presence hampers thinking about the future and undermines expectations about getting better. Pain made them feel psychologically vulnerable by creating uncertainty and threatening their social

identity {Graziottin, 2011 #4}. Consistent with previous studies on the significance of pain in one's personal experience (Theme 1), we found that adherence to therapy is inextricably coupled with the patient's lived experience and the meanings attributed to the presence of the disease. Indeed, patients with a higher acceptance of their disease are more likely to agree on proposed therapeutic options to better cope with the pain itself {Horne, 1999 #22; Ballantyne, 2007 #16}. In order to allow a conscious acceptance of the present situation, health professionals should assist cancer patients in identifying significant experiences associated with pain symptoms and collaborate to increase the perceived meaning of pain therapy {Potter, 2003 #17}.

Many healthcare-related factors interact in increasing adherence (Theme 2). Foremost among these are the recognition of the physician's role as a trustworthy professional and the expectations that the entire healthcare team place in the prescribed therapy. Essential for generating participation in treatment and strengthening adherence, however, is that these elements be regularly reinforced through dialogue and collaboration. Specifically, receiving clear, detailed and reassuring information about the drug regimens, including their undesired side effects, and the real benefit to be gained from the pain medications enhances the quality of relationship between the patient and the healthcare team. In contrast, adherence becomes problematic when patients distrust opioid analgesic therapy because they were not adequately informed about their medications, the expected outcomes, and when potential side effects were concealed. Such issues can be effectively addressed with a trusting, emphatic communication within an open healthcare team-patient relationship that values shared commitment and difficulties {Haynes, 2008 #18; Spinsanti, 1998 #34}.

As the doctor-patient relationship continues to evolve, recognition and respect for patient autonomy and self-determination has gained more and more importance, with a relevant role in promoting treatment adherence {d'Ivernois, 2004 #35; Aronson, 2007 #13}. Physicians are viewed as a source of authority and their advice on pain therapy is regarded as valuable. Indeed, the patients shared the view that they need to take part in setting the goals for their medications plan, see them through, and be praised for reaching treatment goals (e.g., how to deliver a subcutaneous injection, follow drug schedules, deal with side effects, etc.), all of which are crucial for their engagement in therapy. Furthermore, receiving individualized information, especially from the unit nurses, helped the patients and their family to cope with pain, to manage pain flare-ups, deal with side effects, and check that the drug-delivery systems were working properly. Adherence to treatment hinged not only on treatment success but also on the development of a personalized therapeutic relationship between the patients, their family, and the healthcare team {Aujoulat, 2008 #26; d'Ivernois, 2004 #35; Sabaté, 2003 #15; Graziottin, 2011 #4}. Extending the relationship with the healthcare team to include the family serves as a useful support to resolve family conflicts {van der Peet, 2009 #14; Ripamonti, 2011 #11}.

The importance that pain therapy can have (Theme 3) for improving their quality of life was shared by all patients. They recognized that pain therapy is indispensable not only for enabling them to carry out

activities of daily living, but necessary for coping with the disease and maintaining an “acceptable quality of life” despite the worries about the possible side effects. Even if several patients were, in fact, apprehensive about the proposed analgesic therapy, when treated with opioids they were trustful as this was the only drug that could adequately control their pain {Bruera, 2009 #6;Jacox A, 1994 #12}. It is also common to observe that in these patients is quite common to attempt also other alternative or strategies to cope with their anxiety and fear about the disease, including psychotherapy and other practices, such as massages, among others {Sabaté, 2003 #15}. Medications, indeed, were the only recognized means to effectively relieve the physical constraining pain. Nonetheless, the occurrence of side effects should not be underestimated. As emerged from the interviews, the recurrence of side effects creates a barrier to continuing with the prescribed therapy {Graziottin, 2011 #4;Potter, 2003 #17}. Some patients stated they preferred enduring a certain amount of pain rather than increase their drug dose and experience debilitating adverse effects.

An additional resource to strengthen adherence to treatment that patients reported to draw from was tapping into their personal resources. Patients made good use of all the available resources in the healthcare team, their family and friends, as well as in themselves, relying on their character, their fortitude, trust in themselves, and religious beliefs. Essential resources for “moving ahead” and “sticking to therapy” were the reception, availability, serenity, and trust the healthcare team showed toward them and their family, in particular, the perception that fighting the pain was just as important for the healthcare team {Aujoulat, 2008 #26;Aronson, 2007 #13}. In line with previous observations, all narratives described trust as the precondition to building a therapeutic relationship and for choosing to adhere to treatment {Garrino, 2009 #36}.

In our study sample, all interviewees adhered to therapy, including those whose adherence was initially discontinuous because they had experienced pain flare-ups or were unable to control the pain when they lapsed in taking their medications. These data disagree with published studies that reported that one half of patients normally do not regularly follow prescribed therapy {Miaskowski, 2001 #7;Ward, 1993 #9;Valeberg, 2008 #10}. A possible explanation for this difference can be explained by **both** the methodology adopted **and the fact that the majority of interviewed patients were under opioid treatment**. A qualitative approach is more likely to recruit volunteers with a positive experience to be narrated than a quantitative descriptive approach. Furthermore, the eligibility criteria could have excluded patients with negative experiences in managing pain therapies due to cognitive impairments **or non effective treatments**. Our data indicate that adherence to prescribed pain therapy improves when the pain intensity increases and treatment is effective in relieving it. Socioeconomic factors (e.g., education level) and depression can yield differences in adherence {Graziottin, 2011 #4;Potter, 2003 #17}. The Analysis of the narratives, actually, did not reveal any particularly relevant difference in the educational level of the participants; an element common to all the narratives was the depressed mood, which chronic pain patients are noted to have, however, depression did not appear to significantly influence adherence.

In brief, adherence to therapy was depicted as a dynamic, evolving process of interaction between the healthcare team, the patients, and their families. As such, it requires continuous monitoring and observation for events that can potentially disrupt it. **Despite the large amount of literature that have explored these themes in the recent years, it still appears that a high proportion of success in the adherence, to any proposed treatment, is health care providers dependent. Unfortunately, it emerged that the perception that professionals have on the importance of pain and its effect on patients' quality of life can influence not only the adherence but the patient participation to the whole care process {Jho, 2104 #37; Gaertner, 2013 #38}. It is foremost important to continuously improving and consolidating the knowledge on the factors that impact on the quality of received care.**

## **CONCLUSIONS**

This study provided a context for examining several factors that can foster or impede adherence to opioid therapy for chronic cancer pain. The general aim was to explore the attitudes and strategies such patients employ at the beginning and during therapy. Patients who may be slow to adhere to therapy will need to be monitored in order to promptly identify the barriers that merit particular attention. Availability, trust, reception, recognition of suffering, providing targeted information, taking time, together with competence in pharmacological pain management, are all factors that interact in the relationship between health providers, patients, and their families. The choice of healthcare providers to engage in a therapeutic relationship project represents a moving experience in their professional lives that can change **not only** the way they see themselves and others **but also the understanding of what success is when dealing with such complex issues.**

## **Conflict of interest**

The authors declare that they have no conflict of interests.

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## **Authors' Contributions**

LG and MMT contributed to the study concept, completed interviews, conducted qualitative analyses, and drafted the manuscript. LG and AB reviewed the analyses and wrote the manuscript; GM, DLA and VD contributed to the study concept and critically reviewed the manuscript. Each author reviewed the final version of the manuscript and approved it for publication.

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