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## HEALTH PROFESSIONS (1-2018)

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# “Could I return to my life?” Integrated Narrative Nursing Model in Education (INNE)

Giovanna Artioli<sup>1</sup>, Chiara Foà<sup>2</sup>, Chiara Cosentino<sup>2</sup>, Francesco Sulla<sup>3</sup>, Alfonso Sollami<sup>4</sup>, Chiara Taffurelli<sup>4</sup>

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**Abstract.** *Background and aim:* The Integrated Narrative Nursing Model (INNM) is an approach that integrates the qualitative methodology typical of the human sciences, with the quantitative methodology more often associated with the natural sciences. This complex model, which combines a focus on narrative with quantitative measures, has recently been effectively applied to the assessment of chronic patients. In this study, the model is applied to the planning phase of education (Integrated Narrative Nursing Education, INNE), and proves to be a valid instrument for the promotion of the current educational paradigm that is centered on the engagement of both the patient and the caregiver in their own path of care. The aim of this study is therefore to describe the nurse's strategy in the planning of an educational intervention by using the INNE model. *Methods:* The case of a 70-year-old woman with pulmonary neoplasm is described at her first admission to Hospice. Each step conducted by the reference nurse, who uses INNE to record the nurse-patient narrative and collect subsequent questionnaires in order to create a shared educational plan, is also described. *Results:* The information collected was submitted, starting from a grounded methodology to the following four levels of analysis: I. Needs Assessment, II. Narrative Diagnosis, III. Quantitative Outcome, IV. Integrated Outcome. Step IV, which is derived from the integration of all levels of analysis, allows a nurse to define, even graphically, the conceptual map of a patient's needs, resources and perspectives, in a completely tailored manner. *Conclusion:* The INNE model offers a valid methodological support for the professional who intends to educate the patient through an inter-subjective and engaged pathway, between the professional, their patient and the socio-relational context. It is a matter of adopting a complex vision that combines processes and methods that require a steady scientific basis and advanced methodological expertise with active listening and empathy – skills which require emotional intelligence.

**Key words:** Integrated Narrative Nursing Model, patient, engagement, education, hospice, chronic disease

## 1. Introduction

For chronic illnesses in particular, education aims is to help the patient, the family and the environment that surrounds them to maintain the ability to effectively manage their life, despite the limitations that the disease presents. Specifically, the implementation of

educational interventions aims to: strengthen the decision-making autonomy of patients in their integrated care pathway, promote and facilitate the appropriate use of hospital and territorial services and to help the patient live an active and peaceful life with chronicity.

According to Nozzoli and coll. (1), education is a process of four *phases*, the first of which being the

*analysis of the need.* In this phase, the nurse, with other professionals, can perform a quali-quantitative and integrated assessment (see; INNEM; 2), aiming not only to identify needs and what is lacking but also the potential strengths on which to act, as well as performing an analysis of personal and social difficulties and weaknesses.

This phase is followed by the *design* phase, which consists of defining and sharing the aims, identifying the contents and choosing the proper methodologies and operating conditions of implementation in order to stipulate a therapeutic contract with the patient and their family.

The third phase is implementation. In this phase, through *in-person* meetings, the professional seeks to propose pertinent, interactive and active learning to facilitate the patient's adaptation to life within the context of the disease.

The final phase is *evaluation*, which consists of monitoring the desired learning and clinical outputs followed by analysis of the achieved results.

As for the *purposes* of education, they should be oriented in order to encourage the patients to know their own body, the disease and its repercussions, in addition to their needs, ideas, expectations, emotions and values.

Furthermore, the health care provider must be able to educate the patient on a multitude of other matters. Following education, the patient should be able to: understand and prevent early symptoms; analyse potentially hazardous situations; adopt adequate conduct in the face of relapse or situations critical to health; manage to solve everyday problems; develop a capacity for agency in the processes of drug delivery and implementing treatment prescriptions; change their physical, social and emotional environment, adapting favourably to the context of their new lifestyle; use the resources of the socio-health and welfare system; know where and when to request a consultation, whom to contact and where to find support and adequate information.

If we are therefore in agreement on the *processes* and the *aims* of education, when regarding *implementation* one must always critically consider the expectation that the patient, though informed, puts into practice the advice and indications given, particularly

if they promote health and are related to quality of life. In order for there to be an effective educational alliance, an empathic relationship of trust and collaboration must first be established between the patient and their health team.

In regards to recent research on education, many studies carried out so far have emphasise the role of the nurse in supporting and promoting *patient engagement* and its discrete components (such as empowerment, self management etc.), proposing contributions based on the disease (such as stroke, diabetes etc.) and based on the most functional protocols for the long-term management of a patient with a specific chronic pathology (3, 4).

In Italy, Graffigna and coll. (5) drafted more general recommendations for chronic diseases, promoting patient engagement in the setting of clinical-care, and highlighting that the health results and the quality of life of these patients does not depend on the mere technical quality of the clinical-care, but rather has deeper roots in the degree to which patients actively collaborate and to which the family are involved, in addition to the patient's social environment. These factors work in tandem with the health system and promote the quality and effectiveness of the care pathway itself.

However, according to Sofaer & Schuman (6), knowing how to enter a process of engagement requires first that the nurses have acquired a specific cultural background that leads them to: 1. consciously apply a completely patient-centered approach; 2. marry the belief that the patient and their family are or may become competent in informed decision-making regarding their health and the health system; 3. develop the will to support the patient and the family, when necessary, to overcome the difficulties and obstacles related to the health system itself.

Among the different methods with which an engaged educational process can be tackled, the design process of the Integrated Narrative Nursing Education (INNE) will be examined here.

This educational model, based on the Integrated Narrative Nursing Model (see INNEM; 2), addresses the individual as a unit made up of a plurality of dimensions (bio-physiological, psychological, socio-cultural and spiritual) and uses qualitative methodologies

and tools, typical of the human sciences (e.g. interview, narrative and patient agenda), integrating them with quantitative methods that derive from the natural sciences (e.g. scales, tests and questionnaires).

Starting from an approach that has its roots in Grounded Theory (7, 8), the research presented here provides a systematic but flexible collection and analysis of data, which leads to the identification of a tailored educational project. The method is inductive and interactive, and it can be imagined as a process which, beginning with the data, proceeds following a circular and recursive path (8).

As already exemplified in the assessment phase (Integrative Narrative Nursing Assessment, INNA), particularly in cases of chronic illness (9), the use of subjective methods, tests and scales allows us to achieve personalised and unique results. These must however be integrated with objective methodologies, which help to frame the ideographic characteristics in nomothetic frameworks, which are more standardised and recurrent in the examined population.

In short, the nurse, must come to an integrated assessment, which will help the design of the INNA. This integrated evaluation uses methodologies deriving from non-overlapping conceptual models, which then require the mastery of epistemological approaches and diversified instruments (2).

Therefore, this method provides training for the professional in regards to how to conduct assessments with both flexibility and specificity in the context of the patient, and how to integrate quantitative aspects, co-constructing both qualitative and quantitative data in order to plan the assessment, the assistance needed, and to reach a truly personalised education.

As we have already argued (9), it is the critical and reflective thought of the nurse, as well as their relational awareness, which help the nurse effectively organise the collected data in a dynamic way, establishing the main needs, care priorities and educational purposes. It also allows them to choose the most appropriate methodology based on the characteristics of the patient, the phase of the disease and the socio-family and cultural situation in which it is arranged. The professional therefore is like a tailor, who “sews” to create the “dress” that fits best for that specific person.

## 2. Aim

On the basis of these premises, the purpose of this study, which analyses a particular case is used to explain the method adopted by a nurse who must use Integrated Narrative Nursing Education (INNE). Starting from a grounded epistemology, guided by the patient’s free narration, we then exemplify the process that gradually integrates this information with what the measurement scales offer in reproducibility and standardisation.

The study focuses in particular on a case of chronic disease, to exemplify the logical and methodological process that underlie such an integrated bio-psychosocial approach, not only aimed at alleviating pain and improving the quality of life of the patient, but also aimed at increasing the engagement level of the patient and the family.

## 3. Method

The Integrated Narrative Nursing Method (INNM) of achieving the central purpose of bringing out the overall characteristics of the patient in front of them needs a rigorous methodology characterised by the recursion of an analysis that alternates between zooming in and focusing on particular details of information collected, and looking at a complete overview of the patient, so as to not lose sight of the individual elements that emerge during the analysis, whilst keeping in mind the overall context.

If, in the context of clinical assistance, the actions of analysis, focusing on specific problems and seeing the overall picture are inseparable and occur almost simultaneously within the mind of the nurse with advanced competence, we explain the logical, methodological path, divided here into four progressive levels, leading to the integrated assessment of the patient. To facilitate understanding of the analysis carried out by the processes adopted, the levels were separated and analysed progressively. Beyond mere expository needs however, it is nevertheless always necessary to remember that, in the welfare practice, these levels are recursively referenced and intersect continuously.



## QUALITATIVE ANALYSIS

### *Level I: Needs assessment*

The first level of evaluation for the patient results from the descriptive and analytical analysis of the qualitative data collected, which in this case is patient-professional narration, which was previously recorded with the consent of the patient and fully transcribed.

The first methodological operation of analysis was the subdivision of the integral narrative into extracts, constructed on the basis of distinct periods of meaning accomplished. Each extract was then progressively assigned a number. Following this first subdivision, the narrative often appears to be disordered and disconnected, consisting more of recursive emotion and autobiographical thought, rather than logical and analytical insight.

It is the critical and reflective thought of the nurse (10) who orders the thoughts in order to bring out the unmet needs that the patient presents, thus responding to a first analytical need. These needs, identified with reference to the list of the 26 needs of the assisted patient identified by Artioli and Coll. (2), are thus listed and supported each by some from the extracts of the narrative.

A conceptual map was then constructed, which connects the emerging primary needs with both secondary and potentially related needs, so as to finally obtain a schematic, whilst at the same time, completing a representation of the patient's current needs and the possible evolution of these needs.

At this first level of analysis, the nurse gets a profile of the unmet needs of the patient, derived from his own words.

### *Level II: Narrative Diagnosis*

In a second, qualitative level of analysis, the professional must arrive at a broader vision of the same narration, which will then be re-interpreted as a unitary unit of data. The professional will recall the impressions gathered during the interview, which can be represented by the patient's non-verbal behavior, tone of voice, posture and silences during the narration. In this type of analysis, it is necessary that the profes-

sional activates their relational competence and their emotional resonances during the course of the narration, asking themselves "*how did I feel?*".

Such data of more interpretative nature, which aims to grasp the essential inner most thought, is aimed at identifying meta-problems of a higher order, derived not only from what is expressed by the patient's words, but also from their general condition, from their non-verbal behavior and the relational aspects of the intersubjective encounter between the patient and the carer.

## QUANTITATIVE ANALYSIS

### *Level III: The use of measurement scales*

The quantitative analysis, which uses tests, assessment scales and questionnaires, is an essential step for pointing out needs and assigning a basic score. However, the choice of which need to study and which tool to use requires the application of specific methodological criteria and good competence in the usage and knowledge of tools available. The first step, at this level, is therefore to identify a database of questionnaires and assessment scales that can be used by the professional to refer to, which is more up-to-date than the tools available in the scientific literature. In the present case, specific reference is made to the standardized and validated scales used on the Italian population presented in the book by Artioli et al. (11).

The choice of the tool used provides a careful reflection on which needs should be brought to attention, and which needs may be secondary in nature, but considered important to the patient and their way of life. This allows for the identification of which needs are saturated by the narration itself, delineated with such centrality that they do not need further quantitative analysis.

Once the primary needs of the assessment have been identified, it is therefore necessary to choose the appropriate tool, so that right construct is evaluated (i.e. the exact nuances of the need under examination) in the right context (i.e. with reference to the specific patient's condition) and that it responds to an efficiency criterion, collecting the most information possible with the least possible number of items.

## INTEGRATED ANALYSIS

### *Level IV: an overview*

After having adopted a synthetic yet analytical point of view of the patient and their problems, we finally combine the information collected in the three levels of analysis in order to obtain an integrated outcome from which the needs, difficulties and the resources can emerge, and therefore, the general characteristics of the patient and their context. To complete the integrated outcome, it is advisable to evaluate the individual and social resources that the person has available, which can be a cushion for current problems and a propulsive drive for the activation of positive behavior aimed at improving one's condition.

Among the constructs that deserve attention, we find for example the prevailing coping strategies and the level of engagement of the patient, which will allow for the activation of an educational plan in which the patient can feel understood and motivated, given that the project is completely tailored based on history, needs and perspectives.

The integrated outcome is therefore central to the caregiver, on which they can prepare an educational path that has a truly personalised value and meaning for the patient.

## 4. Research context

The study was conducted in a Northern Italy Hospice, where the Nurses Coordinator presents incoming patients to nurses and social-health workers on duty. The introduction happens through a summary of the data available from pre-entry documents, and after this, professionals on duty, along with the physician responsible for treatment, receive and assess the patient's problems for the first time. Aiming to this, an interview is held with the patient and their family, in order to provide them with detailed and precise information on the Service, as well as to collect data on the difficulties that patients and family are facing.

In the case described here, the meeting took place in a Hospice in 2016, and was conducted by a nurse. She had to compile the pre-entry documentation,

drawing interesting and sometimes illuminating data from the explanation of the problem, which were then integrated with those collected at the entrance in order to prepare a personalised protocol, that takes into account the "idios" (singularity), as well as the "nomos" (general values) characteristics.

The collected information constitutes a core part in defining the contents of and methods aimed at educational planning. When properly managed, they constitute the first step in building a trusting relationship with the patient, and therefore promoting engagement, which is realised only if the patient feels included in the mind of the professional.

## 5. Results

### *5.1. Case Description*

Daniela is a 70-year-old woman suffering from multi-metastatic pulmonary neoplasia (including lumbar spine), diagnosed 2 months before her entry.

She carried out the first cycle of chemotherapy. The Hospice was then suggested methods of controlling pain and other symptoms offering psychological support to the patient and bringing relief to the family, currently composed of a son and his daughter-in-law that Daniela had to live with because of her health conditions for roughly a months time.

### *5.2 Patient Description*

Daniela arrives accompanied by her son and daughter-in-law in their private car. She gets out of the car, helped by her son. There are evident difficulties in her movements and a pained expression on her face. The son extends her stick to one side and holds her on the other. The nurse shows up quickly and proposes to help them.

Daniela looks like a petite, smiling woman. Though modest in style, she has her hands manicured and her clothes ironed; she looks graceful and refined. She politely follows the formalities of the interview and does not show altered thought processes, both in form and content. She shows initial embarrassment in regards to her muscular hindrance, mainly due to the pain, saying:

*“The only position that gives me a little ‘break’ is with the back partially raised and turned slightly on the right side (she massages her leg). Here it goes! Thank you very much”.*

She is open to the dialogue and collaborates with the requests gradually proposed by the nurse. *“Of course, you can, otherwise how can you help me? Continue asking!”*. Daniela describes her personal life freely, adopting a concise style that doesn't get lost in detail.

### 5.3 Need Assessment: which are the primary unmet needs?

The professional at this level asks: *“Which are the primary unmet needs?”*. With the aim to answer this, the interview begins with a general question: *“Mrs. Daniela, I would like to get to know your situation better and understand what you are experiencing, the changes in your life and the problems you are living with, so that together, we can evaluate what we can do to help you. Do you want to tell me a little bit?”*

The four central needs identified by the nurse are the following: pain, self-esteem, self-efficacy, quality of life, self-care and loss of social role (socio-cultural dimension). These needs appear many times in the patient's free story as not being satisfied, and therefore are unmet.

#### PAIN

##### **Patient Narration Extracts**

*“Unfortunately, I can withstand being seated only for a few minutes, because this pain (indicates the lumbar spine) is unleashed shortly after I sit down, so I'd rather place myself ‘lying down’ a little”.* [extract n. 2]

*“The only position that gives me a little ‘break’ is with the back partially raised and turned slightly on the right side (she massages her leg) ...”.* [extract n. 1]

*“And then I really need it too, because now this pain is preventing me from living: I walk like a snail, I cannot sit for more than a few minutes and always terrified that this unbearable pain will be triggered”.* [extract n. 6]

*“It takes an extremely long time to get up, I cannot even wash properly, not to evacuating”.* [extract n. 7]

*“If it were not for the pain, I could say it would be all bearable after all, ... instead HE makes everything terrible: I no longer have my life! It is always from here that it*

*starts, from this point (she always indicates the same point at the level of the lumbar spine), and then descends along the legs up to the knee like a kind of shock, which also takes away my strength, but it is above all in this leg (indicates, massaging her right leg) that the pain rapidly becomes unbearable, even reaching 10”.* [extract n. 10]

##### **Narrative outcome**

This patient reports a pervasive, unbearable back pain that has taken away her life. It prevents her from sleeping, causing her to *“despair, until I no longer understand anything”*. She also refers to pain with a direct impersonation *“HE makes everything terrible”*.

#### SELF-ESTEEM AND SELF-EFFICACY

##### **Patient Narration Extracts**

*“Caught between tiredness and pain, I can no longer even deal with myself, I have always been strong and independent, and I never wanted to disturb anyone, much less my son and daughter-in-law ... and now they have had to host me at home because I am no longer able to do anything alone. Myself, five years ago, I cared for my husband until the end, all alone, without disturbing my son!”.* [extract n. 3]

*“I do not claim that you can solve all of my problems, I just hope you can give me some help and above all I would like to recover some of my autonomy, to going back to resemble at least a little bit to what I used to be before”.* [extract n. 16]

##### **Narrative outcome**

This patient describes herself in life as a productive person and seems frustrated by the fact that she *“can no longer even deal with myself”*. It is not by chance that what is vitally important for her is *“going back to resemble at least a little bit to what I used to be before, recovering some of my autonomy”*.

#### QUALITY OF LIFE

##### **Patient Narration Extracts**

*“I felt very tired, I was sick and I could not eat, but above all this pain appeared in the back (still points with*

*the hand in the direction of the lumbar spine) that descends along the legs and that has taken away my life". [extract n. 2]*

*"Since there is this pain instead I can no longer sleep, I wake up continuously, I have to take more painkillers per night, I get moments of despair where I do not understand anything anymore". [extract n. 8]*

### **Narrative outcome**

The perceived quality of life seems to be low enough to declare that *"it is preventing me from living ... I no longer have my life"*.

### **SOCIOCULTURAL DIMENSION: PERSON, FAMILY, COMMUNITY**

#### **Patient Narration Extracts**

*"At least I can let my son rest a bit, since I have a bit upset his life for the last two months.*

*So instead of helping them, I loaded them with a very heavy weight, while they would need to sit still and alone: they already had enough of their problems. I know that they love me and that they do it willingly, but I see that they are collapsing...". [extract no. 4]*

*"My son is a good boy, but he has always been rather fragile, with periods of anxiety that led him to try different drugs, sometimes abusing them...". [extract n. 13]*

*"I have always tried to protect him, for example during his father's illness, but perhaps I exaggerate too... he has a wonderful wife, who loves him a lot and has a strong character, but probably starts to get tired of always having to support him, I do not know ... I only know that lately I think they have had a tenuous relationship and me, with my illness, I'm certainly not helping them...". [extract n. 14]*

*"I also get aggressive, especially at night, when the pain rises... I fear that my son has resumed excess usage of drugs and various substances, which he had already used in the past...". [extract n. 15]*

### **Narrative outcome**

From this story emerges a great concern for the son. The patient shows an attachment and a high sense of protection towards him, even admitting that the son

has always been rather fragile, with periods of anxiety that led him to use drugs and other substances *"I have always tried to protect it."*

For Daniela, the figure of the daughter-in-law and the real caregiver of the whole family, seems to be particularly important. *"It seems to me that they have a tenuous relationship and I am not helping them with my illness: he is very worried and anxious, ... besides for both the few hours of sleep caused by my frequent nocturnal awakenings, is making things worse... I fear that my son has resumed excesses with drugs and various substances, which he had already used in the past"*.

#### **5.4 Narrative diagnosis: "Who really is the patient?"**

At this stage, the professional asks: "Who is Daniela beyond the individual unmet needs reported?". This is an analysis carried out on the same narrative content used at level I, but, unlike the previous assessment in which the nurse, for care purposes, looks for what is important for the patient, in this case the textual analysis is striving to find out how these needs are inherent to the specific patient, with their individual and socio-family peculiarities. The narrative diagnoses derived from the text, which arise from the richness of the patient's contribution, are fundamental when establishing a truly personalised educational alliance. In the case of Daniela, they are specifically the following:

A. *"I no longer a support, I must be supported instead"*: The dependence on the caregiver

The story of Daniela shows the problem of addiction (practical and emotional) in her son. *"Can I help you? Yes, thank you, so I let my son rest a bit, since I have a bit upset his life for the last two months."*

But, from the narration, it emerges that the daughter-in-law is the true caregiver of the whole family, since it is up to her to bear the weight not only of her husband's fragility, but also of Daniela: *"He has a wonderful wife, who loves him very well and has a strong character, but probably begins to be tired of always having to support it [...] lately it seems to me that they have more tenuous relationships and I with my illness I am certainly not helping them"*. Daniela explains that her son, though an adult, is still harnessed by addictive dynamics with his mother and his wife, as well as with drugs and substances. *"He is very worried, anxious, he does not know*

*what he has to do, he always leans a lot on his wife*". Feeling a burden in a couple that in itself struggles to manage the daily life, grips Daniela perhaps more than the disease itself: *"for both the few hours of sleep caused by my frequent nocturnal awakenings, is making things worse"*.

B. "I, who have always been strong and independent": The loss of the social role

Daniela spontaneously describes the social role she played in the past and how she now feels that she has lost her son, revealing the sense of guilt for not being able to help: *"I have always been strong and independent, that I never wanted to disturb anyone [...] and now they have had to host me at home because I'm no longer able to do anything by myself! So instead of helping them, I loaded them with a very heavy weight"*

Daniela describes the role of caregiver she also provided, until recently, towards her husband: *"I five years ago I treated my husband until the end, all by myself, without bothering my son"*. It seems, in a nutshell, that Daniela puts the needs and needs of others, rather than their own, in the foreground. This has always been her relational model. Giving, doing, caring for someone gave meaning to her life and her identity as a wife and mother.

C. *"Return to resemble what I was before."* The search for lost autonomy

Since Daniela is a person who is more oriented towards giving rather than receiving, she does not appear sad and in need of care. Despite the marital mourning, concerns for a son who assumes little independence, the relatively recent diagnosis, the severity of the prognosis, the impact of the disease symptoms and the quality of life (nocturnal and diurnal), Daniela hardly complains with a victimised attitude even when considering the situation in which she finds herself: *"Yes, I have a bit of pain, but that's okay; if I walk slowly and with a little help, I can do it! It's better than sitting up!"*. Conversely, she presents herself to the world as if she wanted to mask her pain, whether it is physical, emotional or relational. *"Now? ... not really pain ... it's a bit painful really ... but bearable"*. Her minimising modality is also evident from the fact that Daniela smiles, praising the beauty of the place and expressing satisfaction about the positive impact of the structure. Whilst this shows skills in personal reflection, it also highlights high discrepancies between reported content (dys-

phoric, anxious) and corresponding emotional-affective expression (light, playful, cheerful). Her positivity will show itself to be combative and resilient, and could be interpreted as unexpressed hope for a possible improvement in her condition, or in the expectation that hospitalisation can improve her autonomy.

When the nurse summarises: *"So, I understand that the main problems that is going on right now are the pain [...], the insomnia and the enormous fatigue that deprives it of all energy and [...] some concern for her condition and that of her son and daughter-in-law. Is that it?"*

Daniela answers: *"Well, I would say, is that not enough? (Smiles) Joking aside, yes, basically these are, but I do not pretend that you can solve them all, I just hope you can give me some help and above all, I would like to recover a bit of my autonomy, to return to look at least a little like what I was before"*.

5.5 *Quantitative analysis: how unmet are the patient's needs? What are their resources?*

As mentioned before, this phase is aimed at measuring the patient's needs by using quantitative tools, in order to corroborate the results of the analysis made during the qualitative phase, which gives information on whether the needs are actually altered and to what extent. In particular, the assessment scales quantitatively detect a phenomenon (in this case a particular need expressed by the patient) and allow the measurement of any changes over time. These tools provide a common and standardised language as well as concepts operationalised as variables. There are several tools used in this phase, which differ according to the need they apply to, and they focus on either specific multi-dimensional or one-dimensional evaluations (10). When selecting the questionnaire that will be utilised for this purpose, professionals should bear in mind that lengthy questionnaires can induce fatigue among respondents and result in uniform and inaccurate answers (12-14).

In this case, the needs and narrative diagnoses that the professional decided to evaluate were: quality of life, loss of her role functioning (socio-cultural dimension), mood, self-efficacy, and coping strategies.

Pain was not assessed, seeing that the patient demonstrated to be perfectly capable to discriminate

her pain level using self-evaluation (as with the Numerical Rating Scale).

With regard to quality of life (QoL), the questionnaire selected was the EORTC Quality of Life Questionnaire-Core 36 (15; 16). The EORTC QLQ-C30 is a questionnaire developed to assess the quality of life of cancer patients. It incorporates five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), a global health status / QoL scale, and a number of single items assessing additional symptoms commonly reported by cancer patients (dyspnoea, loss of appetite, insomnia, constipation and diarrhoea) and perceived financial impact of the disease.

The patient reported the following results:

Functional scales where 0% means high impact and 100% means no impact:

Global health status (QL2) 16.7%

Physical functioning (PF2) 0%

Role functioning (RF) 0%

Emotional functioning (EF) 33%

Cognitive functioning (CF) 50%

Social functioning (SF) 0%

Symptom scales where 0% means no impact and 100% means high impact:

Fatigue (F) 88%

Nausea and vomiting (NV) 33%

Pain (P) 100%

Dyspnoea (D) 33%

Insomnia (I) 100%

Appetite loss (AL) 33%

Constipation (C) 66%

Diarrhoea (D) 0%

Financial difficulties (FD) 33%

A significant impairment in quality of life in general (16.7%) was confirmed. In particular, there was serious impairment to physical, role, and social functioning conditions (all 0%). Her emotional functioning impaired too (33%). However, in this questionnaire, emotional functioning is investigated through 3 items only. For this reason, and because of what had emerged from the narrative diagnosis (*"I would like to look like my old me"*), we decided to further investigate her mood tone as the second level of qualitative analysis had revealed a discrepancy between the content of what she had been saying and how she had

been expressing it; while the content seemed to reveal dysphoria, her way of speaking seemed to conceal the impact of it.

To investigate the mood, we used the HADS – Hospital Anxiety and Depression Scale (17), which is a 14-item self-report screening scale that was originally developed to indicate the possible presence of anxiety and depressive states. It contains two 7-item scales: one for Anxiety (A) and one for Depression (De) both with a score range of 0–21. Items referring to symptoms that may have a physical cause (e.g. insomnia and weight loss) are not included in the scale. The patient obtained a score of 10 on the anxiety scale, meaning that she is a borderline case for anxiety; she obtained a score of 15 on the depression scale, meaning that she is a case for depression.

In order to measure the patient's personal resources, for adapting to stress caused by the disease, the professional decided to identify her coping strategies and her perceived self-efficacy – the belief *"I am capable of"*.

The COPE-NVI-25 scale (18), which measures five coping strategies, showed that Daniela has a fighting-spirit problem-focused coping style ( $M = 4$ ). Strategies related to a positive attitude ( $M = 2.67$ ) and search for a social support ( $M = 2.6$ ) were found to have a minor impact on the patient. These strategies were followed by transcendent orientation ( $M = 1.75$ ). The least utilised by the patient was shown to be avoidance and denial of the problem ( $M = 1.4$ ).

Self-efficacy was measured using the General Self-efficacy Scale from the Italian adaptation by Sibilis, Schwarzer and Jerusalem (19). It is a 10-item psychometric scale (responses are made on a 4-point scale) that is designed to assess optimistic self-beliefs to cope with a variety of difficult demands in life. Daniela obtained an above average score ( $M = 3.5$ ), which coincides with a high-perceived self-efficacy.

The PAM-13-Patient Activation Measure by Graffigna et al. (20) was utilised for measuring engagement level. The PAM scale defines four increasing levels of activation: 1. disengaged and overwhelmed; 2. becoming aware but still struggling; 3. taking action; 4. maintaining behaviour and pushing further. Daniela obtained a score of 35, which places her on level 3. Individuals at level 3 of activation have the key facts

and are building self-management skills. They strive for the best practice behaviour and are goal-oriented. Their perspective is “*I’m part of my health care team*”.

### 5.6. Integrated outcomes

From the integrated set of collected data, we can assume with some certainty that Daniela’s quality of life is compromised. The collapse suffered in the two-month period between diagnosis and the evaluation was drastic (QL2 16.7%). Although levels of physical impairment are evident “*I felt very tired (F = 88%), I had nausea (NV=33%) and I could not eat, [...] this back pain appeared (P = 100%) (PF 0%)*”, psychological suffering is also evident, linked to Daniela’s concern for “*my son, since I upset his life a bit for the last two months. [...] I know that they love me and that they do it willingly, but I see that they are collapsing [...] I have always tried to protect him*”. The loss of her active and effective role within the family system in terms of being family’s caregiver was drastic (RF 0% and SF 0%) and pushes her to manifest the desire “*going back to resemble at least a little bit to what I used to be before*”.

The identification of the discrepancy between dysphoric and anxious content “*HE makes everything terrible: I no longer have my life*” and emotional-affective expressions often light and playful “*well, I would say, is that not enough? (She smiles)*”, along with reported emotional functioning scores (EF 33%), led the nurse to investigate Daniela’s mood. This led to a stronger focus on the meta-problem of autonomy loss, highlighting the presence the presence of a state of anxiety, even if borderline (A = 10), and an important depressive state, even if not directly manifested by Daniela (De = 15). The narrative diagnosis has also provided the right starting point to clarify Daniela’s resources. Daniela, being a “*strong and independent*” woman, still has a combative coping (coping oriented to the problem M = 4), a high level of self-efficacy (M = 3.5) and an individual level of activation that places her in the condition of being able to build a good engagement with the care staff and her care process, adequately defining her educational objectives and implementing the appropriate behaviours to achieve them (PAM = 35). The graphic depiction of Daniela’s strengths and weaknesses is the conceptual map showed in Figure 1.

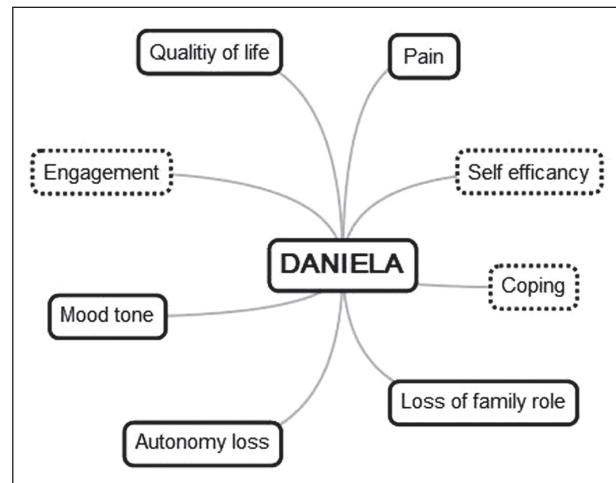


Figure 1.

## 6. Towards the co-construction of the educational intervention

Following integration of these elements, what should the trustee do at this point? In the case of Daniela and her family, reliance on the advanced experience of Hospice professionals could be a true relief for several reasons: 1. It would allow for the alleviation of different symptoms (e.g. pain) and related needs (e.g. poor movement, insomnia, lack of appetite, quality of life);

2. Hospitalisation would make it possible to recover self-governance, which had been lost due to disruption caused by the illness and by loss of role, and which must be regained in a healthy manner in order to help maintain the greatest possible sense of agency in leading one’s own existence;

3. Daniela tendentially has shown to possess active coping mechanisms and a high self-efficacy – both resources that must be preserved so that they do not fade under the heavy burden of the disease. These resources must however be redirected towards herself this time, rather than towards others. The educational intervention takes into account both the objective needs arising from the disease and the subjective ones more linked to identity changes;

4. For her family, the hospitalisation will seem to be a precious resource. In this sense, the trustee could address the intervention to the daughter-in-law and

the son, whom Daniela does not want to be looked after by as an invalid. The trustee must therefore collaborate with the family so that Daniela can realise that desire not expressed, but well explained, to recover, in Hospice, a sense of autonomy and personal dignity. This could also be of great help to the family, alleviating the worries and anxieties of the child, and raising the emotional and practical weight of which Daniela's daughter-in-law has been bearing.

The set of processes from the integrated outcome, clearly shows how the investigation of not only unmet needs and difficulties, but also personal and family resources can represent a fertile ground for designing a truly engaged partnership between the care giver, the patient and the social-relational context.

Based on these considerations, where should the educational effort of the nurse be placed according to the INNE model? In the case of Daniela, the effort should be directed towards making the patient recover the right to control her life, to instill confidence in being able to do various things, and above all, to allow herself, and perhaps a few others in her life, to place herself at the center of her own life. The precise purpose of the educational intervention at its core is to allow Daniela to recover the importance of her life, despite this being undermined by the painful experience of the recent diagnosis and the side effects of the treatment.

When addressing the question "Who is this person?", fundamental to the orientation of the education process, the nurse knows that she will not have to help Daniela from the outside with an intervention that adopts the image of a shoulder to cry on, even if given in good faith. This type of intervention would have little success in this case, as Daniela is not used to receiving but is rather more oriented to give. Knowing this, the nurse will have to place herself at the relational level as a guide, who, in an equal context, gives Daniela the chance to: free herself from "*HE*" (the pain), helping her to recover her desired autonomy; have confidence in that there is still space for personal direction and a sense of dignity in her life and that which remains to her; and to direct her natural energy and combativeness towards herself, more than towards others.

The inter-subjective meeting between professional and patient also means that Daniela does not feel alone in this change – especially considering that it is

not known *a priori* the degree to which Daniela will be able to face this change.

In any case, if the nurse has worked carefully, Daniela knows she can always count on a nurse who has grasped the true meaning of her illness, which often goes beyond the needs and the symptoms reported. This is a nurse who showed interest and expertise, understanding both who the patient really is, and the family system in which Daniela lives.

## 7. Conclusions

Starting from an educational perspective, and considering the significance that this perspective has in the current debate, the aim of this paper was to demonstrate that the efficacy of an intervention lies in the understanding that the professional should have towards the patient. The professional should predispose a path of assistance and education that may improve a specific symptom verbally communicated or physically expressed by the patient, but also one that takes into account the intra-psychological and inter-personal dynamic, which is unique to every patient. In this dynamic, the symptom, the need, the problem, and the help from the caregiver, acquire a precise importance.

This approach foresaw the use of several tools. Firstly, a good knowledge of the patient's needs is necessary (2). This information may be acquired through active listening to the patient. At this level of analysis, the words utilised by the patient fill a semi-structured grid that holds certain information. This grid should be in the mind of the professional when they are transcribing or recording what the patient is saying. The patient's needs do not show up in the narration in a logic or linear way. It is more likely that the patient will express their needs in an irregular, circular, overlapping way, made by references, intersections and interruptions. The patient provides the "raw material"; the professional gives this material a structure. The professional that uses the INNA (9) has the 26 needs described by Artioli et al. (2) in mind. They must ask themselves: "*which of these needs are unmet in the patient*". The answer to this question is the first step in the construction of a personalised path of assistance, based on satisfying unmet needs.



The second level of analysis is the narrative diagnosis, where the narration is now free from the grid. At this level, the professional must ask himself: “*who is the person in front of me?*”. The answer to this question is very important to the process of designing both the intervention and the education of the patient. This answer guides the relational modality that comes into contact with the patient.

At the third level of analysis, the professional must ask himself: “*how severe is the alteration of the needs compared with the reference parameters?*”. At this level, the professional uses standardised instruments to confirm or contradict the centrality of the needs that emerge from the patient’s narratives. Furthermore, this analysis provides both an intra-subjective (same person over time) and inter-subjective (different people, same time) comparison. At this level of analysis, the professional must be cautious when deciding the right moment and the right way to administrate the questionnaires, and at the same time, they should select the best instrument in terms of length and comprehensibility.

At the fourth and final level, the integrated outcome guides the professional in the identification of the overall basis on which the intervention should be designed, on a path that starts with an assessment phase and leads to the education of the patient. During this path, the re-administration of the questionnaires over time in addition to follow up narrative interviews, should be foreseen.

This will allow the professional to monitor in a dynamic, recursive, and circular way, not just the satisfaction of the needs told by the patient, but also their general adaptation to their life.

We wish that the here-described INNA model could provide a valid methodological support to those professionals that have a more current and correct epistemological vision of patient education. Indeed, education cannot be considered mere information based on knowledge that goes from the care provider to the patient in one direction, often in a standardised way. Education should be a truly engaged inter-subjective path that involves the care provider, the patient and his/her socio-familiar-relational context, resulting from to understanding, active listening and empathy. It should be considered both a process and a method that

requires solid scientific foundations and inter-professional training, and should be constantly updated.

Therefore, professionals who deal with education should not be the expert teacher of health, which informs and instil knowledge from the outside, but rather a “tailor”, who is able to “deliver” a tailored suit, which fits the assisted patient to perfection, as well fitting the familial-relational environment that the patient is in.

It is a professional who, even once the dress has been delivered, is always willing, with professionalism, competence, self-confidence and with a humble heart, to redo the edge, to readjust the shape, if it becomes too much tight or too loose, to patch a possible tear in the best way, pandering the adjustment in the life of each of its “customers”, in a completely idiosyncratic way.

What we have described so far represents a path that, according to the authors, becomes essential in order for an educational intervention to be effective.

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# Evaluation of fatigue in patients with pancreatic cancer receiving chemotherapy treatment: a cross-sectional observational study

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**Abstract.** *Background and aim of the work:* Cancer-related fatigue (CRF) is one of the most common symptoms experienced by cancer patients (CPs) and negatively affects quality of life. Although CRF is frequently experienced, it is often underreported, underdiagnosed and undertreated. The objectives of this study were to evaluate the level of fatigue in patients with pancreatic cancer undergoing chemotherapy and to analyse its correlation with patients' demographic and clinical variables. *Methods:* A cross-sectional observational study was implemented in the Oncology Day Hospital of a Northern Italian hospital. A sample of 48 patients receiving chemotherapy were evaluated through the Brief Fatigue Inventory Italian version (BFI-I) between 1 May and 12 October 2016. Data were statistically analysed. *Results:* Most of our patients (94%) experienced fatigue. Women as well as patients with an age  $\geq 65$  years reported more fatigue. Anemia, pain and a weight loss of over 16 kg in the last 6 months were significantly related to the perception of fatigue. Regarding life habits, smoking was related to high global score of BFI-I. *Conclusions:* In accordance with literature, our study suggests that fatigue is a frequent symptom influenced by many constitutional, clinical and environmental factors. Our results highlight the need for an early and regular evaluation of fatigue among cancer patients, in order to implement all those pharmacological and non-pharmacological interventions with proven efficacy in attenuating this symptom.

**Key words:** pancreatic neoplasm, pancreatic cancer, fatigue, chemotherapy, Brief Fatigue Inventory

## Background and aim

Pancreatic cancer is the seventh leading cause of cancer death (1) and, in 2017, pancreatic cancer deaths exceeded breast cancer deaths (2). In the United States, approximately 50,000 individuals are diagnosed with exocrine pancreatic cancer each year with fatal outcome for most of them (3). AIOM (Italian Association

of Medical Oncology) show that 12,500 new cases of pancreatic cancer occurred in 2015, which represented about 3% of all incident cancers (4). In Italy, pancreatic carcinoma is one of the top five causes of cancer death in males and the fourth place in females, with greater incidence in the North of Italy (5). Pancreatic ductal adenocarcinoma has the lowest five-year survival rate as compared to others cancers (6).

In literature there is no univocal definition of Cancer-Related Fatigue (CRF), however the most recurrent is that proposed by the National Comprehensive Cancer Network (NCCN) (7), which defines it as a persistent distress, a subjective feeling of physical exhaustion, related to cancer or to its treatments. The fatigue experienced by cancer patients is totally disproportionate in comparison with the physical activity undertaken, highly impacts on the performance of daily normal activities, significantly worsening the quality of life (7, 8). Fatigue can exacerbate other symptoms and negatively influence mood (9). It is different from normal fatigue since it does not find relief with rest and may persist for months or even years after the completion of chemotherapy treatment (10). CRF has been reported as the most common and, for many people, the most stressful symptom related to cancer disease by the NCCN (7). In accordance with most authors, fatigue is one of the most common symptoms related to cancer, affecting patients in many domains such as physical, emotional, cognitive and behavioral spheres. It includes subjective feeling and objective symptoms that may persist from the diagnosis of cancer to the end of life (11-13). CRF has been hypothesized as the result of a complex interaction among multiple factors related to both the disease and the side effects of the treatments. Nevertheless, it could also be influenced by other clinical or environmental factors such as malnutrition, sleep disorders, pain, anxiety and depression (14). CRF may be present for a short period or persist for years after the end of treatment and therefore it can be classified as acute or chronic. In acute fatigue, the recovery mechanisms maintain all their effectiveness, allowing the body to regain its strength and to reintegrate the consumed energy through an adequate period of rest; in chronic fatigue, the person cannot recover an adequate energy level even after prolonged rest period and/or suitable supportive therapies (13-16). The prevalence of fatigue in cancer patients during chemotherapy treatment ranges from 25% to 100% (11, 17). The different ranges reported in literature can be related to the study samples, the treatments received and the symptom evaluation methods. It can also be influenced by other concomitant pathological conditions, such as anemia and depression, conditions often present in patients with various types of cancer (18).

Patients describe fatigue as a sense of chronic tiredness, overwhelming depression, oppressive exhaustion and loss of life energy. The terms most commonly used to describe this condition are: listlessness, weakness, sluggishness, apathy, laziness, abatement, exhaustion, etc. (15). Patients are unable to concentrate and often present other associated depressive symptoms (19).

In particular, the symptoms of fatigue most commonly reported by patients are related to many domains:

- physical level: impossible to lead a normal life and to carry out usual activities; feeling of tiredness corresponds to an increased need for sleep and rest;
- psychological level: reduction of motivation and interest, feelings of sadness, frustration, irritability, loss of the ability to appreciate life and intimacy with partner, difficulty in concentrating;
- social level: loss of interest in relationships with friends and colleagues;
- professional level: difficulty in keeping a job, need to change work, request to reduce work time (20).

Commonly, fatigue is undertreated although it can represent the most debilitating symptoms with negative impact on patient and family quality of life (15). Recent research on the biological mechanisms that underlie CRF has focused on inflammation as a key pathway (21). The associations between CRF and alterations in the immune and neuroendocrine system has been documented. The same association has been observed in the Interferon-alpha therapy which predisposes to the development of fatigue (22). In particular, changes in leukocyte subsets, dysregulated cortisol rhythm, reduced glucocorticoid receptor sensitivity, and alterations in the autonomic nervous system have been correlated with the development of CRF. These systems are closely linked to inflammation and may influence fatigue by initiating or maintaining elevated inflammatory activity (21).

The management of CRF is difficult due to its uncertain and complex etiology as well as its subjective characteristics (23). The guidelines developed by the NCCN recommend early treatment of all conditions that may contribute to the onset of fatigue, which include pain, emotional disturbances, sleep disorders,

anemia, malnutrition, poor physical activity and comorbidities for all patients in active treatment, even in the long term, and at the end of life. Recommended treatments include educational and psychological interventions as well as strategies for fatigue and energy management, distraction techniques, pharmacological and non-pharmacological interventions (7).

Over the last years, the efficacy of different pharmacological approaches has been tested: antidepressants, corticosteroids, drugs for anemia and psychostimulants (24, 25). Among these drugs, only psychostimulants have been shown to improve CRF (25). Non-pharmacological interventions have the advantage of coping with multiple symptoms without inducing any side effect, which makes them particularly acceptable for cancer patients. In the last decade, research on the efficacy of non-pharmacological treatments has been increasingly implemented, with particularly promising results as evidenced by randomized controlled trials (RCT) related to the effectiveness of physical exercise (26), psycho-educational approaches (27) and energy conservation (28). A review of 57 RCTs that tested the efficacy of non-pharmacological interventions concluded that exercise and psycho-social interventions led to a similar reduction in CRF (29).

Although CRF is frequently experienced by cancer patients it is often under-recognized by health-care professionals and consequently under-treated (9).

### *Aim*

The objective of this study is to evaluate the level of fatigue in patients with pancreatic cancer treated in an oncology day hospital and to analyze its correlation with patients' demographic variables, clinical conditions, life habits and chemotherapies.

## **Methods**

### *Study design*

To analyze the level of fatigue in patients with pancreatic cancer treated with chemotherapy, a cross-sectional observational study was conducted through

the administration of a questionnaire, during the period between May 1 and October 12, 2016.

### *Participants*

In this study, we included all patients aged 18 years or over, suffered from a pancreatic cancer and treated in the Oncologic Day Hospital of a Northern Italian medical center, during the observation period of this study, with the following chemotherapy treatments: gemcitabine, gem+abraxane or folfirinox. All patients enrolled (n=48) were able to understand the questionnaire, to complete it independently and to give us their informed written consent for participation in the study, following our explanation of its purpose and design.

We excluded patients who were minors, affected by other types of cancer, treated with other chemotherapies and/or not able to give us their informed written consent due to intellectual disability, cognitive deterioration or no knowledge of Italian language.

Data were anonymously collected according to the current privacy regulations.

### *Instruments*

To evaluate the fatigue level, we administered the Brief Fatigue Inventory (BFI), a simple scale validated in several languages (30-35), including Italian (BFI-I) (36). The validation studies of this instrument showed good acceptance by the subjects and good internal consistency (30), also in the validation studies of the Italian version (Cronbach's  $\alpha=0.94$ ) (36).

The BFI is composed of 9 items aimed at assessing the severity and impact of fatigue on daily functioning in patients with cancer or treatment-related fatigue in the previous 24 hours. Three items ask patients to rate the severity of their fatigue at the moment of questionnaire administration at its "usual" and at its "worst" level during the previous 24 hrs using a 0-10 Likert scale, where 0 corresponds to the description "no fatigue" and 10 with "fatigue as bad as you can imagine".

Six items focused on how much fatigue had interfered with aspects of the patient's life during the previous 24 hours. Interference items include general activity, mood, walking ability, normal work (which in-

cludes both work outside the home and daily chores), relations with other people, and enjoyment of life. These items are measured on a 0-10 Likert scale where 0 means “does not interferes” and 10 “completely interferes”. A global BFI score is calculated as the mean of all nine questions, and higher scores correspond to more severe fatigue. Patients who could answer at least five of the questions were included. The level of fatigue can be divided into “mild” (1-3), “moderate” (4-6) and “severe” (7-10) in accordance with literature (30, 37-39).

### Statistical analyses

Descriptive statistical analyses were performed: means and standard deviations for continuous data, and percentages for categorical data, while t-test and ANOVA were applied to identify significant differences among continuous data. Categorical variables were calculated through the contingency tables and the differences were detected through the Chi-square. We analyzed both the total mean score of BIF-I as a continuous variable and the four levels of questionnaire score as categorical variables in order to apply a sort of sensitivity analysis, in accordance with other studies (34, 36, 38). Cronbach's Alfa allowed us to determine the internal consistency of the questionnaire items. The statistical analysis was performed using the SPSS software.

## Results

Our sample consisted of 48 patients: 29 males (60.4%) and 19 females (39.6%). 62.6% of them were  $\geq 65$  years old. The most frequent comorbidity was represented by cardiovascular diseases (45.8%); smoking was the most frequent life habit (22.9%). Most of the interviewed patients were treated with gem-abraxane (85.4%) (Table 1).

The internal consistency of the scale was very good: Cronbach  $\alpha=0.905$ .

We divided the fatigue into four level groups according to the BFI-I score: absent (score=0), mild (score range=1-3), moderate (score range=4-6) and severe (score range=7-10). 94% of patients experienced

**Table 1.** Constitutional and clinical variables of our sample

Variables	N	%
<b>Gender</b>		
Females	19	39.6
Males	29	60.4
<b>Age (years)</b>		
18-50	9	18.7
51-64	9	18.7
$\geq 65$	30	62.6
<b>Comorbidities</b>		
Cardiovascular	22	45.8
Endocrine	6	12.5
Neurological	1	2.1
Musculoskeletal	2	4.2
Urogynecological	3	6.3
Infectious	3	6.3
Unknown	7	14.5
No comorbidity	4	8.3
<b>Life habits and correlated disorders</b>		
Smoking	11	22.9
Substance abuse	1	2.1
Eating disorders	5	10.4
Normal	30	62.5
Unknown	1	2.1
<b>Chemotherapies</b>		
Gem-Abraxane	41	85.4
Gemcitabina	6	12.5
Folfirinox	1	2.1

fatigue according to BFI-I score, mostly mild (n=26) and moderate (n=18).

As shown in Table 2, many constitutional and clinical variables are statistically significantly correlated with the four level groups of fatigue: females ( $\chi^2=8.723$ ,  $p=.033$ ), patients with age  $\geq 65$  years ( $\chi^2=14.521$ ,  $p=.024$ ), patients affected by cardiovascular comorbid diseases ( $\chi^2=62.262$ ,  $p<.001$ ), patients with smoking habit ( $\chi^2=31.077$ ,  $p=.002$ ) presented statistically significant higher levels of fatigue. Both mild and severe anemia were frequently associated with fatigue whereas only a weight decreased from 6 to 15 kg in the last 3 months was associated with severe fatigue. The other variables selected, chemotherapy drugs, depression and pain, did not present any statistically significant correlation with fatigue (Table 2).

**Table 2.** The constitutional and clinical variables correlated with the BFI-I score groups

Variables	Absence fatigue n=3	Mild fatigue n=26	Moderate fatigue n=18	Severe fatigue n=1	Total n=48	Statistical test Probability
<b>Gender, n (%)</b>						
Females	--	7 (26.9)	11 (61.1)	1 (100)	19 (39.6)	$\chi^2=8.723$ p=0.033
Males	3 (100)	19 (73.1)	7 (38.9)	--	29 (60.4)	
<b>Age (years), n (%)</b>						
18-50	3 (100)	4 (15.4)	2 (11.1)	--	9 (18.8)	$\chi^2=14.521$ p=0.024
51-64	--	5 (19.2)	4 (22.2)	--	9 (18.8)	
≥65	--	17 (65.4)	12 (66.7)	1 (100)	30 (62.5)	
<b>Comorbidities, n (%)</b>						
Cardiovascular	--	15 (57.7)	6 (33.3)	1 (100)	22 (45.8)	$\chi^2=62.262$ p<0.001
Endocrine	--	4 (15.4)	2 (11.1)	--	6 (12.5)	
Neurological	--	1 (3.8)	--	--	1 (2.1)	
Musculoskeletal	--	--	2 (11.1)	--	2 (4.2)	
Urogynecological	3 (100)	--	--	--	3 (6.3)	
Infectious	--	1 (3.8)	2 (11.1)	--	3 (6.3)	
Unknown	--	--	4 (22.2)	--	4 (8.3)	
No comorbidity	--	5 (19.2)	2 (11.1)	--	7 (14.6)	
<b>Life habits and correlated disorders, n (%)</b>						
Smoking	--	6 (23.1)	5 (27.8)	--	11 (22.9)	$\chi^2=31.077$ p=0.002
Substanceabuse	--	1 (3.8)	--	--	1 (2.1)	
Eatingdisorders	3 (100)	2 (7.7)	--	--	5 (10.4)	
Normal	--	17 (65.4)	12 (66.7)	1 (100)	30 (62.5)	
Unknown	--	--	1 (5.6)	--	1 (2.1)	
<b>Chemotherapies, n (%)</b>						
Gem-Abraxane	3 (100)	20 (76.9)	17 (94.4)	1 (100)	41 (85.4)	$\chi^2=3.474$ p=0.747
Gemcitabina	--	5 (19.2)	1 (5.6)	--	6 (12.5)	
Folfirinox	--	1 (3.8)	--	--	1 (2.1)	
<b>Pain, n (%)</b>						
Absent	3 (100)	18 (69.2)	6 (33.3)	1 (100)	28 (58.3)	$\chi^2=8.856$ p=0.182
Mild	--	7 (26.9)	11 (61.1)	--	18 (37.5)	
Severe	--	1 (3.8)	1 (5.6)	--	2 (4.2)	
<b>Weight, n (%)</b>						
Unchanged	3 (100)	16 (61.5)	3 (16.7)	--	22 (45.8)	$\chi^2=30.374$ p=0.011
Increased	--	3 (11.5)	4 (22.2)	--	7 (14.6)	
Decreased from 1 to 15 kg in the previous month	--	1 (3.8)	3 (16.7)	--	4 (8.3)	
Decreased from 6 to 15 kg in the previous 3 months	--	6 (23.1)	5 (27.8)	--	11 (22.9)	
Decreased by over 16 kg in the previous 6 months	--	--	2 (11.1)	1 (100)	3 (6.3)	
Unknown	--	--	1 (5.6)	--	1 (2.1)	
<b>Anemia, n (%)</b>						
Haemoglobin ≥ 11g/dl	3 (100)	16 (61.5)	5 (27.8)	--	24 (50)	$\chi^2=8.940$ p=0.030
Haemoglobin 8-10g/dl	--	10 (38.5)	13 (72.2)	1 (100)	24 (50)	
<b>Depressive disorders, n (%)</b>						
Yes	--	4 (15.4)	2 (11.1)	--	6 (12.5)	$\chi^2=2.478$ p=0.871
No	3 (100)	22 (84.6)	15 (83.3)	1 (100)	41 (85.4)	
Unknown	--	--	1 (5.6)	--	1 (2.1)	

The global score of BFI-I showed higher values among the patients aged from 51 to 64 ( $M=3.02$ ,  $SD=1.66$ ) and  $\geq 65$  ( $M=2.91$ ,  $SD=1.92$ ), with a statistically significant difference between the two genders: males had a mean score of 2.18,  $SD = 1.66$  and females one of 3.71,  $SD=1.78$  ( $t=3.043$ ,  $p=.004$ ).

As shown in Table 3, the mean scores of BFI-I statistically significantly differed among respondents regarding the following variables: comorbidities ( $F=2.782$ ,  $p=.019$ ), life habits ( $F=2.98$ ,  $p=.029$ ), pain ( $F=4.710$ ,  $p=.014$ ), weight ( $F=4.419$ ,  $p=.003$ ) and anemia ( $F=12.835$ ,  $p=.001$ ). In particular, the BFI-I scores showed high level of fatigue among patients affected by musculoskeletal comorbidities (4.2%), smoking

population (22.9%), patients with mild pain (37.5%), patients who decreased weight by over 16 kg in the last 6 months (6.3%), patients with Hb values ranged between 8-10 g/dL (50% of our sample) (Table 3).

The impact of fatigue on all daily activities was prevalently absent or mild, with severe influence only on two dimensions, mood and enjoyment of life, as shown in Figure 1.

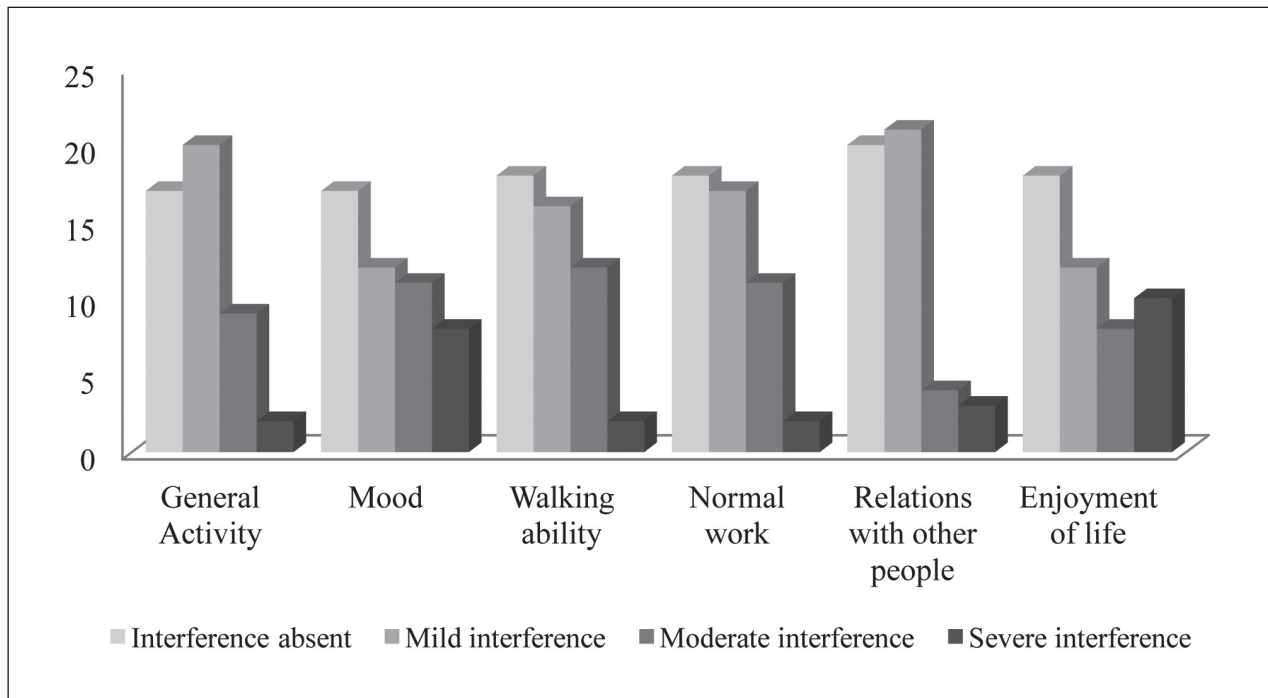
## Discussion

The findings of our study revealed that 94% of our participants experienced CRF during the course of

**Table 3.** The constitutional and clinical variables correlated with mean global score of BFI-I

Variables	BFI-I Mean ( $\pm$ SD)	Confidence interval 95%	Statistical test Probability
<b>Comorbidities</b>			
Cardiovascular	2.66 (1.95)	1.80-3.53	
Endocrine	2.57 (1.22)	1.28-3.85	
Neurological	0.55 (0.0)	-	F=2.782
Musculoskeletal	5.16 (1.17)	-5.42-15.75	p=0.019
Urogynecological	0.07 (0.12)	-0.24-0.39	
Infectious	3.81 (1.32)	0.52-7.10	
Unknown	2.77 (1.43)	1.44-4.10	
No comorbidity	4.44 (1.18)	2.55-6.33	
<b>Life habits and correlated disorders</b>			
Smoking	3.29 (1.33)	2.39-4.18	
Substance abuse	3.00 (0.0)	-	F=2.986
Eating disorders	0.68 (0.95)	-0.49-1.86	p=0.029
Normal	2.84 (1.90)	2.12-3.55	
Unknown	6.00 (0.0)	-	
<b>Pain</b>			
Absent	2.15 (1.83)	1.44-2.87	F=4.710
Mild	3.75 (1.51)	3.00-4.51	p=0.014
Severe	2.88 (2.04)	-15.46-21.24	
<b>Weight</b>			
Unchanged	1.89 (1.44)	1.26-2.53	
Increased	3.04 (2.10)	1.10-4.99	F=4.419
Decreased from 1 to 15 kg in the previous month	3.63 (1.88)	0.64-6.63	p=0.003
Decreased from 6 to 15 kg in the previous 3 months	3.03 (1.45)	2.05-4.00	
Decreased by over 16 kg in the previous 6 months	5.62 (1.50)	1.88-9.37	
Unknown	6.00 (0.0)	-	
<b>Anemia</b>			
Haemoglobin $\geq 11$ g/dl	1.93 (1.58)	1.26-2.59	F=12.835
Haemoglobin 8-10 g/dl	3.64 (1.73)	2.91-4.38	p=0.001





**Figure 1.** The impact of fatigue on daily activities, mood and relationships

treatment. This result is in line with the highest prevalence rates of fatigue reported by other studies, which ranged CRF between 25 to 100% during the course of chemotherapies (11, 17, 39-42). The prevalent constitutional factors associated with fatigue were represented by female gender and older age, in accordance with recent research (17, 42-46). Among clinical variables, anemia, loss of weight and pain were associated with the highest scores of BFI-I in our study. This result overlaps literature and clinical experience concerning the close relationship between fatigue and physical impairment induced by both cancer and chemotherapies. In particular, low hemoglobin levels are associated with greater fatigue in cancer patients (9, 18, 39, 40, 42, 47, 48) as well as pain symptoms in accordance with most reports (14, 17, 40, 49). Weight loss is a significant symptom in this type of cancer, often associated with neoplastic cachexia. Our analysis shows that a weight loss >16 kg in the previous six months is related to higher mean score of fatigue. As highlighted by other authors, an important weight loss can be considered a factor that affects the perception of fatigue

in many patients (50). From our analysis, we can infer that fatigue can be a consequence of both chemotherapies and cancer but not of other comorbidities, since we found higher levels of fatigue in patients who did not have any concomitant disease in comparison with others who did. We have to put in evidence that, among the comorbidities reported by our patients, the ones most correlated with fatigue were cardiovascular and musculoskeletal diseases, a result that is in line with another study (40). Smoking has also proved to be a factor that affects the perception of fatigue: smoking patients reported higher mean score of fatigue than non-smokers in our study as in others (17, 51). Although the treatment with Gemcitabine+Abiraterone, to date the elective treatment for metastatic pancreatic cancer, has been strongly associated with fatigue as a prevalent side effect (52), we did not find any significant correlation between this treatment and fatigue.

The BFI-I has shown to be a questionnaire easy to administer and simply to answer. The internal consistency of the scale was very good, similar to the value obtained in the BFI Italian validation study (36).

## Conclusions

We observe that the majority of our participants experienced mild and moderate fatigue. Several factors influenced the perception of fatigue: gender, pain, important weight loss, anemia and smoking. These data highlight how fatigue is frequently present as a consequence of cancer and its treatments, placing importance on CRF diagnosis and recognition to implement early on all those pharmacological and non-pharmacological interventions with proven efficacy in reducing it.

This study has many limitations, in particular its limited sample size, insufficient to draw definitive conclusions. Another limitation is represented by the period of BFI-I administration from May to October, concomitant with the warmest part of the year, which can exacerbate the perception of fatigue. In addition, other relevant risk factors for fatigue as reported in literature (41), physical activity, sleep disorders and clinical stage of cancer, were not investigated.

We can conclude by suggesting that fatigue is a multidimensional symptom which can be influenced by a variety of constitutional and clinical factors. It represents one of the most prevalent and debilitating conditions observed in cancer, for which we can suggest a holistic therapeutic approach, based on the active involvement of the person in care and treatment for fostering clinical recovery with respect for patient dignity (53, 54). Education about fatigue should be offered in a tailored way to all patients with cancer, in particular to those beginning potential fatigue-inducing treatments (7, 9). Moreover, professionals should give their psychological support to patients, reassuring them that fatigue can be overcome or reduced concomitantly with the treatment implementation. In this regard, only an empathic attitude can help professionals to better understand the level of fatigue suffered from patients in order to help them to face their fear of disease progression.

Further studies focused on fatigue and its multi-factor aspects are recommended in patients with pancreatic cancer who undergo chemotherapy.

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# Preventing and managing workplace violence against healthcare workers in Emergency Departments

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**Abstract.** *Background and aim:* Healthcare workers (HCWs) employed in Emergency Departments (EDs) frequently face with patients becoming violent because of long wait or diseases or under the influence of alcohol or drugs. Globally, workplace violence (WPV) in EDs is a major challenge to safety for HCWs, involving significant consequences to the victims, patients, and healthcare organizations. We reviewed the current literature with the aim to explore the topics focused on and to detect new evidences about approaching the issue of WPV toward HCWs in EDs. *Methods:* A search for articles regarding WPV toward HCWs employed in EDs and published from January 2007 through December 2017 was performed; using predetermined criteria for inclusion, selected articles were reviewed and qualitatively assessed for the aims of the review. *Results:* We found 60 papers which matched our inclusion criteria; the topics, discussed in order of frequency from highest to lowest, were: "Risk Assessment", "Occurrence Rates", "Risk Management", and "Physical/non Physical Consequences". Dementia, schizophrenia, anxiety, acute stress reaction, suicidal ideation, and alcohol and drug intoxication were found as predictors of physical violence perpetrated by patients against HCWs. *Conclusion:* A strategic way to the effective management of WPV should prioritize training courses focused on: constructing HCW-patient relationship, improving the workers' communication skills, accurate reporting of each violent incident, and improving the labor context through management commitment and employee involvement in WPV prevention programs. A special effort is required in implementing workplace design effective in minimizing stressful conditions in waiting rooms which turned out to be the most frequent site of assaults.

**Key words:** assault, occupational risk, safety measures, risk assessment, risk management

## Introduction

Workplace violence against healthcare workers (HCWs) employed in Emergency Departments (EDs) is a major challenge to HCWs' workplace safety and health worldwide, involving significant consequences to the victims, patients, and healthcare organizations. EDs are high-risk settings for WPV, compared to all health care settings (1-6); by literature, ED HCWs face many acute and chronic, often unpredictable, stressors

every day, including sudden death, trauma and hospital overcrowding and frequently deal with patients with great potential for violent behavior due to their disease state, long waits or drug and alcohol intoxication (1, 8-9). In a recent research, Ferri et al. (1) showed that in an Italian ED the 63% of violent events occurred in the waiting room, hypothesizing that there is a relationship between WPV and high level of anxiety and stress endured by both patients and their carers or relatives that is compounded by long waits. Long waits and the

stress of waiting in combination with substance abuse and psychiatric comorbidities of patients can lead to WPV (10, 11).

Sequelae of violent attacks against HCWs may include not only somatic injuries but also psychological consequences, in fact, anger, fear or anxiety, post-traumatic stress disorder symptoms, guilt, self-blame and shame, decreased job satisfaction and increased intent to leave the organization, lowered health-related quality of life (HRQoL), were found as frequent consequences of workers' (short or long-term) exposure to WPV (12, 13). The psychic consequences of WPV for ED HCWs who have been the victims of WPV often lead to absenteeism, poor morale and decreased productivity (14-16). More specifically, research examining the effect of WPV on ED nurse productivity revealed that ED nurses exposure to violent events significantly decreased productivity in the areas of Cognitive Demands and Support/Communication Demands in contrast to their feelings that they were able to maintain their work performance and provided safe and competent care (17).

The aims of this review were to explore the most common themes raised in the literature on WPV committed by patients and visitors against HCWs in EDs in the last 10 years. Although WPV against HCWs is a global problem, to date there is no general agreement among researchers on the definition; for the purposes of the present review, WPV was defined: "Any incident in which a person is abused, threatened or assaulted in circumstances relating to their work; this can include verbal abuse or threats as well as physical attacks", according to the definition adopted by the Health and Safety Executive (HSE) (18).

## Methods

A search for articles regarding WPV toward HCWs employed in EDs and published from January 2007 through December 2017 was performed using two common literature databases: PubMed and Web of Science; selected keywords were used to search articles for the aims of this review. The keywords were: Violence, Emergency Department, Healthcare worker, Assault, Prediction, Prevalence, Occupational Risk,

Safety Measures, Risk Assessment and Risk Management. The keywords were systematically combined together to conduct the search. For example, "Healthcare worker," AND "Violence" AND "Occupational risk" was one combination. Our search was aimed to identify original research articles (i.e. non-reviews) using the above-mentioned keywords with the following exclusion criteria: (1) not written in English; (2) not published after January 2007 (the year 2007 was chosen, with the aim to analyze the research studies of the last 10 years); (3) studies not regarding EDs, and (4) not full reports (i.e. letters to the editor). The screening of articles was carried out in two phases. In the first phase, articles were screened on the basis of title and abstract. Two independent reviewers (G.d and V.P.) assessed the abstracts and categorized them as relevant, not relevant and possibly relevant. In the second phase, the full-text articles were evaluated for eligibility. Two reviewers (G.d. and V.P.) independently applied inclusion and exclusion criteria to potentially eligible papers and both reviewers then independently extracted data from the original articles. Any disagreements were independently checked by a third reviewer (M.M.) and discussed with the other reviewers until consensus was reached. Every full-text article that met the inclusion criteria was reviewed and categorized into one or more of the following four categories based on its subject matter: Risk assessment (articles addressed to the examination of WPV perpetrated by patients as well as the probability that they will occur), Risk management (articles aimed at detecting effective interventions to minimize the WPV risk to an acceptable level to protect workers), Occurrence rates (e.g. incidence or prevalence of patient violence), Physical/non physical consequences (e.g. injuries or mental disorder following patient violence).

## Results

Our search of the two literature databases resulted in a total of 653 publications that matched our inclusion criteria. Of those, 593 were removed because they did not meet inclusion criteria (e.g. conference proceedings or not concerning HCWs of EDs). Therefore, 60 papers remained in the study. The topics, discussed in order of frequency from most frequent to least fre-

**Table 1.** Summary of literature review findings and articles categorization based on addressed topics

Author and year	Risk assessment	Risk management	Occurrence rates	Physical/non Physical consequences
Ferri et al. 2016 (1)	X	X	X	X
Vezyridis et al. 2015 (19)	X		X	
Hamdan & Hamra 2015 (11)	X	X	X	X
Gacki-Smith et al. 2009 (20)	X	X	X	
Hyland et al. 2016 (21)	X		X	
Gillespie et al. 2016 (22)	X		X	X
Arimatsu et al 2008 (23)	X		X	
Wu et al. 2015 (24)	X	X		
Wong et al. 2015 (25)		X		
Baydin et al. 2014 (6)	X		X	X
Magnavita et al. 2012 (9)	X		X	
Abou-ElWafa et al. 2014 (26)	X		X	X
Angland et al. 2014 (27)	X			
Morphet et al. 2014 (28)	X			
Daniel et al. 2015 (29)	X			
Burchill et al. 2015 (30)	X			
Shaw et al. 2015 (31)	X			
Kansagra et al. 2008 (10)	X			
Chapman et al. 2009 (32)	X			
Jiao et al. 2015 (34)	X		X	X
Wei et al. 2016 (35)		X	X	
Gillespie et al. 2012 (36)		X		
Wong et al. 2016 (37)		X		
Gerdtz et al. 2013 (38)		X		
Gillespie et al. 2014 (39)		X		
Li et al. 2017 (67)	X	X	X	
Nikathil et al. 2017 (68)		X	X	
Copeland et al. 2017 (69)	X		X	
Partridge et al. 2017 (70)	X	X	X	
Han et al. 2017 (71)	X			X
Gillespie et al. 2014 (40)		X		
Peek-Asa et al. 2007 (41)		X		
Somville et al. 2016 (42)			X	X
Adriaenssens et al. 2012 (43)		X	X	X
Gillespie et al. 2013 (44)				X
Gillespie et al. 2013 (45)	X	X		
Stene et al. 2015 (46)		X	X	
Eslamian et al. 2015 (47)		X	X	
Kowalenko et al. 2013 (2)			X	X
Baykan et al. 2015 (48)			X	
Ramacciati et al. 2015 (49)	X		X	X
Gates et al. 2011 (17)		X		X
McPhaul et al. 2008 (50)		X		

*(continued)*

**Table 1 (continued).** Summary of literature review findings and articles categorization based on addressed topics

Author and year	Risk assessment	Risk management	Occurrence rates	Physical/non Physical consequences
Hsieh et al. 2016 (51)		X	X	X
Park et al. 2015 (52)				X
Shablon et al 2012 (53)				X
Terzoni et al. 2015 (54)	X		X	X
Mantzuranis et al. 2015 (4)	X			X
Alameddine et al. 2015 (55)	X		X	X
Zafar et al. 2013 (56)		X	X	
Bigham et al. 2014 (57)			X	
AL Bashtawy et al. 2016 (58)			X	
Kitaneh et al. 2012 (59)	X		X	
Zampieron et al. 2010 (60)	X		X	
Pich et al. 2011 (61)	X	X	X	
Rees et al. 2010 (62)		X		
Kelley 2014 (63)		X		
Ferns 2007 (64)	X	X		
Gillespie et al. 2010 (65)	X	X		
Abualrub RF et al. 2011 (66)	X	X	X	

quent, were: “Risk Assessment”, “Occurrence Rates”, “Risk Management”, and “Physical/non Physical Consequences”. 34 papers focused on “Risk Assessment”; 32 papers on “Occurrence Rates”; 29 papers on “Risk Management”; 19 papers on “Physical/Non Physical consequences”. Seven papers discussed both “Occurrence Rates” and “Risk Assessment”; four papers focused on both “Risk Assessment” and “Risk Management”, two papers were addressed to all the 4 topics.

## Discussion

### *Risk Assessment of WPV*

The results of the present literature review show that in the last 10 years, the main topic of the checked papers was focused on “Risk Assessment”, with the aim to examine the risk factors of WPV perpetrated by patients against HCWs, as well as the risk that WPV will occur. The checked papers relating to “Risk Assessment” focused on: the predictors of violence perpetrated by patients; the determinants within the EDs; the perceived risk of violence among HCWs. Regarding the predictors of violence perpetrated by patients, Ferri et al. (1)

reported that verbal violence was frequently perpetrated by patients in a lucid and normal state of consciousness; dementia, schizophrenia, anxiety, acute stress reaction, suicidal ideation, and alcohol and drug intoxication were found as predictors of physical violence perpetrated by patients against HCWs. These findings are consistent with the workplace violence literature (5, 19-27, 34-36) that showed an higher perceived risk of physical violence among ED HCWs facing patients affected by mental health disease or disorder or under the influence of drugs or alcohol, than facing patient in a lucid and normal state of consciousness. These evidences support the need for EDs to have action plans aimed to assess prior every patient for the risk of being violent and to make known to colleagues that a patient is at risk for becoming violent (34). Chapman et al. (28) developed the STAMPEDAR assessment tool to identify patients and visitors at risk for violent behaviors, based on the work of Luck et al. who developed the STAMP acronym (29). The acronym STAMPEDAR stands for staring, tone and volume of voice, assertiveness, mumbling, pacing, emotions, disease process, anxiety, and resources. Though the tool does not allow to predict whether the patient will become violent or not, STAMPEDAR is effective to alert ED HCWs on behavioral



precursors to violence (e.g., staring, tone and volume of voice, assertiveness, emotions, disease process). This approach is aimed to preventing WPV through early detection of potentially violent patient and it is in line with literature which evidenced the need to implement procedures to identify in advance the patients as well as being in alert if the patients were to return to the ED in the future.

With regard to the determinants of violence within the EDs, they were most frequently identified as: inadequate HCW-patient relationship, high anxiety level among the staff, poorer perceived safety climates, high job demands, long waiting times for patients. HCWs' characteristics that were associated with the experience of physical WPV included, but were not limited to age less than 30 years and female gender (20). Although these evidences, Kansagra et al. (10) showed that staff who had worked more than 5 years perceived less safe than staff who had worked shorter periods of time. This finding may be due to the fact that staff felt less safe and able to manage violent patients as they have been witness of many episodes of WPV in the past.

Organizational factors were evidenced as frequent determinants of WPV. In particular, Wu et al. (20) demonstrated the relationship between high job demand and WPV; in fact, an excessive service volume, high-stress situations, and overload of physicians in daily practice were related to poor-quality medical care and, consequently, to dissatisfied patients, which revealed being the main cause of WPV against physicians. In the light of these findings, organizational interventions aimed at managing the job demand and at improving the safety climate should be adopted as a strategic way in increasing worker safety and in protecting HCWs from WPV and its negative consequences.

By literature, the surveys targeted on the staff perception of safety were detected as a valuable strategy to assess WPV risk and to achieve the goal of WPV risk reduction. In fact, Shaw et al. (27) found that among nurses of a pediatric ED, the assessment of perceived safety led to detect improvement interventions based on HCWs' suggestions and consisting in increased presence from hospital security staff (55%) and local police (71%). This finding is consistent with WPV literature; in the past, Burchill C. (26) de-

veloped the Personal Workplace Safety Instrument for Emergency Nurses (PWSI EN) and revealed its effectiveness in measuring the perception of safety in EDs' nurses and in finding solutions for managing WPV. Based on perceived safe assessment in EDs, Kansagra et al. (10) showed that nurses perceived less safe than the other HCWs in EDs, and interpreted this finding as a consequence of the close association between ED nurses and patients throughout the visit which may expose them to higher risk of violence and, consequently, lead them to perceive themselves less safe. This finding is in line with other studies which have shown that nurses experienced more physical assaults than other HCWs (21).

#### *Risk management of WPV*

Among the 29 papers focusing this topic, 19 papers discussed the management interventions targeted to the staff (e.g. training, improvement of skills in de-escalation approach to violent patients, teamworking, reporting WPV incidents); 10 papers addressed the worksite analysis with the aim to eliminate or minimize potential hazards for WPV.

With regard to training, the selected papers focused most frequently on: constructing the HCW-patient relationship, improving the workers' communication skills, accurate reporting of each violent incident, and improving the labor context through management commitment and employee involvement in a WPV prevention program. Wu et al. (20) showed that training based only on lectures was less effective in preventing WPV compared to WPV training programs in hospital settings based on interactive and dynamic learning methods for ED workers (e.g. teaching strategies such as small-group learning, interactive learning, and simulation exercises may be applied during training in medical schools. In line with this findings, Wong et al (21, 31) found that an interprofessional simulation-based team-training curriculum successfully increased staff ability to manage factors impacting the care of potentially aggressive patients in the ED. Training revealed effective also to minimizing the phenomenon of under-reporting WPV incidents; in fact, Stene et al. (37) showed increased compliance of HCWs to report these violent incidents, after educational program for

WPV, aimed to encourage HCWs to WPV reporting.

With regard to worksite analysis, several measures have been purposed to remove the hazards from the workplace or to prevent contact between HCWs and hazards identified by the workplace security analysis. The main security measures evaluated to minimize WPV risk were: alarm systems and other security devices, panic buttons, hand-held alarms or noise devices, cellular phones and private channel radios where risk is apparent or may be anticipated; closed-circuit video recording for high-risk areas on a 24-hour basis; employee "safe rooms" for use during emergencies; shatter-proof glass in reception, triage and admitting areas or client service rooms; with regard to waiting room, should be prioritized interventions to make them comfortable and to minimize stress, in fact Ferri et al. (1) showed that 63% of violent events perpetrated by patients took place in the waiting room, and were related to intolerance for long waiting times, and misunderstanding in communications or missing information; these findings are consistent with WPV literature. In particular, Angland et al. (23) suggested that to prevent the aggression that may arise from waiting times, electronic boards indicating approximate waiting times may be useful. Also, information guides and videotapes on the patient's journey through the ED may be of benefit, and communication training for ED staff is also recommended.

Many authors showed the importance of limiting access through security officers, which can manage the access to the patient treatment area; in fact, patients' and visitors' possibility to access the patient treatment area was felt by ED workers as threat to the safety of ED workers (23, 42, 43); in particular, Gillepsie et al. (43) demonstrated that if access were not always controlled and violent patients and visitors were able to enter the treatment area, emergency nurses felt unsafe and perceived an high risk of suffering a physical assault. It is also important that early communication between security officers and ED workers takes place before violent events occur.

#### *Physical/non-physical consequences of WPV*

All the 19 studies focused on this topic evaluated the psychic repercussions of the attacks; the main con-

sequences reported by abused or assaulted professionals, especially those verbally abused, were to mental health and well-being of the workers in terms of fear, irritation, anger, depression, anxiety, guilt, humiliation, feelings of helplessness, and disappointment. These sequelae, as reported in the literature, can reduce the ability of HCWs to share and understand the patients' needs and, sometimes, are predictors of burnout (1, 45). Moreover, Gates et al. (17) revealed that ninety-four percent of nurses experienced at least one post-traumatic stress disorder (PTSD) symptom after a violent event, 17% suffered for probable PTSD, and found that such symptoms consequent to physical violence had a negative impact on the cognitive ability of emergency nurses to perform their work compared to their ability before a violent incident.

The detrimental effects of stress symptoms suffered by assaulted HCWs involve all the staff; in fact, lost productivity was found in assaulted HCWs suffering stress symptoms, due to absenteeism, and difficulties in approaching patients; in particular, Hamdan & Hamra (11) found that after an episode of WPV, 26.4% of physicians and 21.8% of the nurses victim of WPV minimized contacts with patients and their companions and 13.6% and 14.5%, respectively, minimized the time of patient care, as well as 11.8% and 8.2%, respectively, avoided taking decisions that might involve medical risks.

#### *Occurrence of WPV*

The 32 checked studies showed that between 24% and 88,8% of HCWs on EDs have been victim of violence by a patient at some stage in the past 12 months; verbal assaults affected from 46,3 to 72.5% of HCWs; physical assaults from 16,5 to 48% of HCWs; sexual harassment from 8.6 to 14% of HCWs. Gacki-Smith et al. (46) revealed that 25% of emergency nurses recruited into a cross-sectional study on WPV, reported experiencing physical violence more than 20 times in the past 3 years, and almost 20% reported experiencing verbal abuse more than 200 times during the same period. Kowalenko et al (2) showed that average violence exposition rate per person per 9 months was 4.15; six hundred one events were physical threats (3.01 per person); two hundred twenty six events were assaults

(1.13 per person); more than two-thirds of physicians have experienced WPV during their career, and more than 50% of physicians have experienced WPV in the previous year.

With regard to the professionals assaulted in EDs, no occupation revealed to be not affected by assaults and threats, although with differences among occupations (1). A recent study by Kitaneh and Hamdan (47) did not reveal statistical differences in exposure to WPV between physicians and nurses, in the past 12 months in Palestinian public hospitals; this finding was confirmed by Guglielmetti et al. (48) which detected nurses and physicians as exposed to the same risk of WPV. On the contrary, Magnavita et al. (9) showed that physicians were more exposed to WPV, compared to other occupations, and hypothesized that the finding was related to their decision-making role and to frequently working alone with patients.

WPV occurrence data suffer of under-reporting WPV by assaulted HCWs; in fact Ferri et al. (1) reported that 84% of HCWs did not report violent events, in line with literature which indicates many reasons for under-reporting of WPV: fear of retaliation from aggressor and his/her family, feelings of shame related to being the subject of aggression, or addiction to WPV considered an integral part of job.

### Limitations

There are several limitations in this study. Firstly, because of the definition of violence is not unique, some selected papers analyzed only physical violence, others both physical and verbal; secondly, the occurrence of the WPV may be underestimated; in fact, several studies showed that in many cases the episodes of WPV are not reported by assaulted workers. In view of the above, to carefully analyze the WPV risk, we used the violence definition made by the HSE, which is comprehensive of both physical and non-physical attacks; moreover, we think that the phenomenon of underreporting of WPV is mitigated by the considerable number of papers which studied the topic of "occurrence rate" and held into account the above limitation.

### Implications for emergency healthcare workers

A special effort is required in implementing workplace design effective in: ensuring the safe egress by staff away from the violent patient or visitor until help can respond, and in minimizing stressful conditions in waiting rooms rooms which turned out to be the most frequent site of assaults against HCWs. A strategic way to the effective management of WPV should also prioritize training courses focused on constructing the HCW-patient relationship, improving the workers' communication skills, accurate reporting of each violent incident, and improving the labor context through management commitment and employee involvement in a WPV prevention program; in fact, the HCW attitudes in assessing and managing WPV showed determinant in minimizing the risk. Wong et al. (21,31) demonstrated the effectiveness in improving HCWs' attitudes toward patients with behavioral emergencies through a better understanding of factors contributing to patient aggression. All HCWs should be also trained to behave carefully toward colleagues when WPV occurs; in fact, assaulted workers frequently suffer feelings of fear, anger, guilt, irritation and helplessness. These sequelae, as reported by the literature, can reduce the empathy capacity of health care workers and, sometimes, constitutes causes of burnout.

Interventions targeted at preventing WPV should consider the post-incident reports of assaults, with the aim to analyze incidents, including the characteristics of assailants and victims, an account of what happened before and during the incident, and the relevant details of the situation and its outcome, processes and procedures that put employees at risk of assault, including how often and when. The analysis of each assault helps to identify new or unknown risk factors and deficiencies or failures in work practices, procedures or controls. Also, the analysis helps to design measures through engineering or work practices to prevent or control these hazards. To date, most of the checked papers highlighted the phenomenon of under-reporting the incidents by assaulted HCWs; educational programs showed effective in encouraging HCWs to WPV reporting; Stene et al. demonstrated that after the ED staff were given the education aimed to report

assaults, the ED staff began reporting those violent incidents that occurred within the ED (37).

## Conclusion

The findings of the present review show that the patients' violence towards HCWs is a major problem for HCWs, healthcare organizations and patients; dementia, schizophrenia, anxiety, acute stress reaction, suicidal ideation, and alcohol and drug intoxication were found as predictors of physical violence perpetrated by patients against HCWs in EDs; despite this evidence, the short-term prediction of behavioral emergencies in an ED, based on such predictors, has limited value compared to community settings; in fact, in the admittance of acute patients such predictors are frequently unknown (5, 8-10).

We found a lack of evidence about the long-term psychic consequences of violence towards HCWs in EDs; in fact, many authors revealed that among HCWs both forms of violence, physical and non-physical, were significantly correlated, in the short-term period, with symptoms of burnout (emotional exhaustion, depersonalisation and inefficacy) and with experience distressing emotions. In particular, Gates et al (17) found high risk of PTSD among ED nurses assaulted and suggested immediate interventions, during the first hours or days after a trauma, to provide the victim with the support system composed of peers and administrative representatives; in fact, workers supported by such interventions would have an opportunity to process the event and put it into perspective, thus minimizing the short and long-term symptoms related to stress and anxiety. According to these findings, we suggest the need to analyze the long-term psychological sequelae of WPV towards assaulted HCWs, with the purpose of designing the effective interventions to assist the victims of violence and to prevent psychological consequences.

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# A randomized comparison trial of two and four-step approaches to teaching Cardio-Pulmonary Reanimation

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**Abstract.** *Background and aim of the work:* The treatment of cardiac arrest in an extra-hospital environment improves with the increase in the number of people able to establish an early Cardio-Pulmonary Reanimation (CPR). The main aim of the study was to assess the validity of the two-step method in case of prolonged CPR. *Methods:* A randomized comparison study was conducted in the University Nursing School of a Northern Italian town, during the 2015/16 academic year, among 60 students, to teach them CPR techniques, through two different teaching methods (4-step and the 2-step of CPR training). The effectiveness of the maneuvers performed on mannequins equipped with skill-meter was verified. *Results:* Our study did not highlight any significant difference between the two methods of CPR training. The comparison between the two methods regarding their efficacy in practical teaching of CPR, highlighted by this study, proved the validity of both the 4-minute continuous method (1st method) and the 30:2 method (2nd method). *Conclusions:* The results of the study showed no differences between the 2-step and the 4-step methods, in the effectiveness of cardiac massage. The correct execution of chest compressions during a CPR is the key to increase the patient's chances of rescue. Research has shown that any interruption in the execution of chest compressions, leads to a progressive reduction of the effectiveness of cardiac massage, with negative consequences on the prognosis of the patient undergoing at CPR.

**Key words:** 4-Step, 2-Step, Cardiopulmonary Resuscitation, Out-of-Hospital Cardiac Arrest, Teaching, Nursing student

## Background

Extra-hospital cardiac arrest is still a serious public health problem. The metaphor of the “Chain of Survival”, coined by the American Heart Association (AHA) and universally adopted, identifies the basic phases for successfully resuscitating victims of cardiac arrest (1). Identifying cardiac arrest can be difficult.

Both bystanders and those who manage the emergency calls must immediately recognize cardiac arrest in order to promptly activate the survival chain (2). The key symptoms for recognizing a cardiac arrest are: the victim is unresponsive, does not breathe normally and does not show any signs of circulation (3, 4).

Unfortunately, only at times bystanders start Cardio-Pulmonary Reanimation (CPR) on their own in

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case of cardiac arrest. It has been demonstrated that CPR telephonically guided by the emergency operative center increases the survival rate (2), reduces the time that elapses between cardiac arrest and the beginning of the first chest compression (5, 6), increases the number of chest compressions performed (7) and improves the prognosis of victims of extra-hospital cardiac arrest (8-10). The emergency center operators should provide instructions to perform CPR with chest compressions only if the cardiac arrest victim is an adult. Immediate CPR can double or quadruple survival after cardiac arrest (11, 12).

The European Resuscitation Council (ERC) supports the recommendations of the International Liaison Committee on Resuscitation (ILCOR), according to which a chest compression with a depth of about 5 cm but no more than 6 cm, is reasonable in the average adult (13). A frequency of at least 100 compressions per minute, without exceeding 120 compressions per minute, with the fewest interruptions possible (14), and with equal times for the compressions and release phases is optimum (15, 16). Teaching CPR is fundamental for training and the most effective method for training it should be identified (17). A model that has been increasingly affirmed in medical and university training since 2000 is Peyton's *Four Step Approach*, a 4-step method of instruction, normally used in the training courses of the European Society of Cardiology (ESC)(18).

The 4-step teaching method developed by Peyton provides the following sequence:

- phase 1: technique performed by the instructor in real time and in silence;
- phase 2: CPR is repeated and commented by instructor with explanations of reasons for each action;
- phase 3: the demonstration is repeated by the instructor under the direction of one of the learners;
- phase 4: the execution of the phase is repeated by a learner.

Although this approach is theoretically very convincing, as a cognitive procedural model there is no evidence that it leads to superior results in terms of learning compared to other teaching methods (19). Several studies compared the effectiveness of the 4-step meth-

od with other teaching models. Greif's randomized controlled trial compared the Peyton 4-step teaching method with the traditional "*see one, do one*" method to teach a specific technical skill such as cricothyroidotomy (20). Orde's study compared the 4-step teaching method with the traditional 2-step method for inserting the laryngeal mask (21). Orde's training method uses steps 2 and 4 of the Peyton 4-step method. The study did not show a statistically significant difference between the 2- and 4-step methods either in terms of acquiring the skill or remembering it over time.

## Aim

The main aim of the study was to assess the validity of the two-step method in case of prolonged CPR. Secondary aims were:

- to verify if periodic two-second interruptions every thirty chest compressions allow the rescuer to maintain an effective cardiac massage for a longer time, regardless of whether the ventilations are performed or not;
- to verify if a feedback system on the effectiveness of chest compressions (Skill-meter®) has a positive influence on massage efficacy.

## Method

### *Study design and participants*

This randomized comparison trial was conducted in the University Nursing School of a Northern Italian town, during the 2015/16 academic year. Our convenience sample consisted of 60 nursing students: 25 in the first year and 35 in the second year of Nursing course. The students of our sample had never performed CPR.

The sample was randomly divided into two numerically homogeneous groups of thirty students: the experimental and the control group. For allocation of the participants, a computer-generated list of random numbers was used. The two initial groups were subsequently divided into three subgroups composed of 10 students each in order to make teaching easier by reducing the ratio of instructor: students to 1:10.

### 1<sup>st</sup> Phase of the study

Before starting the experiment, the 8 CPR instructors were divided into 3 randomized instructor groups: three instructors composed the experimental group aimed at teaching only 2 of the 4 CPR steps described by Peyton, the other three instructors composed the control group to teach the traditional four-step CPR method and the last two instructors composed the evaluation group with the task of evaluating all students' performance (18). The three groups were double-blinded since the instructors of each group did not know the teaching methodology of the other groups. Moreover, instructors and students were not allowed to attend the other groups' training and performance.

Before the beginning of the training, each instructor was asked to simulate his/her activities to other instructors in order to ensure that performances were homogeneous. Eight work stations were created, six for student training of and two for instructors' eval-

uation. All settings were equipped with ResusciAnne<sup>®</sup> manikin with Skill-meter<sup>®</sup>, self-expanding balloon with a medium-sized mask. All the equipment, manufactured by the same company, presented the same technical characteristics.

The research protocol provided for the following procedures for each group:

- 15 minutes of training for cardiac massage and ventilation with ambu bag;
- access of three students maximum at a time to each workstation.

After completing the training, the students were randomly sent to the two evaluation stations, where their 2-minute CPR performances were assessed by the two instructors (Figure 1).

### 2<sup>nd</sup> Phase of the study

After completing the first phase of the study, the two training methods were compared to evaluate the

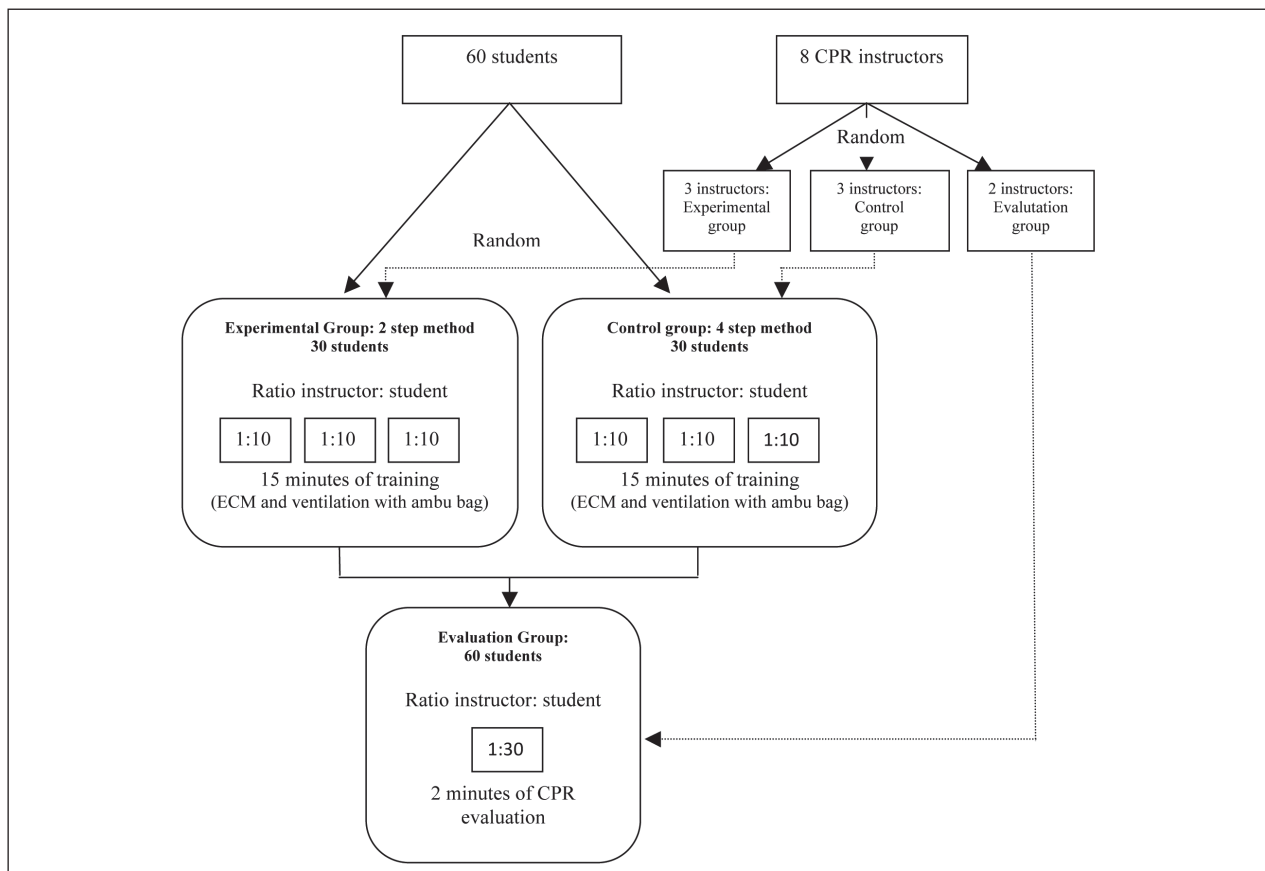


Figure 1. 1<sup>st</sup> Phase of the study



better one for carrying out the External Cardiac Massage (ECM). Method 1 provided the execution of 4 minutes of uninterrupted ECM either with or without the aid of an evaluation tool during practice. Method 2 provided the execution of ECM for 4 minutes with a pause of 2 seconds (theoretical time for the ventilations) every 30 compressions. In this case also the experiment took place either with or without the aid of an evaluation tool. The 8 CPR instructors were randomly divided into four groups (two groups per each method) and the 60 students were numerically homogeneously inserted into the four groups (15 students per group). Two work stations were assigned to each group. The students assigned to the two groups of Method 1 were asked to practice ECM by checking the Skill-meter® for 1 minute; after this, one group continued to practice the cardiac massage with only the aid of a metronome, whereas the other group practiced ECM for 4 minutes supported by both metronome sound and Skill-meter® monitor.

The students inserted in the two groups of Method 2 were asked to practice ECM by checking the Skill-meter® for 1 minute; after this, one group continued to practice the cardiac massage with the aid of only a metronome, whereas the other group practiced ECM for 4 minutes supported by both metronome sound and Skill-meter® monitor. For both training

methods, each student was given 5 minutes of time (Figure 2).

Data from the 1st and 2nd phases of the study were collected on two electronic boards. For each student, we collected personal data, height, weight and his/her performance of ECM (number of massages with insufficient force on the chest of the manikin, the number of massages with excessive force exerted and the correct ECMs) and ventilation (number of insufflation with insufficient pressure to fill the lungs, number of insufflation with excessive pressure and number of correct insufflations).

#### *Ethical considerations*

All students enrolled gave us their informed written consent for participation in this study, following our explanation of its purpose and design. Participants' anonymity and confidentiality were assured and their decision regarding participation in this study was respected. The study was authorized by the Director of the Nursing Degree Programme.

#### *Statistical analyses*

Descriptive statistical analyses were performed: means and standard deviations for continuous data,

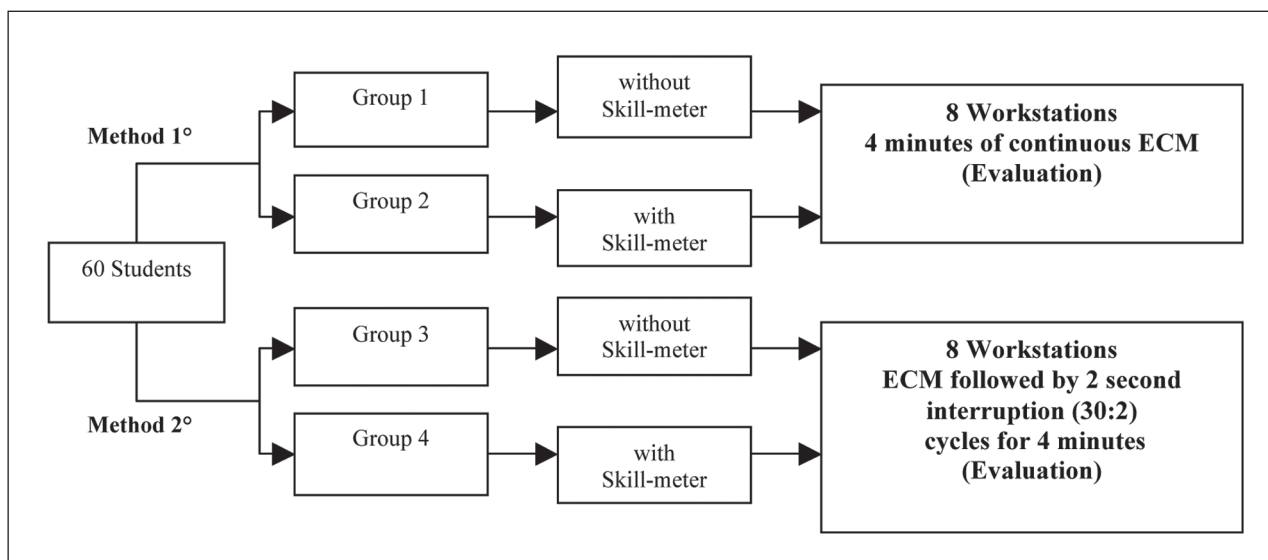


Figure 2. 2<sup>nd</sup> Phase of study

and percentages for categorical data. *t*-test and ANOVA were applied to identify significant differences among continuous data. Categorical variables were calculated through the contingency tables and the differences were detected through the Chi-square. Multiple comparisons were performed using Tukey's Honestly Significant Difference (HSD). We considered statistical significance to have been attained if  $p < .05$ . The statistical analysis was performed using the SPSS software.

## Results

Sixty students were enrolled in the study: 10 males (16.7%) and 50 females (83.3%). The mean age of our sample was 22.03 years on average ( $SD=4.403$ ). Regarding the physical characteristics of the students (Table 1), divided by gender, significant differences were found both in weight ( $p=.0001$ ) and height ( $p=.0001$ ), as highlighted by another study (21).

In our sample, the efficacy in performing CPR was not influenced by gender, weight or height of students. Regarding the two methods of CPR, the *t*-test did not show any significant difference ( $p=.885$ ), although the number of effective chest compressions was higher in the 2-step method ( $M=75.24$ ,  $SD=33.56$ ) than in the 4-step method ( $M=73.30$ ,  $SD=32.03$ ) (Table 2).

**Table 1.** Constitutional variables of our sample

	Males n=10	Females n=50	Total n=60	Statistical test Probability
<b>Weight (Kg), n (%)</b>				
40-50	0 (0)	10 (20)	10 (17)	
51-60	1 (10)	35 (70)	36 (60)	$\chi^2=33.4$
61-70	5 (50)	4 (8)	9 (15)	$p=.0001$
71-80	1 (10)	1 (2)	2 (3)	
81-90	2 (20)	0 (0)	2 (3)	
91-100	1 (10)	0 (0)	1 (2)	
<b>Height (cm), n (%)</b>				
150-160	0 (0)	22 (44)	22 (37)	
161-170	3 (30)	27 (54)	30 (50)	$\chi^2=34.8$
171-180	4 (40)	1 (2)	5 (8)	$p=.0001$
181-190	3 (30)	0 (0)	3 (5)	

In the second experiment, the number of chest compressions statistically significantly differed between the two methods ( $t=2.936$ ,  $p=.005$ ). In fact, the simulator calculation of the average of the total chest compressions performed, demonstrated that, with the 1st method, the students performed an average of 409.96 compressions ( $SD=28.90$ ), while with the 2nd method, the average number of compressions was 386.28 ( $SD=33.01$ ).

Regarding the efficacy of the chest compressions, there were no differences between the 1st teaching method and the 2nd one (Table 3). However, 4-min-

**Table 2.** Comparison of chest compression and ventilation effectiveness in the 2 and 4 step methods

	N	M±SD	Standard error	Statistical test Probability
<b>Insufficient chest compressions</b>				
<i>4 - step method</i>	16	39.93±33.30	8.474	$t=.512$
<i>2 - step method</i>	17	33.59±37.13	9.006	$p=.612$
<b>Too strong chest compressions</b>				
<i>4 - step method</i>	6	29.00±28.06	11.457	$t=.148$
<i>2 - step method</i>	6	26.50±30.35	12.390	$p=.885$
<b>Effective chest compressions</b>				
<i>4 - step method</i>	30	73.30±32.03	5.848	$t=-.227$
<i>2 - step method</i>	29	75.24±33.57	6.233	$p=.821$
<b>Effective ventilations</b>				
<i>4 - step method</i>	30	7.97±3.09	.564	$t=-.223$
<i>2 - step method</i>	29	8.14±2.79	.517	$p=.824$

**Table 3.** Comparison of the chest compression effectiveness in the 2 and 4 step methods

	N	M±SD	Standard error	Statistical test Probability
<b>Insufficient chest compressions</b>				
4-step method	28	160.54±12.72	22.814	$t=-.838$
2-step method	31	188.06±130.52	23.443	$p=.405$
<b>Too strong chest compressions</b>				
4-step method	5	22.60±37.30	16.681	$t=.929$
2-step method	5	7.00±4.47	2.000	$p=.380$
<b>Effective chest compressions</b>				
4-step method	28	243.00±115.93	21.910	$t=1.251$
2-step method	32	203.19±128.78	22.766	$p=.216$

ute uninterrupted massage for 4 minutes (Method 1) produced better results: effective massages were 243 on average ( $SD=115.93$ ), which corresponded to 59.3% of the average total compressions performed with the 1st method, against 203.19 massages on average ( $SD=128.78$ ) of the ECM followed by interruption (30:2), method 2, which instead corresponded to 52.3% of all massages performed with the 2nd method.

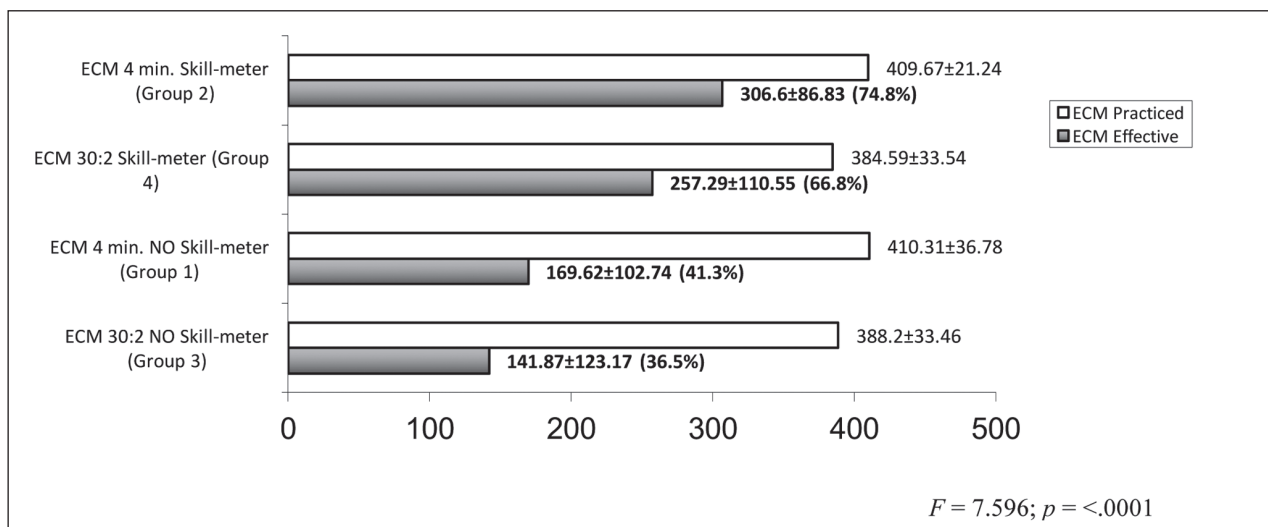
Regarding the use of the skill-meter, group 2 obtained the highest number of effective chest compressions ( $306.60\pm86.83$ ,  $p<.0001$ ); it practiced the massage in 4 minutes without interruption with skill-meter support, reporting a percentage of 74.8% cor-

rect compressions; group 4 follows, with 66.8% correct massages ( $257.29\pm110.55$ ) (Figure 3).

However, the multiple comparison showed significant differences between group 2 and group 1 ( $MD=-134.979$ ,  $p=.012$ ) as well as between group 2 and group 3 ( $MD=-147.533$ ,  $p=.003$ ), but not between group 1 and group 4 ( $MD=98.534$ ,  $p=.095$ ).

## Discussion and conclusions

Our study did not highlight any significant difference between the 4-step and the 2-step methods

**Figure 3.** Effectiveness of chest compressions in the two training methods, with or without use of the skill-meter

of CPR training. Therefore, the results obtained from this research suggest the validity of the Orde 2-step method (22) as well as the Peyton 4-step method. This result was further confirmed by the comparison between the two methods regarding the efficacy of chest compressions and ventilations and errors recorded by the simulators' skill-meters. Differently from a recent study (21), the personal and physical characteristics of our students did not affect their training performances in CPR.

Furthermore, the 2-step method permitted students to have more time to perform the practical maneuvers through the simulator, whereas the instructor had more time to do corrective interventions. For this reason, the 2-step method could be useful for health care workers and non-professionals who need practical training in CPR maneuvers and airway management (22). Moreover, we suggest that the choice between the Peyton and Orde method could depend on the organizational peculiarities of health setting or training course that promotes training.

The comparison between the two methods regarding their efficacy in practical teaching of CPR, highlighted by this study, proved the validity of both the 4-minute continuous method (1st method) and the 30:2 method (2nd method).

Finally, we suggest that the choice between the 1st or 2nd method could be inferred from the results obtained by the four groups of our students who used the Skill-meter® during CPR. In fact, our results highlighted the effectiveness of both methods in groups 2 and 4, where students used the Skill-meter®. This result indirectly suggests that the correct choice of teaching method depends on the availability of simulator equipment and not on the typology of method: for health settings or institutions with low technology instruments, which do not permit the evaluation of students' performances during chest compressions, the method which involves 4 uninterrupted minutes of massage could be preferred, whereas, the availability of medium-high technology simulators, could permit the use of the traditional 30:2 method.

We conclude by highlighting that both clinical learning and competency development are essential parts of nursing teaching (23) and realistic simulation can be an effective training method, especially if it is

supported by the presence of trained instructors (24, 25).

The main limit of the study was represented by the small size of our sample, not homogenous for gender but only for age. Furthermore, the skill retention after a period of time was not verified due to the difficulty to collect the same sample in a follow-up (most of students subsequently participated in complete CPR course, or they began working, or transferred to other locations).

To confirm our results, further studies with bigger sample, including subjects with different professional and personal characteristics, are necessary.

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# The palliative care in dementia context: health professionals point of view about advantages and resistances

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**Abstract.** *Background and aim:* The 38/2010 law has expanded the provision of palliative care to patients with chronic-degenerative diseases. The ISTAT data show that 60% of the dying population is suffering from these diseases and could, according to the literature review, benefit particularly from such treatments. This study investigates the point of view of healthcare professionals, working in the context of dementia, regarding the knowledge and application of palliative care in the field of dementia. The focus is on the analysis of the resistance that may prevent the spread of palliative care, slowing the application of such care in different settings of terminality. *Methods:* The method is a qualitative phenomenological approach. A grid of semi-structured interviews was created and was proposed to 33 health workers (18 women) who work in Health Centres or in the Alzheimer Nucleus of Northern Italy. *Results:* Most operators think they understand palliative care, they believe it to be useful and necessary, but often only connect it with terminal illness. Others have a broader vision based on a more abstract and theoretical level than on real practical knowledge. A majority of respondents think that the spread of palliative care is slow and difficult because of the prevalence of the biomedical model that holistically and prejudicially hinders the introduction of new models. *Conclusion:* Appropriate training is the fundamental key to overcoming resistance. The professionals interviewed showed that they were aware of their lack of knowledge and declared that they had little competence in managing the complexity of long-term pathologies.

**Key words:** palliative care, dementia, chronic diseases, application resistances, health care operators

## Background

The first important definition of palliative care was given by the World Health Organization (WHO) in 1990 (1). The most important points of this authoritative document concern the centrality of the patient, the consideration of the multifaceted nature of the human condition and the identification of quality of the life as a final goal (2, 3). It considers the patient as a

whole, consisting of an interconnected plurality of dimensions (e.g., biological, physiological, psychological, socio-cultural, spiritual) (4, 5).

Palliative care has been created to provide active and total assistance to patients affected by a disease that no longer responds to specific treatment and whose direct evolution is the end of life. In 1999, the WHO (6) defined this condition as terminality, a state no longer reversible through treatment, characterised

by a progressive loss of autonomy, and by the manifestation of physical and psychic symptoms that involve the family unit and social relationships. At this stage of the disease, the medical system interrupts all attempts at healing, limiting itself to treating the symptoms and alleviating suffering (7), through a remodelling of the assistance interventions in progress in relation to the new goals of treatment (8).

A big step forward was the introduction of the 38/2010 law that clearly and precisely defines the basic elements that constitute palliative care in our national context and sets out to address such care even for the patient suffering from a chronic illness with an evolutionary trend pathology, thus opening the horizons to a new vision of a person having the right of access to such care. Chronic conditions are defined as medical conditions associated with symptoms or disabilities that require long-term management (9) and the persistence of a morbid state to which the possibility of a resolution is not seen (10). Although some chronic disease conditions only cause minor disadvantages, others can cause important symptoms and limitations of activities (11). The management of these conditions can be difficult for patients, as it must include learning strategies for living with symptoms and disabilities, and addressing identity problems that may result from the same chronic condition (9). In many types of chronic disease the symptomatology is similar to that of cancer diseases; the only aspect that differentiates them is the prognosis. The chronic patient can live for years with their pathology that goes through different phases, characterised by episodes of exacerbation. The trajectory, not always predictable, often ends in a gradual or rapid decline that leads to death (12).

By 2050, there will be a demographic and epidemiological transition that will lead to an 8-fold increase in the number of people aged over 80 and to an incidence of chronic conditions of 20% (9). According to the WHO, the need for palliative care services will continue to increase, due to the increase in chronic diseases and the aging of the population around the world (13). National health systems must therefore include palliative care in the continuum of care, for people with chronic conditions, through prevention strategies, early diagnosis and planned treatments (14).

The analysis of epidemiological data highlights how dementia can be considered to be among the most serious of chronic diseases, due to the numerous disabilities of the people affected, the significant social and health impact, and the growing increase in the world population. Therefore, dementia represents a global public health priority in relation to the alarming data associated with it, as defined in the WHO Report.

The symptoms of the dementia patient are complex: restlessness, wandering, incontinence, delusions, hallucinations, reduced motility and eating disorders (15). In the international context, about 46.8 million people suffer from dementia. Of these, 60-70% suffer from Alzheimer's, and this figure will tend to double every 20 years, up to 74.7 million in 2030 and 131.5 million in 2050, with 7.7 million new cases each year (1 every 4 seconds) and an average survival of 4-8 years after the diagnosis (16).

The significant impact in economic, social and ethical terms, and the complexity of the phenomenon, require an extraordinary capacity for governance capable of integrating very different skills and knowledge. In Italy, the Ministry of Health established a National Chronicity Plan, in which it emerged that the "integrated management model" is now considered the most appropriate approach to improve care for people with chronic illnesses. In fact, such patients need, not only effective and modulated treatments at different levels of severity, but also continuity of assistance, information and support (17). Dementia, not curable but treatable, can last longer than ten years, so the treatment of dementia poses at least two orders of problem: (a) the identification of the needs of the person and of those who take care of them in the various phases of the disease and in the different contexts of life; (b) the integration of responses to different and changing needs (18).

It is therefore essential to analyse this pathology in the field of palliation. However, in the medical and nursing literature, palliative care applied to dementia is still an under developed issue today. Therefore, this study launches a new challenge: to move towards a cultural change that arises from the recognition, by professionals, of a medicine centred on "caring" rather than on "curing".

## Aim of the work

The aim of the study is to investigate the point of view of health professionals working within the field of dementia, dealing with pathologies considered interesting for their chronicity characteristics but especially for the critical issues related to daily care practice. The analysis focuses specifically on the knowledge and availability of the application of palliative care in these areas, with particular attention to the analysis of the resistances that could prevent the spread of, or slow down the application of, such treatments within contexts different from terminal illness.

## Methods

*Qualitative research methods* are increasingly important in the development of nursing knowledge and improving the quality of care. Qualitative research responds appropriately to the need to describe, explore and explain increasingly complex phenomena, with an approach centred on the subject and not on the variables.

Specifically, this study made use of a *phenomenological approach* to research. The goal of the phenomenological approach applied to qualitative research is purely descriptive and is limited to outlining the experiences of participants as they have been lived. The goal is not to create theories or models of the phenomenon under consideration but to try to discover the subjective and personal meanings that participants give to their reality (19, 20).

### *Instrument*

The data were collected through a semi-structured interview built ad hoc. The interview is characterised by flexible questions that represent a perimeter within which the interviewee and the interviewer have freedom of movement, while maintaining the rigor that allows the latter to deal with all the topics necessary for the cognitive objectives (20, 21). The interview grid was tested through a pilot survey administered to a coordinator of the medical team of a hospice in northern Italy. His availability and decades of experience in this

field, has allowed the researcher to modulate the questions effectively, as well as to confirm the elements to be explored. Following the pilot phase, and based on the research objectives, 13 questions were composed to explore the following areas of investigation: (a) Opinion and knowledge of palliative care (interview questions example: “*Do you know what palliative care is? Do you know them?*”); (b) Opinion on the application of palliative care in a chronic context (e.g., “*What specific advantages could the application of palliative care bring to your working context?*”); (c) Use of palliative care in the context of work (e.g., “*Would you be willing to introduce new methods of care and assistance to the patients in your daily practice?*”); (d) Resistances to the application of palliative care (e.g., “*In your opinion, how could the resistances be overcome?*”). With the prior written consent of the participants, the interviews were audio-recorded. Their duration ranged from 30 to 40 minutes. They were conducted in the period between October and December 2016 and were then fully transcribed in order to be analysed.

### *Participants*

The selected participants are health professionals, who work as health care professionals with dementia patients. More specifically, the inclusion criteria of selection for the study were: voluntarily consenting to participation, operating in a care setting in the area of dementia, personally assisting patients with moderate to severe dementia, participating in a team of health professionals in the management of clinical cases of dementia.

The participants were recruited from the Health Care Residences, or the services of protected residences, or the Alzheimer Nucleus of Northern Italy, in the provinces of Pesaro, Modena, Reggio Emilia, Verona, Mantova and Monza, through the use of a convenience sample.

A total of 33 professionals took part in the research (18 female), of which 15 were physicians (8 male), 12 were nurses (9 female), 3 were psychologists, 1 was an occupational therapist (male) and 2 were social health professionals (both female).



### Data analysis

The texts of the interviews were transcribed, giving each operator a name of convenience (only the name of the profession was made recognisable).

The transcriptions were submitted to an analysis of the content, according to some well-defined steps (22): (a) Detection of the issues emerging from the transcripts, in which the members of the research group reach agreement on the definition of the salient contents that emerge from the operators' narratives; (b) Passage from the final themes to a report capable of underlining the meanings connected to the participants' experiences. The analysis and the connections between the meanings that emerged lead to a reconstruction of a representative sense of the experiences of each interlocutor and at the same time allow us to outline recurring modalities of attribution of meaning to the experiences that accompany them.

## Results

From the analysis of the interviews, a series of macro-areas emerge that correspond to the issues investigated with the interview grid. Each macro area is composed of sub areas that highlight the prevalent contents (meanings) specified by the participants (Table 1).

### 1. Opinion and knowledge of palliative care

#### a. Knowledge of palliative care

The majority of the professionals declare that they know about palliative care and describe it from two different points of view: connected exclusively to terminality (17 out of 33), and to be used at the end of life (P2: "Palliative care is a set of different treatments, that are provided basically to people nearing death and to people who have incurable diseases, therefore to cancer patients rather than to patients with serious infectious diseases") or as a holistic approach to the care (15 out of 33) in a broader and more complex view of the patient (M4: "What we face daily comes into palliative care. We aim at a global well-being aimed at the person at 360 degrees.").

Only a small percentage of professionals (3 out of 33) say they do not know about it, or say they vaguely remember references to it (I2: "I have heard about it, but now if I had to say exactly what it is, I don't remember.").

#### b. Opinion on the usefulness of palliative care

The professionals, questioned about the usefulness of palliative care, in almost all cases report an extremely positive opinion, considering it indispensable in the practice of care (20 out of 33) (M12: "It is also fundamental in non-oncological and terminal diseases. Its usefulness is inescapable"), others (9 out of 33) define it - despite a minor emphasis as - useful, considering it a great opportunity to be undertaken in the care pathways (I11: "I think it's a great opportunity for the person and for the family.").

Only one operator considers palliative care as unnecessary, defining it as risky and unreliable (I6: "I prefer normal treatments, because in my opinion it is always a risk, I wouldn't trust a lot.").

### 2. Opinion on the application of palliative care in a chronic context

#### a. Usefulness of palliative care in chronic diseases

The point of view of the professionals has been specifically investigated regarding the usefulness of palliative care in chronic illness, such as for Alzheimer patients.

Although palliative care is an area considered by some to be still unexplored and little known, the majority of respondents (23 out of 33) testify that palliative care is absolutely essential not only in oncological contexts, but should begin to be a presence in all health areas (recognised utility) (M10: "It is the future, I believe in it and it must be applied to chronic-degenerative diseases and I'm fighting for it, I hope it can become a tool in the central health care sector in the near future.").

There are some professionals (4 out of 33) who, not fully aware of what palliative care involves; they did not express such a definite judgment (doubtful utility due to lack of knowledge). Some think it depends on the degree of the disease and on the patient's clinical situation, others on the wishes of the family and on the patient him/herself (doubtful utility due to lack of knowledge) (A1: "I don't know exactly what it might

**Table 1.** The results

Macro area	Sub area	Meanings
1. OPINION AND KNOWLEDGE OF PALLIATIVE CARE (PC)	a. a. Knowledge of palliative care	- terminality - holistic approach - no knowledge
	b. Opinion on the usefulness of palliative care	- indispensable - useful - unnecessary
2. OPINION ON THE APPLICATION OF PC IN CHRONICITY	a. Usefulness of palliative care in chronic diseases	- recognised utility - doubtful utility due to lack of knowledge - innovative topic - unrecognised utility
	b. Benefits of palliative care in chronicity	- control and management of symptoms - global management - improvement in team work
3. USE OF PALLIATIVE CARE IN PRACTICE	a. Use of palliative care	- daily use - pain therapy and terminal phases - sporadic - not used - no answer
	b. Usefulness of palliative care in resolving critical issues	- useful - doubts as to usefulness
	c. Availability to open up to new ways of treatment	- availability
	d. Availability of the working context to open up	- favourable - lack of knowledge - lack of dialogue / comparison - opposed
	e. Urgency in the application of palliative care	- immediate urgency - urgency only in the terminal phases - no urgency
4. RESISTANCE TO THE APPLICATION OF PC	a. Slow and difficult diffusion	- biomedical model - pharmaceutical and political interests - lack of training - Catholic Church culture - lack of laws and well-defined guidelines
	b. Resistance to the application	- cultural resistance / prejudice - lack of training - lack of personal motivation - resistance to the use of morphine
	c. Overcoming resistance	- training - communication

bring, or if it is really valid, for example, for dementia, also because I have never had the opportunity to try it out.”).

Others (3 out of 33) believe palliative care is an innovative topic, that has not yet taken hold in Italy and which needs to be extended to all realities, with

the help of palliativist doctors and, above all, through a cultural change that allows it to establish itself. It is highlighted that there is still little knowledge of palliative care in contexts of chronicity, as it is an extremely new topic (M7: “Then we say that we are still at the be-

ginning and we need a lot of knowledge of this new culture, which, however, must be more specific to our field.”).

Among all the interviewees, we distinguish only one operator who believes palliative care associated with chronic diseases is absolutely useless (unrecognised utility), as it cannot be standardised in the way that has already happened for cancer patients (M5: “It is useful with cancer patients because it started many years ago and is standardisable in some aspects, but if we refer to the emotional and psychological field of patients, both chronic and demented, we are lacking in knowledge.”).

#### *b. Benefits of palliative care in chronicity*

The professionals have highlighted how the introduction of palliative care in chronic conditions could lead to an improvement in the control and management of symptoms, such as pain, respiratory crises and dysphasia. It can also lead to better management of complications caused by chronic disease (M13: “In diseases such as Alzheimer’s, being a highly complex disease and with a slow course, I would apply palliative care, always and especially in the terminal phase to alleviate the complications of the disease.”).

The professionals underlined how the use of palliative care can allow a global management of the patient and the family members, guaranteeing a holistic vision by all health professionals. The advantages are found in: - improvement of quality of life; - reduction of suffering; - accompanying the patient (I4: “It is precisely a day-to-day caring for the patient and their family, which is what we do, and what’s more, it also means listening to what they have to say and then finding the right path to help them and accompany them on their journey.”).

According to other operators, the introduction of palliative care in chronic contexts could lead to an improvement in team work and the possibility of building an integrated territorial network among the various professionals. Team work, according to this vision, can provide more adequate interventions according to the patient and the stage of illness (M11: “Certainly introduce interventions that should be coordinated with other professionals. It would be useful to have a team that evaluates, together with the general practitioner and the patient’s family, the most appropriate interventions depending on the stage of the disease.”).

### *3. Use of palliative care in the context of work*

#### *a. Use of palliative care*

Some of the professionals (16 out of 33) tell us that they use palliative care every day. Specifically they refer to using it daily, since it is inherent in their role (M10: “I apply it daily during the course of my profession and I have also had experience in a personal context.”).

Other professionals (3 out of 33) claim that the use of palliative care within their structure is as a protocol exclusively used as pain therapy and in the terminal phases (I12: “The diagnostic therapeutic treatment path we have worked on involves the phase of palliation for patients with dementia even if only in the terminal phase. The course would have to be recalculated as palliative care is applied too late.”).

Others (4 out of 33) tell instead of having used it in the past, of having experienced it only a few times or that, within their structure, it is not used in a systematic way but only for sporadic use (for example on the basis of the presence or not of a palliativist doctor) (M7: “In the structure, not in a systematic way because we have to do a training course for all staff, to provide everyone with basic knowledge of the palliative culture and later, more specifically, in the department that we are going to organise in those terms.”).

Many interviewees (7 out of 33) claim to have never had anything to do with it, that in their structure they have not used it, or, in any case, they are not even familiar with it. Some even claim that there is no dedicated team, that there are no guidelines and describe their department as not suitable for treatment of this type (I6: “No, in the ward where I work, it is neither known nor applied”; M11: “We don’t have a dedicated team or even guidelines.”).

Other professionals (5 out of 33) say they do not know how to answer this question because they are having trouble understanding what is really meant by using palliative care, not knowing what it really is and what it consists of (M5: “No, is there palliative care?”; I1: “I can’t give you an answer, because I don’t know what it does.”).

#### *b. Usefulness of palliative care in resolving critical issues*

The majority of professionals (25 out of 33) believe that the application of palliative care is useful in resolving various critical issues present in everyday

work: - fewer worries about the emotional management of patient and family suffering; - fewer doubts about the interventions and the management of some symptoms such as pain and the use of analgesics; - a shared management necessary to work in an integrated manner to safeguard the patient; - avoid unnecessary hospitalisations and too much technicality (I10: "Yes, absolutely yes, help the patient at that time, but also help the awareness and the accompaniment of family members, so it becomes a type of shared management in the phase of terminality and suffering. It is absolutely primary for us, precisely to work in a complete manner and to safeguard the patient.").

A minority of professionals (5 out of 33) have strong doubts about the fact that palliative care can resolve daily critical issues (T1: "But I do not think it works with the big problems to be faced every day that have to be solved"; M6: "No, I do not think it can solve problems.").

#### c. Availability to open up to new ways of treatment

Despite the different points of view, most of the operators (24 out of 33) declare that an attitude of readiness to innovate is necessary, with a view to the usefulness of learning, and of being able to work better in a team. For example, some professionals propose the introduction of a psychologist into their structure or the possibility of using palliative care not only in the terminal phase of illness but also in the early phase (I1: "Of course, our work is also based on this: we need to be able to accept new things and above all put them into practice.").

#### d. Availability of the working context to open up

However, most professionals (20 out of 33) think that their colleagues would support the introduction of palliation, as the idea that it is useful is shared and there is a lot of sensitivity on the subject. It is very noticeable availability especially by nurses.

Some professionals think it is a way to confront problems, but the need for skills and training also emerges (I12: "I notice enlarged sensitivity with respect to these treatments; some people don't know them but they understand their necessity.").

Many professionals, however, point out that for some colleagues a lack of knowledge prevails, since one does not invest in a specific formation and in the course of studies one does not speak about it; others have distorted knowledge, as they link palliative care

only in relation to cancer patients; others consider it a real taboo (M12: "Some people do not really know it, in particular the general practitioners who should be the most interested.").

Only two operators point out how, in the structure in which they work, there is a lack of comprehension on this issue and that they do not talk to colleagues about this topic (I7: "I do not know, we never talked about it"; P3: "I do not think there is, we do not talk about this topic.").

Only one operator declares that his colleagues would be opposed to the use of palliative care in the structure in which he works (I9: "All my colleagues are against it!").

#### e. Urgency in the application of palliative care

Many professionals (10 out of 33) believe that palliative care should be urgently applied and are driven by important motivations: - feeling powerless next to patients who suffer; - wanting to give patients a better quality of life and end of life; - being able to respect the wishes and needs of patients and their family members (M4: "I would say that it is very urgent: the goal of quality of life is fundamental.").

Some professionals (4 out of 33) consider it necessary, but refer only to the application of palliative care in the terminal phase of disease, and, even then, according to the classic application (I12: "It is urgent, but certainly not immediately when the person is still in good condition.").

A small number of respondents (8 out of 33) agreed that the real urgency is not in having to apply, or not having to apply palliative care, but in other priority issues (no urgency). This is linked to the fact that, on the one hand, there is little time available to be able to insert palliative care into everyday work practices, on the other hand, there is a belief that something like this is already being done as part of patient care, and that this is sufficient (I6: "It would be a good idea, but it is not really urgent"; T1: "In my opinion there is no high urgency.").

### 4. Resistance to the application of Palliative Care

#### a. Slow and difficult diffusion of palliative care

All respondents think that the diffusion of palliative care is difficult and slow because:

- a biomedical model predominates, in which there is no wish to surrender to the disease and the triumph of death over life (M3: *"There is no mentality, in the sense that one does not speak of death. So if you do not talk about death you can't even talk about palliative care."*); - the company is characterised by an interest in pharmaceutical companies and politics; - in health-care facilities, assistance is hasty; there is a lack of time and of staff expertise in this matter; there is still a lot of confusion on the subject because - as mentioned - there is no training and there is little interest from health professionals in this developing area of medicine that (T1: *"In my mind, there is a lack of adequate training. I think there is a reduction in staff and an increase in the user base that causes us to run in all directions without being able to devote time to important things, such as, for example, the introduction of palliative care."*). On the other hand, the Catholic culture is deeply rooted in the value assigned to life, in which the idea that man must bear earthly suffering predominates (M4: *"Because of the Catholic Church. The diffusion of palliative care is culturally hampered by the fact that it is confused with the definition of port to death, the last days of life. In Italy, a country so rooted in Catholic culture, there is a perception of pain as being the way to salvation"*). Palliative care is also linked exclusively to the end of life, It is lacking laws and well-defined guidelines to allow professionals to work in the best way (P1: *"I often see that nurses are more concerned with administering therapy or writing up deliveries and do not evaluate everything that is around the patient, because, unfortunately, they don't have the time."*).

#### *b. Resistance to the application of palliative care*

Some professionals (7 out of 33) argue that the resistance is mainly cultural: the idea is that it is caused by the prejudices present in our society, also influenced by the Catholic Church and the fear of communicating to the patient and family members the diagnosis of an incurable disease. In a society where commitments are deemed to be burdensome and highly empowering, selfishness and rejection of disease seem to be predominant (I12: *"We live in a society influenced by the Catholic religion that causes poor integration with palliative care. Also, there is an extreme individualism devoted to power, beauty and non-acceptance of disease and death."*).

Other professionals (7 out of 33) think that the resistance is a consequence of the lack of training, which could be overcome on several levels: for example by informing people more, by training in the concepts and through master classes, conferences and congresses dedicated to palliative care. (M4: *"Training at 360°, with masters, conferences, seminars."*).

Some professionals (2 out of 33) attribute the resistance, not so much to the lack of training, but more to the personal motivation of the operators, as their ability to get involved (M7: *"Training is not enough to find the inner motivation and get involved with your first patient, because palliative care brings us close to death, a fundamental existential aspect of life; we need to find opportunities and tools that encourage motivation."*).

Some respondents (2 out of 33) think that the resistance is related to the use of morphine as it is considered as a drug that causes the death of the person and it is administered as the last resort, at the last moment, when it is often too late (M8: *"There is fear, yet someone sees morphine as killing ... we proceed to spot leopard, some know its use well, others not."*).

#### *c. Overcoming of resistance*

Almost all professionals (27 out of 33) think that training in palliative care would be essential and fundamental: it would help to overcome resistance and could change the cultural model. Training is therefore seen as a cornerstone to ensure dignified care and professional growth in step with the times, not based on prejudice and the classic "ways of doing things" that are now obsolete and outdated (I10: *"Training and information at the various levels of the profession are urgent ... Training must be understood by all the actors involved, because each actor has a precise and important role in the implementation of palliative care."*).

To overcome the resistance, some professional operators (6 out of 33) think that the key can also be found in communication with family members and professionals, in an exchange of ideas, in a social network, which is open to the sharing of choices and experiences (M8: *"We need to involve family members in the choices ... every day there should be an exchange of information that can make a common understanding grow."*).

## Conclusion and Discussion

From the literature, a theme emerges that palliative care, in the current context, is mainly addressed to cancer patients in the terminal phase of their life (23). However, epidemiological data show how the demographic transition expected in the coming years will lead to a significant increase in the number of people with chronic diseases (9). Da questi dati, si evince quindi come il problema sia ancora sottostimato.

The analysis of the scientific literature shows, on the one hand, a lack of studies in this area, but at the same time, the intent of palliative care experts to extend such care even to people suffering from chronic-degenerative diseases (24, 25), providing an integrated approach with pharmacological therapies from the initial stages of diagnosis (26-28).

Based on these premises, the data emerging from this research show a wealth of information and specific aspects that make the results particularly interesting when compared to the initial objectives.

Most professionals, regardless of their professional role, think they know palliative care, but some only connect it with the terminally ill. Others have a wider vision, but it is based more on an abstract and theoretical level than on real practical knowledge. Knowledge of this subject seems to be, in summary, confusing and superficial. The answers of the professionals, regarding if and how palliative care is used within their own working reality, are most heterogeneous. A lack of homogeneity is noticed both between professionals working in the same structures and between those who carry out the same profession. This is due to a lack of knowledge of the subject and a lack of awareness of the application of palliative care in practice. There is a discrepancy between the individual availability of the professional and that of the work context, because, according to the perception of many interviewees, the context in which they work is still not very mature for the introduction of innovative ways of treatment. From this, it emerges that the availability of the individual is not lacking, but rather the tools and knowledge provided by the work context.

An important fact to underline is that, despite the confusion and the lack of knowledge, almost all the interviewees have a positive vision of palliative care,

considering it useful and necessary even in chronic patients. The issue of chronicity has brought out different opinions of the operators regarding the usefulness and urgency of the application of palliative care in this area. For some professionals, it is useful and urgent because its use could improve the management of symptoms, the overall care of the patient and their family and contribute to the development of a multidisciplinary team. For some professionals, palliative care is considered an innovative topic but not of primary importance. In contrast to these professionals, a much lower percentage does not consider it useful for chronic patients.

With respect to enforcement resistance, palliative care is still considered as to be a weak discipline. It is almost always associated with the concept of the end of life. The most common types of resistance, emerging from the analysis of the interviews, are those related to cultural factors, where medical biology predominates, and those related to the training deficit in this area. There is resistance linked to prejudice due to lack of knowledge, such as the fear of the use of morphine/opioids. This is because these drugs are usually associated with terminality and there is motivational resistance, linked to the personal sensitivity of each professional and his ability to engage in the discussion. It is interesting to underline that, from the point of view of professionals, resistance can be overcome by communication at various levels, highlighting how little work is done in the team and how little one considers the opinion of the patient and his family about his care.

Training is the basic key to the possible overcoming of resistance and to allowing palliative care to spread to different fields, such as chronicity. To substantiate this, there is the emergence of a strong will among the majority of professionals working with dementia, towards a change of model, in the awareness of being poorly prepared and with a sense of inadequacy in the management of critical issues.

In conclusion, the questions that arise spontaneously from this exploratory study are: *“What kind of professionals have we become and in what direction are we going?”*, *“As professionals and human beings, are we preparing to face and manage such a heavy burden of responsibility?”* The results show that there is a long way to go towards an awareness of the needs that chronic

degenerative diseases cause in patients and their families, and of their human and professional role in their fulfilment.

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# Distraction technique for pain reduction in Peripheral Venous Catheterization: randomized, controlled trial

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**Abstract.** *Background and aim of the work:* Procedural pain during Peripheral Venous Catheterization (PVC) is a significant issue for patients. Reducing procedure-induced pain improves the quality of care and reduces patient discomfort. We aimed to compare a non-pharmacological technique (distraction) to anaesthetic cream (EMLA) for the reduction of procedural pain during PVC, in patients undergoing Computerized Tomography (CT) or Nuclear Magnetic Resonance (NMR) with contrast. *Methods:* This is a Prospective, Randomized Controlled Trial. The study was carried out during the month of October 2015. A total of 72 patients undergoing PVC were randomly assigned to the experimental group (distraction technique, n=36) or control group (EMLA, n=36). After PVC, pain was evaluated by means of the numeric pain-rating scale (NRS). Pain perception was compared by means of Mann-Whitney Test. *Results:* The average pain in the distraction group was 0.69 (SD±1.26), with a median value of 0. The average pain in the EMLA group was 1.86 (SD±1.73), with a median value of 2. The study showed a significant improvement from the distraction technique ( $U=347$ ,  $p<.001$ ,  $r=.42$ ) with respect to the local anaesthetic in reducing pain perception. *Conclusions/Implication for practice:* Distraction is more effective than local anaesthetic in reducing of pain-perception during PVC insertion. This study is one of few comparing the distraction technique to an anaesthetic. It confirms that the practitioner-patient relationship is an important point in nursing assistance, allowing the establishment of trust with the patient and increasing compliance during the treatment process.

**Key words:** distraction, fear, peripheral venous catheter, procedural pain perception, local anaesthetic

## Background and aim of the work

Procedural pain is a clinical manifestation of intense episodic pain following a therapeutic intervention. This consists of transient exacerbations reaching an intensity peak within a few minutes, against the background of a persistent pain manifestation (1, 2). In everyday clinical practice, many procedures are carried out that cause pain for the patient (3). During any procedure including the use of needles, besides pain

reduction, it is fundamental to control fear and stress (4). Fear is the response to a perceived threat that is consciously recognized as a danger (5) and varies along a continuum from “none” or “very little” to a serious fear of needles (6).

A potential risk for patients during painful procedure could be vasovagal response. A vasovagal response consists of the establishment of bradycardia and arterial hypotension, presenting as vertigo, shock, syncope, tonic-clonic seizures, increase in pain sensa-



tions, excessive sweating and nausea (4, 7). For this reason, techniques were created for the rapid management of stress and fear (8). Many intervention possibilities, pharmacological or otherwise, decrease pain. Many can concretely help a patient to face and solve their own fear of pain. These techniques can be utilized with adults and can be carried out autonomously or in teams by nursing personnel (9).

Lynn (10) and Goodspeed & Lee (11), highlight the necessity, both for the nurses and for the patient, of adequate room during venepuncture. Adequate room allows space for the patient to lie down during the procedure, can reduce the risk of a vasovagal reaction, and allows for recovery time after the procedure. A peaceful space, where there is no feeling of oppression, would very much help the patient to face the situation with lower anxiety and fear. In addition, such a setting would favour establishing good nurse-patient communication, conducive to creating a positive trust relationship and fear reduction.

In order to reduce perceived pain, some pharmacological techniques are used. In a study carried out by Burke et al. (12), lidocaine 8.4% administered subcutaneously as local anaesthetic, before the introduction of a Peripheral Venous Catheter (PVC), resulted in more effective perceived pain relief than placebo. A systematic review carried out by Eidelman et al., found that the effects of a topically applied mix of lidocaine and prilocaine (Eutectic Mixture of Local Anaesthetics, EMLA) are superimposable with the subcutaneous application of lidocaine (13). The study also stated that using EMLA is preferred since it is less invasive. EMLA is indicated for superficial analgesia of skin in concurrence with superficial surgical interventions, insertion of peripheral venous catheters and for superficial analgesia of genital mucosa (14). In Italy, EMLA is primarily utilized in paediatrics to reduce pain associated with needle insertion. Its' application is an intervention that can be carried out by the parents or health care professional. Its' effect is actuated by means of a reversible block of conduction along the nerve fibre paths; the numbing effect extends for some hours after application (14).

As far as non-pharmacological techniques to reduce pain, the pain-free technique is utilized to carry out subcutaneous and intramuscular injections (11).

A novel solution described in the literature involves the combination of cold, vibration and distraction. The medical device used for this is called "*Buzzy bee*" (15). The device is shaped like a bumblebee, vibrates and contains an ice pack. The device is placed a short distance upstream of the venepuncture site, is turned on for the duration of the procedure, and manages to block nervous pain transmission, providing significant relief to the patient.

The Mindful Moist mouth technique maintains that, in order to reduce the bothersome sensation of a dry mouth caused by stress, it is sufficient to chew gum or squeeze the tip of the tongue, thus stimulating saliva production. Another solution is the use of stress balls as a distraction device. However, these devices primarily function to set up adequate breathing, since in times of anxiety and fear, breathing tends to become tachypneic.

The "*Three-step progressive muscle relaxation training*" behavioural technique is based on the approach of readdressing a person's attention, trying to let the muscles relax in three areas of the body: feet, knees and hands. Another technique that has the same objective of focusing attention away from the procedure is visualization. The most utilized method is that of geographic visualization, whereby the person is invited to mentally visualize a real or imaginary place that suggests a feeling of calm, tranquillity and safety (16).

Among the non-pharmacological techniques, distraction has been shown to be simple and of immediate application, while requiring no prior training (16,17). Distraction is not a passive strategy oriented to amuse the patient, but it is a way to focus their attention on an alternative stimulus, which allows for the modification of the patients' sensorial perception. By concentrating on something other than pain, the patient can distance himself from anxiety and fear. Any distraction should be appropriate to the patient's age and, wherever possible, reflect their interests and preferences (18).

While commonly utilized in paediatrics, such distraction techniques have grown in importance even among adults. This is demonstrated by several studies carried out internationally over the last few years (16, 17, 19-22). The distraction techniques described in the literature are physical exercise, concentration and

mental exercise. Various studies have investigated such techniques in paediatrics. MacLaren & Cohen confirm the efficacy of non-pharmacological techniques for the treatment of paediatric-neonatal pain (18). The reduction of anxiety and fear associated with pain, use of appropriate tools, and involvement of parental figures in symptom management are essential therapeutic elements that must always be integrated with medication strategies.

The aim of this study is to compare the effectiveness of non-pharmacological techniques (distraction) to pharmacological anaesthetic cream (EMLA) for reduction of procedural pain resulting from the insertion of a peripheral venous catheter in adult patients undergoing Computerized Tomography (CT) or Nuclear Magnetic Resonance (NMR) with contrast.

## Methods

### *Study Design*

We conducted a monocentric, randomized, open-label, clinical trial. For trial management, data elaboration and presentation, the CONSORT guidelines for reporting of randomized parallel groups trials were followed (23).

### *Primary Outcome*

Evaluating the reduction of pain perception when inserting a PVC in participants undergoing NMR and CT with contrast, possibly achieved by means of the distraction technique.

### *Secondary Outcome*

Evaluating the correlation between fear and pain when positioning the PVC, in participants undergoing NMR and CT with contrast.

### *Participants*

The participants involved in the study were people undergoing NMR and CT with contrast, not admitted to hospital and accessing the Complex Operating Unit

of Radio-Diagnostics of the Teaching Hospital Luigi Sacco in Milan.

### *Inclusion and Exclusion Criteria*

The selection of the participants followed specific inclusion and exclusion criteria.

#### *Inclusion criteria:*

- People aged 18 or over.
- Capacity to sign the informed consent in compliance with good clinical practices and current national laws.
- Outpatients and day patients.

#### *Exclusion criteria:*

- People with cognitive impairment.
- People unable to read and understand Italian.
- Hypersensitivity to the active ingredients or any excipients in EMLA.
- Congenital or idiopathic methemoglobinemia (contraindication to EMLA use).

### *Sample Size*

Based on the results of a prior study (17), the hypothesis was derived that patients treated by means of the distraction technique would have an average pain score of  $1.5 \pm 1.2$  as compared to patients without distraction but with EMLA, for which an average pain score of  $3.3 \pm 2.0$  was hypothesized. With an Alpha level of 5% and a power of 90%, it was necessary to analyse 27 people per group. Considering the possibility of participant drop-out, the sample size was increased by 30%, thus bringing the total number to 72.

### *Recruitment*

The study was carried out during the month of October 2015. All participants were recruited by one author (BI), who also collected all data. In the waiting room of the Radiology Operating Unit, the author explained the study aims, as well as the two main interventions characterizing it and collected written informed consent. Once consent was obtained, the patient was randomly assigned to a treatment group as detailed below. Participant recruitment and PVC insertion occurred in separate rooms.

### Randomization

Randomization was carried out by means of the blocks method, with blocks of 6. The randomization list was maintained in closed opaque envelopes. Envelopes were opened by the practitioner who performed the PVC after the participant had been declared suitable and informed consent was received. The randomization list was created online by means of specific software (<https://www.sealedenvelope.com/simple-randomiser/v1/lists>). The person who collected the data (BI) was blind to the randomization and therefore did not know its content.

### Location

The Radiology Division of the Hospital where the study was carried out supplies over 150 types of different radiological services. Specific competencies are present in diagnostic characterization of diffuse infiltrating pulmonary diseases, mammary pathology, pathology of AIDS, newborn's congenital dysplasia, chronic Inflammatory bowel disease and treatment of hepatic primitive tumours by TACE (Trans Arterial Chemo Embolization). The site was chosen due to the number of users accessing the radio-diagnostic services and making use of contrast, which clearly requires PVC insertion. These participants were outpatients.

### Procedure

#### *Experimental intervention*

The distraction technique consisted of formulating simple questions on different subjects (Table 1), with the possibility to give a free and articulated answer, thus distracting the participant from the invasive procedure in progress.

A guideline that the person tasked with collecting the data would have to follow was formalized in order to formulate questions. At the end of the procedure, the nurse asked the person to grade, in accordance with the Numeric Rating Scale (NRS), the pain perceived during the procedure.

#### *Control intervention*

Control intervention consists of the application of EMLA cream, which is the most frequently recommended medicinal analgesic during venepuncture (24). Participants were randomised into the control group. The cream was applied by means of a pressure dressing for 15 minutes at the venepuncture site, in compliance with the therapeutic indications of the local anaesthetic (25). Carrying out the rest of the procedure corresponded with the current procedures mandated in the operating unit where the study was carried out.

#### *Instruments*

Procedural pain was evaluated by means of the Numeric Rating Scale (NRS). This measure was car-

**Table 1.** Example of distraction topics utilized (Andrews & Shaw, 2010)

Topic	Discussion scenarios
Experience of a journey or a holiday	Description of places visited, emotions of that time, people that were with the patient at the time, and memories of particular experiences.
Hobbies or interests	Description of one's own hobbies or interests, whether they are shared with other people, how long is dedicated to such pastimes, whether the person practices or follows any particular sporting activities and how important is that sport in their life.
Relationship with caregivers or friends	Description of the person's family, children, grandchildren and, friends, of an amusing and/or moving occurrence experienced together with them.
Town the person lives or lived	Description of the town the person lives or lived in, the town's people and customs, of popular traditions and of the organization of cultural, educational and entertainment events in that town.
Feeling	Description of the participant's health or emotional status;
Sing a song	Ask the participant whether they want to sing a song, even if only in their own mind.

ried out immediately after the PVC insertion (12). Post-consent and prior to PVC, the patient was evaluated with respect to venepuncture fear by means of the Visual Analogue Fear Scale (VAFS)(26,27). All data collection cards were guarded by the authors in a room accessible only to them.

### Data Analysis

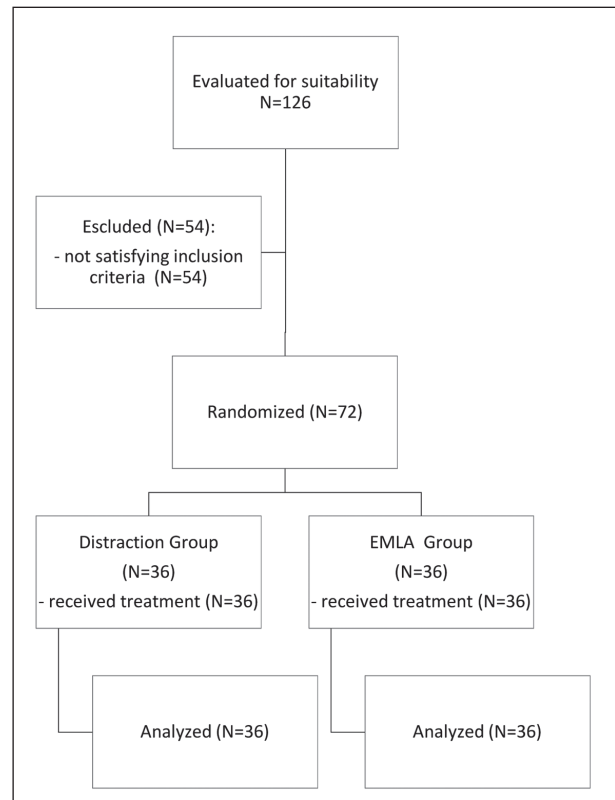
The data were collected in an Excel worksheet and described as numbers and percentages if qualitative, and by mean and standard deviation or median and interquartile range (where appropriate), if quantitative. Normal distribution for continuous variables was evaluated using the Shapiro-Wilk test. The continuous variables in the two groups were compared by means of Student's *t*-test if normally distributed; categorical variables were compared instead using Pearson's *chi-square* test. In case of non-normal distribution, the comparisons between the two groups were carried out by means of the non-parametric Mann-Whitney test. The correlation was evaluated between fear level and pain level in the two groups, by determining Spearman's *Rho* coefficient. For all statistical analyses, a significance threshold was considered as *p value*<0.05. Data analysis was carried out in accordance with intention to treat. Statistical analysis was performed with *SPSS*® version 21.0 (Chicago, IL, USA) (28).

### Ethical Considerations

The study protocol was approved by the Ethical Committee of the Teaching Hospital Luigi Sacco in Milan (Protocol no. 0019382 of 27 July 2015). Written Informed Consent was obtained from all patients included in the study, before their registration and group assignment. The study was conducted in compliance with the Helsinki declaration and with the current Italian legislation on privacy (29).

## Results

The sample was composed of 72 participants conforming to the inclusion criteria, chosen from 126 evaluated subjects. There were no dropouts from either group (Figure 1) and each patient was analysed in the assigned group, by means intention to treat analysis.



**Figure 1.** Randomization Flow Chart (Consort, 2010)

The average age of the distraction group was  $61.9 \pm 16.2$  years and  $63.0 \pm 13.25$  years in the EMLA group. Data analyses indicated the presence of 46 males and 26 females. 21 males (58.3%) and 15 females (41.7%) were assigned to the treated group, 25 males (69.4%) and 11 females (30.6%) to the control group. The majority of the people suffered from oncological pathologies. In addition, seven people were recognized as suffering from cardiovascular illnesses (19.4%) for both sub-samples, two from gastrointestinal pathologies (5.6%) in the treatment group and three (8.3%) in the EMLA group and finally, two people (5.5%) in the treatment group suffered from other pathologies. The most frequent venepuncture site was the antecubital area (basilic or median veins), where 68 PVC (94%) were positioned. Two PVC (3%) were inserted in the dorsal metacarpal veins and as many in the wrist area (cephalic vein).

In the treatment group the antecubital fold was chosen as the puncture site in 35 cases (97.2%), while the wrist was used only once (2.8%). In the EMLA

group: the elbow fold was chosen in 33 assisted people (91.7%), the back of the hand in two cases (5.6%) and the wrist in just one case (2.8%). The venepuncture site displayed no significant difference between the two groups ( $p=.357$ ).

The majority of subjects in both groups had previously had needles inserted (91.7% in the treatment group and 94.4% in the control group). This result was not significantly different between the two groups ( $p=.643$ ), neither was the gauge of the needle used ( $p=.827$ ). The two populations were superimposable for the main defining characteristics at the beginning of the study (Table 2).

Before inserting the peripheral venous catheter, participants were asked to rate their own fear level regarding the PVC insertion using the VAFS. The maximum fear level was 10 and the minimum 0. Statistical analysis showed no significant difference in

fear level between the two groups (Distraction Group: Median=1, First Quartile=0; Third quartile=5, IQR=5; EMLA Group Median=0, First Quartile=0; Third quartile=2, IQR=2;  $U=532$ ,  $p=0.156$ ,  $r=.17$ ).

After PVC insertion, pain was measured by means of the NRS. Values for the distraction group ranged between 0 and 2 with a median of 0. In comparison the EMLA group range was wider, 0-5.25 with a median of 2 ( $U=347$ ,  $p<.001$ ,  $r=.42$ ) (Table 3).

Thus, the distraction technique resulted in a significant improvement in reducing procedural pain in comparison to the control, as showed also in Figure 2.

We found a moderate, but significant correlation between fear and pain, with an  $r_{s(72)}=.247$  ( $p=.037$ ). As observed previously, fear levels were uniform between the two groups. Therefore, participants' fear from previous experiences did not influence pain perception during PVC insertion.

**Table 2.** Characteristics of patients included, venepuncture site and needle size

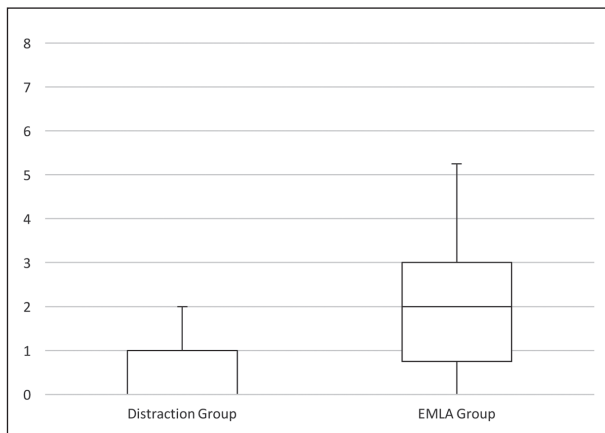
	Distraction group (N=36)	Emla Group (N=36)	p value
Age (Mean±SD)	61.9±16.2	63±13.25	.510*
Gender, N (%)	N(%)	N(%)	
Male	21 (58,3)	25 (69,4)	.326 <sup>§</sup>
Female	15(41,7)	11(30,6)	
Pathologies	N(%)	N(%)	
Oncological	25 (69.4)	26 (72.2)	.528 <sup>§</sup>
Cardiovascular	7 (19.4)	7 (19.4)	
Gastrointestinal	2 (5.6)	3 (8.3)	
Other	2 (5.5)	0 (0.0)	
Puncture site	N(%)	N(%)	
Hand back	0 (0.0)	2 (5.6)	.357 <sup>§</sup>
Antecubital Fold	35 (97.2)	33 (91.7)	
Wrist	1 (2.8)	1 (2.8)	
Previous needles	N(%)	N(%)	p value
Yes	33 (91.7)	34 (94.4)	.643 <sup>§</sup>
No	3 (8.3)	2 (5.6)	
Needle size	N(%)	N(%)	
18 Gauge	2 (5.6)	3 (8.3)	.827 <sup>§</sup>
20 Gauge	30 (83.3)	28 (77.8)	
22 Gauge	4 (11.1)	5 (13.9)	

SD= Standard Deviation; \* Student t test; <sup>§</sup> Pearson Chi-square test.

**Table 3.** Pain level after venepuncture

	Mean±SD	Median	Q1	Q3	IQR	p value
Distraction Group	0.69±1.26	0	0	1	1	<.001*
EMLA Group	1.86±1.73	2	0.25	3	2.75	

SD= Standard Deviation; \*Mann-Whitney Test



**Figure 2.** Pain perception in the two groups (Numeric Rating Scale=0 to 10)

## Discussion

Despite the lack of directly comparable studies, the present study is relatable to Mutti, et al. who investigated the decrease of procedural pain by means of the distraction technique, without a specific intervention as control (17). Results from the primary objective suggest that the distraction technique is not only more functional and non-invasive, but also cheaper, since its cost is zero. Furthermore, the technique has no side effects, as a medication might, and can be utilized with any patient. Distraction is a powerful non-pharmacological technique that is simple and immediately applicable and requires no special training (16, 17). As stated in the background, by concentrating on something other than pain, the patient can distance himself from anxiety and fear. This should also influence physiological reaction to fear and anxiety, reducing breath and heart rate and preventing vasovagal response. The open questions used to distract the patient's attention away from pain further serve the development of a positive relationship between nurse and patient (16,

17). Such a relationship can become essential in the patient's compliance with a specified treatment plan. It has been shown previously that the practitioner-patient relationship is pivotal in the treatment process (16, 17). Here we show that the distraction group median was 0 on the NRS scale and the EMLA group had a median of two ( $U=347$ ,  $p<.001$ ,  $r=.42$ ). These findings support those previously published and highlight the superiority of the distraction technique to either no-treatment or pharmacological treatment. Consistent with WHO Guidelines on the pharmacological treatment of persistent pain in children suffering from serious pathologies (30), this study confirms that acting on the multi-factorial dimensions of pain (emotional, behavioural and cognitive), can influence a patients' pain perception. Studies by Lotto & Alberio (7) and by Zengin, et al. (4), state that there is a correlation between fear and increased perception of pain sensations. The perceived fear level varies depending on the environment and of the procedure being carried out (4). The current study was carried out in an outpatient treatment setting, while the Zengin, et al. (4) study was conducted in the operating room. As argued by Zengin, et al. (4), the fear level shown by a person about to undergo a surgical intervention is higher than that of a person undergoing a less invasive procedure in an outpatient care context. This may explain the different correlation between fear and pain found in the two studies. Zengin, et al. (4), observed a strong correlation between the two phenomena, while we observed only a weak correlation between the two ( $r_{s(72)}=.247$ ;  $p=.037$ ).

The present study has some limitations that should be considered. Firstly, it is monocentric and involved outpatients. Secondly, since it is an open-label study, a possible detection bias should be considered. Finally, we didn't evaluate if the effectiveness of the intervention varies because of the questions provided. The results therefore, should be considered in light of

these aspects that could reduce their external validity. Despite these limitations, the distraction technique showed a promising effectiveness in the reduction of pain during PVC insertion.

## Conclusions

Standard approaches to the reduction of procedural pain perception in adults vary widely depending on the individual practitioner. Due to the ease of application, our study suggests that the distraction technique can be employed anywhere painful procedures are enacted. The distraction technique in the present study was more effective than a pharmacological intervention in decreasing procedural pain during the insertion of a peripheral venous catheter.

### *Future research*

Considering the results of the present study, it is interesting to evaluate the application to other pain-inducing interventions, such as: venous or arterial blood sampling, insertion of urinary catheter, mobilization, dressing change. It would also be useful in future, to compare among themselves different types of distraction, in order to evaluate the possible existence of different degrees of effectiveness among them, or to verify their efficacy in relation to the type of population on which they are used. In regard to the correlation between needle fear and pain, there are few studies comparing these phenomena in different environments, such as outpatient care, home care, hospital admission or operating theatre. In view of the scarcity observed in the literature, this could be a starting point for future research.

### *Relevance for clinical practice*

This study confirms the practitioner-patient relationship is an important point in nursing assistance, allowing the establishment of trust with the patient and increasing compliance during the treatment process. The present study is one of few comparing the distraction technique to an anaesthetic (31); therefore it constitutes a starting point for further investigations

with the benefit of being inexpensive and applicable to all. Finally, this study confirms that patients reporting fear of needles have, at some time in the past, been subjected to a painful experience, without adequate intervention on the part of health professionals. Therefore, we believe that, by using appropriate techniques to decrease perceived pain, it will be possible to prevent the development of future phobias, in addition to reducing the distress experienced in the course of the procedure.

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# Pain assessment in the Emergency Department. Correlation between pain rated by the patient and by the nurse. An observational study

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**Abstract.** *Background and aim of the study:* Pain is always present in the Emergency Department (ED), but is often underestimated. The primary purpose of this study is to analyze the degree to which the intensity of pain is underestimated or overestimated in the perception of the nurse and the patient in the ED. The secondary objective of this research is to study possible factors that lead to these discrepancies in assessment. *Methods:* The observational study was carried out in two Hospitals in Central Italy. The sample population was based on 130 patients and 26 nurses. A questionnaire was given to the patients who provided personal data followed by information regarding their pain, including an assessment of the intensity of pain on a scale from 0 to 10. A similar questionnaire was given to the nurses. *Results:* The average score based on the numeric rating scale (NRS) to assess the intensity of pain perceived by the patients is 6.16, while the numerical average estimated by the nurses based on their assessment is 5. Using the t test we found that the average between nurse and patient assessments was very significant. The analysis of the nurses' characteristics and professional experiences, age, years of employment and years of service in the ED are all significant variables affecting the discrepancy between the nurses' and patients' assessments of pain. As previous studies have shown, nurses tend to underestimate the degree of pain. In fact, in only 55.5% of the cases was there a correspondence in the evaluations of the intensity of pain done by nurses and patients, and in no case did the nurses' evaluation exceed that of the patients. *Conclusions:* This study reveals the persistent difficulty in pain management, while attempting contemporaneously to communicate the importance of the assessment, since adequate understanding of pain renders it possible to recognize and treat it.

**Key words:** Emergency Department, nurse, pain, pain management

## Introduction

Pain, whether sudden, acute, or chronic, is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage." (1). The occurrence of pain is one of the main reasons for patients to seek aid from the Emergency Department (ED) (2, 3). As much as 70% of ED cases are due to pain (4). Despite these statistics, pain is not always properly

treated and is sometimes underestimated (5). Though there are many campaigns and training programs to sensitize health care providers to the correct assessment of pain, this symptom is sometimes inadequately considered, resulting in oligoanalgesia of the patient (6).

The reasons why pain is not immediately managed with medication or recognized by caregivers in the ED may be explained by adverse effects which may result

from the use of some medications; the risk of masking signs and symptoms, thus leads to misdiagnosis, and lack of trust in the patients' own expression of pain (7).

Furthermore, EDs are often subject to overcrowding which results in long waiting time before patients receive specialized ambulatory treatment or diagnostic exams. Overcrowding may prevent the nurse from providing correct pain management, adequate assessment and timely treatment (8, 9). Crowding in the ward is the main cause of mistaken pain assessments: the nurse is unable to focus on a correct evaluation of pain intensity due to the disorderly atmosphere typical of emergency wards, characterised by long waiting lines. This pushes the nurse to base assessments more on objective symptoms rather than on pain, a highly subjective and personal factor which is underestimated and not considered as a fifth vital sign. A proper assessment of pain is the first step towards alleviating and treating pain (10), yet this fundamental truth is often underestimated by doctors with respect to the patients' expressed degree of pain (11). Underestimation of pain occurs even among nurses responsible for triage as they accept patients into the ED (12, 13). This may result in many negative outcomes for the patient who foremost is not receiving analgesic medication, or experiences delay in receiving medication (14). A major recognition of pain by the nurse derives from a greater sensitivity to pain and the importance of its treatment, starting from a greater awareness of the great gap between the nurse's assessment and what the patient feels.

## Objectives

Nurses have to undergo pain sensitivity training in order to be aware of the big difference that exists between their assessments and those of the patients so as to be able to minimise it. The aim of this study is to determine the congruence between patients' and nurses' assessments of pain intensity in two Italian EDs.

## Materials and methods

Data was collected from October to December 2015 in two EDs in the hospitals in Foligno (Perugia)

and in Assisi (Perugia), second-degree and third-degree level facilities, respectively, in Central Italy.

## Design

The methodology adopted for this study was a descriptive cross-sectional study of a purposive sample of ED patients who came to the department with a primary complaint of pain, and a convenience sample of emergency nurses.

## Sample

In order to select a sample population, criteria of inclusion and exclusion used in previous studies were applied (12,13). The criteria of inclusion for participation of patients in the study are as follows:

1. Age  $\geq 18$ ;
2. Subjects whose lives are not in immediate danger or in such critical condition as to require immediate recovery and urgent care;
3. Patients capable of understanding and using the NRS.

The criteria of exclusion that prevent participation of patients in the study are:

1. Subjects whose lives are in immediate danger or in such critical condition as to require immediate recovery and urgent care;
2. Patients incapable of using the NRA due to difficulty in communicating, mental disabilities, learning disabilities or those suffering from dementia;
3. Prisoners or young offenders.

The only criteria for inclusion of nurses was at least six months of service completed in the ED, applicable as well to the nursing coordinator in the emergency unit.

The nurse-patient ratio is 1:5 while in previous studies the ratio was 1:4; however, the number of nurses and patients was greater in previous studies (12, 13).

Furthermore, in order to avoid potential errors in the selection of the available sample and to maintain the greatest possible objectivity, the researcher was not permitted to deliberately choose participants.

### *Instruments*

Data gathering was done with two tools: two specifically designed datasheets, one for the patient and another for the nurse. Particularly, two data sheets were completed: one by patients seeking assistance from the hospital and one by nurses responsible for triage. The patient's data sheet includes a personal section followed by a part concerning pain, which describes what kind of pain it is, and if it is a referred pain or localized pain – in this case the exact origin is required (for example musculoskeletal, abdominal, or chest pain, etc.). The duration of the pain is established, and if the pain is acute or chronic, the patient evaluates his level of pain. Pain was calculated on a horizontal numerical scale, therefore, measurement of pain intensity was added to the study-specific protocol and the numerical rating scale (NRS), with the endpoints 0="no pain" to 10="worst possible pain," was used (NRS categories are 1–4 mild pain, 5–6 moderate pain and 7–10 severe pain). The NRS has been validated and is a reliable instrument to use in an active setting (15) and its use in EDs is preferable to the VAS (Visual Analog Scale). Though results often overlap between the two measurement instruments, the former is better known and easier to use (16). The tool used for pain assessment, that is, the NRS, is already being used in the aforesaid hospitals.

The nurse's data sheet is the usual triage record for the patient's admission in the Emergency Department. In fact it is composed of personal data of the nurse that includes information about post-university education, working years, years of service in the ED, and participation in training courses on assessment and treatment of pain. The second part concerns the pain evaluation that the nurse makes concerning the same patient, using the NRS. It was not necessary to obtain the Research and Ethics Approval because the triage record was already in use in the two hospitals.

### *Procedure*

Upon access to the ED, a third party informed the patients of the procedure of the research and asked if they were willing to participate. Consent to provide data was equivalent to consent to participate in the re-

search project. After obtaining the consent, the nurse asked the patient to give the information on pain and drafted the corresponding data sheet. Therefore, the patient access the triage area and is evaluated by the triage nurse who completes the data sheet concerning the pain of the same patient. However, the nurse decides the score of the NRS in advance, without knowing the rating given by the patient to the nurse stationed upon access to the ED.

### *Planning and development of the study*

The compilation of the questionnaire and collection of data, which contained a series of questions regarding the educational and professional background of the interviewee, was designed in such a way as to ensure anonymity and respect Italian laws on privacy. The data sheet forms an integral part of the triage record that each nurse has to fill out for the patient's admission in the triage area. That is why the Research and Ethics Approval was not required since the triage record was already in use in the two hospitals.

### *Statistical analysis*

The data was organized on an Excel 2007® spreadsheet (Microsoft Corporation, WA, USA) then elaborated according to the statistical program Stata 14.1 (Copyright 1996–2015 StataCorp LP, 4905 Lakeway Drive, College Station, TX 77845 USA) applying the Pearson  $\chi^2$  Test, and the Fisher Exact Test, with an expected significance level of 0.05. "Pwcorr" command was used to obtain pairwise correlation coefficients between the variables ( $p < 0.05$ ).

## **Results**

From October to December 2015 there were 255 pain-related accesses in the ED in the hospitals in Foligno and in Assisi (Italy). Particularly, 85 took place in the ED in Assisi and 170 in Foligno, differentiating 16 red codes, 59 yellow codes, 80 green codes and 100 white codes. In accordance with the criteria of inclusion and exclusion, only the pain-related green and white codes were taken into account for this research survey: there were a total number of 180, and were excluded the patients with difficulty in communicating

**Table 1.** Differences between nurse and patient average (SD) NRS Scores

	n	Mean - (IC)	Min	Max
Nurse	126	5 [4.688 - 5.312]	2	9
Patient	130	6.16 [5.825 - 6.445]	2	10
Diff.	126	0.913 - 1.357] *		

\*p<0.0001

Legend:

- n=number of observations of the pain;
- Min=the minimum score observed by nurse/patient using the NRS;
- Max=the maximum score observed by nurse/patient using the NRS;
- Diff.=difference between the observations of the nurse and patient

Note: there is a difference between the number of observations of the nurse and patient because there are four cases of "pain not observed."

and cognitive deficits. Among all these accesses, 130 cases were selected randomly that were then submitted to the statistical analysis.

A total of 130 patients and 26 nurses participated in providing data. The mean regarding data on the NRS to assess intensity of pain perceived by patients was calculated at 6.16 (SD 1.74) while the average assessed by the nurses was 5 (SD 1.77). Furthermore, while the

minimum numerical value attributed to intensity of pain was 2 for both nurses and patients, the maximum value expressed on the NRS was 10 for the patients and 9 in the assessment of the nurses (Table 1).

With the use of the t test it was possible to determine the average difference between the assessments of the nurse and patient, thus showing that the difference between the two assessments was significant (p<0.0001).

The observation of the assessment of pain by patients and nurses (Table 2) reveals that 18.25% (23 cases) of patients were confirmed to suffer mild pain, 30.95% (39 cases) moderate pain and 50.79% (64 cases) severe pain. Nurses assessed 45.24% (57 observations) as mild pain, 30.95% cases (39 observations) as moderate pain, and 23.81% cases (30 observations) as severe pain. Thus it was possible not only to note a tendency in nurses to underestimate the degree of pain but even in cases where patients assess the pain as severe. The difference in assessments between nurses and patients was statistically significant (p<0.001).

In examining results concerning the level of incongruence between the assessment of patients and nurses, an attempt was made to analyze the characteristics of the individual nurse and his or her professional and educational experience through the use of

**Table 2.** Pain assessment of patients and nurses

Patient \ Nurse	NRS			Total
	1-4	5-6	7-10	
<i>NRS 1-4 mild pain</i>	23*	0	0	23
	100.00	0.00	0.00	100.00
	40.35	0.00	0.00	18.25
<i>NRS 5-6 moderate pain</i>	22*	7	0	39
	56.41	43.59	0.00	100.00
	38.60	43.59	0.00	30.95
<i>NRS 7-10 severe pain</i>	12*	22*	30*	64
	18.75	34.38	46.88	100.00
	21.05	56.41	100.00	50.79
<b>Total</b>	7	39	30	126
	45.24	30.95	23.81	100.00
	100.00	100.00	100.00	100.00

Pearson chi-squared test=64.6850

P<0.001

\*P<0.05

**Table 3.** Individual correlation variables to the level of congruence in assessments

Variabile	R value
Age of nurse	-0.3234*
Gender of nurse (M=1 ; F =2 )	0.0104
Years of employment	-0.2841*
Years in Emergency Service	-0.3065*
Courses in Pain Management	0.1154

\*p&lt;0.005

the Pearson correlation coefficient (Table 3). The questionnaire compiled by the nurse provided the factors for analysis including age, gender, years of employment, years of service in the ED and possible participation in specific training on pain management and assessment.

The age of the nurse, years of employment and years in Emergency service are significant in so far as these three factors are inversely proportional to the level of congruence in assessments. The greater the age of the nurse, and the higher the number of years of employment and time worked in Emergency Departments, the higher is the difference in the evaluation of pain assessments of nurse and patient.

## Discussion

Among pathologies most often found in EDs, a rating of pain intensity above 6 is considered as severe pain (17). In a previous study (12) the average intensity of perceived pain by patients was 7.5 in triage while nurses rated the level at 5.1. Successively, in 2008 Martin Duignan and Virginia Dunn (13) repeated the statistical analysis and found that the patient's average intensity rating was 6.45 while that of the nurse was 5.2. Our study resulted in a calculation of patients' average assessment of intensity at 6.16 while the average pain rated by nurses was 5. Thus, the patient's average of 7.5 found by Puntillo undergoes a progressive decrease to 6.16 with a corresponding decrease from levels of severe to moderate pain. Similarly the average assessment of the nurse decreased to 5. However, in this case, there is less discrepancy between nurse and patient in assessments of lower values. In the Duignan

study (13) 45% of the nurses assessed the category of their patients' pain differently from that of the patients themselves; in 90% of the cases the rating was lower. In only three cases did nurses overestimate in comparison to the patients' assessment. In the present research study, 55.5% of the nurses estimated a degree of intensity congruous to that estimated by the patient but in no case did the nurse overestimate. Having found under-assessment, Baharuddin (18) could attribute this underestimation to the context and general environment of the ED: overcrowding in EDs could be a factor that leads to indifference among caregivers towards pain, and thus to underestimation and undertreatment.

Every patient when turning to the ED for assistance does not always desire medication to alleviate the pain (19). Only half the number of patients who turn to EDs due to pain, request and receive analgesics and among these the majority express satisfaction with hospital services (20, 21).

Unlike similar studies (13), ours correlates the demographic characteristics of nurses to the variables in assessment of pain. This study concludes that age, years of employment and years in Emergency service are detrimental to congruence in assessment by nurse and patient resulting in a wider divergence between points attributed to the degree of pain.

It is still the case that overestimation of pain occurs among young, inexperienced nurses, while, on the contrary, nurses with long experience tend to underestimate pain (22).

Use of nursing protocols for pain management with implementation of medication can reduce intervention delays and the occurrence of oligoanalgesia (23, 24), for pediatric patients also (25, 26).

In any event, difficulties in pain assessment may not always be due to problems related to caregivers in EDs. Marco et al. (27, 28) conducted several studies regarding the self-reporting of pain correlated to a number of demographic factors particular to the population. Higher pain scores were significantly correlated with younger age and the number of ED visits in the previous 12 months. Female gender, African race and patients with Medicaid coverage similarly reported higher scores. Nevertheless, gender alone does not significantly influence pain scores among patients coming to EDs (29).

## Limitations

Our study has several notable limitations. The main is that it was conducted in two hospitals in a single geographical region, and the results may not be generalized to include other locations.

## Conclusions

This study demonstrates how difficult it is to assess pain in EDs. The nurse, in fact, tends to underestimate the patient's pain intensity level, as shown by the results of this survey, and by many other articles in literature. The combined use of pain measurement with the same tool by the nurse and the patient would allow a step forward to be taken towards raising awareness of professionals to such a delicate topic. The measurement of pain by both parties will stimulate the nurse in realising the difference between her assessment and that of the patient. Moreover this would imply a reduced oligoanalgesia since the nurse, upon noticing the level of pain declared by the patient, will tend to pay greater attention to the fact. The nurse's pain assessment has to be based, in fact, essentially on what the patient says - pain is totally subjective and only the suffering person is aware of it - supported by other parameters regarding the opinion and critical sense of the nurse who observes, speaks to and interrogates the person. If these criteria are complied with, the gap between the nurse's pain assessment and that of the patient can be bridged. This will trigger greater sensitivity of nurses to the issue of pain, help in creating a stronger therapeutic rapport with the patient, and reduce the oligoanalgesia phenomenon. To favour this change, we would need to organize a training course that can involve the nurse firstly as a person, and then as a healthcare practitioner. A training path has to be set to show nurses the real status of pain assessment in the ED, the evident underestimations, the causes that lead professionals to size down the points referred by patients and the consequences of this fact. This study moreover offers a further contribution to increase nurses' awareness and greater attention to recognizing pain. Good documentation can lead to good pain management, while

a lack of adequate awareness acts as an impediment to pain assessment.

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# The lived experience of parents whose children discharged to home after cardiac surgery for congenital heart disease

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**Abstract.** *Background:* Congenital Heart Diseases (CHDs) afflicting children are estimated in 8 per 1000 live births. Recent advances in surgery and medical treatments allowed an improvement in survival rates leading to changes in diseases management as chronic conditions. Parents involvement during clinical pathways is considered an essential component of care, but frequently they experience stress and anxiety conditions during the care path. These feelings are typical of the pre and peri-operative period, however they don't disappear easily and sometimes they can increase after hospital discharge, affecting the family environment and its behaviors. *Aim of the work:* The purpose of this qualitative study is to examine the lived experience of parents during the time just after their children return home from hospital after undergoing surgery for CHD. *Methods:* Parents were enrolled and interviewed as a prepositive sampling until concept saturation using Cohen's phenomenology approach. A quantitative approach was also applied using SF-12 questionnaire. The study was conducted in two Italian hospitals: the Pediatric Heart Surgery Center of the Fondazione Toscana G. Monasterio Institute in Massa and the Pediatric Cardiac Surgery Center of the Federico II University Hospital in Naples. *Results:* The main themes emerged after the analysis were "happiness and uncertainty"; "chronic psychophysical fatigue"; "the rediscovery of a strong link with health care professionals". *Conclusions:* Fully understand the life experience of these families will allow the implementation of targeted health interventions through the implementation of shared strategies and tools to reduce families and children discomfort after hospital discharge.

**Key words:** parents, qualitative, children, congenital heart disease, experience

## Introduction

The current prevalence of Congenital Heart Disease (CHD) is eight children per 1000 live births (1, 2). The involvement and support of parents of sick children is an essential component of care and is universally recognized in the delivery of correct holistic

assistance by nurse (3). In the last ten years researchers have recorded a net improvement in survival rates of patients undergoing pediatric heart surgery interventions (4). The recent advances in cardiac surgery and pharmacological treatment have been shown to be increasingly effective in treating major congenital heart disease and to be able to change life-threatening



illnesses in chronic diseases (5, 6). Regardless of the type of heart defect a child has, families of children suffering from CHD experience anxiety and stress (7, 8). These feelings are typical of the pre and peri-operative period (9), however once at home, these feelings do not always disappear. When these children return home, mothers, who are often the primary caregivers, experience an increase in workload (10). This is inevitable given the fact that they must work night and day, and this generates additional stress from sleep disruption and chronic sleep deprivation (11). Fear and stress can lead to the development of acute stress disorder (ASD) and post-traumatic disorder (PTSD). Moreover, as with many caregivers of chronic pathologies, a social isolation begins that amplifies the perception of depressive disorders. Parents of children with CHD also reported higher levels of psychological symptoms, such as stress, anxiety and depression, than parents of healthy children (12).

This workload and the negative feelings that may arise within the parental dyad during a child's return home from hospital may affect the family environment and also the child him/herself (10, 13, 14). The children of parents that suffering from PTSD have a greater risk of developing sleep and eating disorders with consequent increase in the number of hospital accesses (12).

The purpose of this study is to understanding the lived experience of parents during the time just after their children return home from hospital after undergoing surgery for CHD.

## Methods

### *Theoretical basis and sampling*

For the purpose of conducting this study, we used the phenomenology of Cohen (15), which unites the descriptive phenomenology of Husserl and the interpretative phenomenology described by Gadmer. We chose this method in order to obtain a deeper understanding of both the lived experience and the meaning that people attach to that experience (16).

We used purposive sampling to recruit participants within two hospitals where children were given

cardiac surgery. Participant meeting the following inclusion criteria were enrolled in the study:

- 1) participants had to be considered by Italian law to be "of age";
- 2) had to be able to speak and understand Italian;
- 3) parents had to discharged as a result of surgical intervention from one to three months preceding the interview;
- 4) they must have expressed their willingness to participate in the study through signing a form to give their informed consent.

The exclusion criteria were: 1) the unwillingness to participate in the study; 2) the willingness to withdraw from it (at any time).

We informed participants that they could withdraw from the study at any time and that this would not compromise the assistance delivered by the hospital in any way.

We guaranteed total anonymity and explained the study type, its aims, and the mode of data collection, analysis and retention. This study fully complied with the principles of the Declaration of Helsinki.

### *Data collection and analysis*

Before data collection, each researcher involved in the study ran a "bracketing" procedure in accordance with the methodology. That is, each researcher transcribed their own prejudices about the topic with the purpose of to set aside it, so that their extrapolation of the themes would not be unduly influenced by their personal attitudes and beliefs (15).

After this phase, four authors conducted the first in-person interviews. Researchers contacted the parents of the children who underwent *cardiac surgery* intervention a few days before their discharge to mention the study and ask their permission to be reconducted. After spending a month after discharge, researchers contacted the parents and made an appointment for interview. The interviews were conducted in a place chosen by participants in order to put them at ease.

Researchers conducted the interviews through a single open question in order to give maximum freedom of expression to participants (15). For the entire duration of the interview, interviewers maintained a welcoming attitude in order to facilitate honest and

open description of experiences. All interviews were audio-recorded. During and immediately after the interviews, researchers recorded notes in their research diaries and made field notes on the environment, interview, body language and their reflections. All interviews had a duration of about 30 minutes. We reached data saturation (17) at the 24th interview.

After participants signed the informed consent form, interviewers gathered all of their socio-demographic information and administered the SF-12 questionnaire (18). The SF-12 questionnaire is the short version of the SF-36 questionnaire (19). Using 12 of the 36 original questions, it asks participants to answer how it feels and how it is possible to carry out normal activities of living, considering the day on which they completed the questionnaire and the previous four weeks. Its score is composed of two synthetic indexes, the Physical Component Summary (PCS) and the Mental Component Summary (MCS). The advantages of this questionnaire, which is recommended for self-administration, are its brevity and relative ease of use. This instrument has been translated and validated for the Italian population (20, 21).

The interviews were transcribed word for word. All researchers immersed themselves in the data, reading and re-reading interview transcripts and field notes in order to proceed with the extrapolation of the themes. All themes were discussed among researchers until they reached an agreement. There were not discrepancies in this phase the validity of themes was obtained by requesting confirmation from the participants who were interviewed. All participants verified and confirmed the accuracy of the themes we extrapolated. The last phase of the analysis was the drafting of this manuscript.

## Results

Participants were mainly women (75%), who were mothers of children who underwent cardiac surgery. The average age of the sample was approximately 38 years, and participants had a middle to high level of education. Almost all subjects were married or cohabiting and half had other children, but no one with congenital heart disease. The average duration of the hos-

pitalisation of participants' children was about 37 days, with a range between three and 120 days. At discharge only one child was resigned with device (Table 1).

Results of our start up analysis through the SF-12 administration are summarized in Table 2.

From analysis of the interviews, four main themes emerged. These were happiness and uncertainty about their child's return home, chronic psychophysical fatigue, the rediscovery of a strong bond with health operators and the desire to control their children constantly. Also, in parenting dyads to "first experience" to these main themes there was a sub-theme of constantly monitoring the weight of the child.

### *Happiness and uncertainty about the return home*

All participants described an initial feeling of joy upon returning to their homes. However, the whole sample admitted that immediately after this joy was a feeling of fear that could be characterized as uncertainty. The return home represented to participants the reconquest of their spaces and habits and the reconquest of healing, but participants also described the feeling of being alone with their child. They felt that they had lost the immediate support of the entire team of caring hospital staff. A quotation that illustrates this main theme is: "...that is beautiful, back home, at last! Your home is always your home, even if at the beginning I was not for nothing quiet...the day of discharge I was almost terrified, a thousand questions, a thousand fears... joy and then still afraid...two things so opposite that lived together inside me..." (AZ01).

### *Chronic psychophysical fatigue*

Another common theme present in the accounts of all participants was the feeling of chronic psychophysical fatigue. For all participants, the return home generated an increase in their workload that led to chronic tiredness. Participants described this tiredness as both physical and mental. Participants said they felt trapped in a vicious circle generated by an overload of work, just as a mother told us, "now as it is now a bit better ... but I've always been tired ... my body, my mind, I always head with my child, a thousand thoughts, we had to care for all, trivial things and more serious... wash it,

**Table 1.** Socio-demographic characteristics

		Frequency	Percentage	Mean (DS)	Range
Age				37.18 (8.976)	18–49
Parental Role	Father	6	25%		
	Mother	18	75%		
Highest Level of Education	Elementary	4	16.7%		
	Middle	8	33.3%		
	Hight	2	8.3%		
	University	10	41.7%		
Civil Status	Married	16	66.7%		
	Single	2	8.3%		
	Cohabiting	6	25%		
Other Children	Yes	12	50%		
	No	12	50%		
Other Children with CHD	Yes	0	0		
	No	12	100%		
Religion	Catholic	24	100%		
Average Hospitalisation Days				37Dd(25.39)	(3-120)
Resigned with the Deans	No	23			
	Yes	1	4.1%		

**Table 2.** Average SF12 Score

SF-12	Mean ( $\pm$ SD)
PCS	42.9 $\pm$ 10.2
MCS	42.7 $\pm$ 12.2

*change it, follow every his step. In the night you no more sleep, a little to control him, a little for the thoughts that slip into your head. Then suddenly it comes again in the morning and starts ... home, husband, the child and other thousand things, in short this cycle never interrupts ...”*(BX02).

#### *The rediscovery of a strong bond with health operators*

Almost as a consequence of the first theme extrapolated, study participants admitted to having noticed the absence of healthcare professionals dedicated to the assistance of their child. That presence that seemed superfluous now makes its absence felt. Professionals dedicated to helping silently had become part of their everyday life and had become almost like family. A mother told us, “...and then...suddenly...here

*is to think of those nurse...you find them on the internet, the calling, you realize that you are missing their words, those words that have given to you the strength to face the difficulties, to go forward and be serene here today...it is true it is their job but is a sensation beautiful have the certainty that some of them...can you say friends? In short we became friends...and I am happy...”*(EU05).

#### *Wanting to control constantly*

Another theme emerged is that participants felt a constant need to check everything that happened and everything that rotated around their child. Initially, this seemed to be a desire to enjoy the moment since the danger had been escaped, participants had new vision for the little things in life. Then, for all participants, this seemed to transform into a constant desire to control their child so that everything was under control and nothing could disturb what they expected. This constant control seemed to be parents' response to their fears, as reported by one of the participants, “...I want to enjoy every moment, I do not think to tomorrow or to the future...I want to live my son one day at a time

*without thinking about other things... I would like to be with him when he is in school when he plays at the park when he relates to others ... in short, at any time of the day, but unfortunately sometimes it is not possible.... and I feel terribly guilty of this.... because I think that she could be feels bad ... when I'm with him I have everything, I have everything..."(A1).*

#### *Constant monitoring of their child's weight*

The theme that emerged only in those who participated in the "first experience" was constant weight monitoring. The parents of children who underwent cardiac surgery for the first time and discharged waiting a possible second intervention reported this theme. It seems that for them, weight was a fundamental parameter, it is immediately measured for the purposes of correct management at home. To proper preparation for a new shelter is only the weight of your baby. A participant told us, "...I know that it is strange, but now do everything and you think of the weight of your child... and you think that if he increases is good, otherwise what is wrong? If it does not increase in weight is because I get something wrong? And at the end you find yourself weigh before eating, after eating, but not only, you weights he after a snack before and after the diuretic...so the weight is at the center of my thoughts because if it not increases in weight will not be able to do the next surgery, and I am afraid, I fear..." (CW03).

## **Discussion**

The purpose of this study was to describe the lived experience of parents of children with heart disease who had returned to their homes after being discharged from hospital after heart surgery. Studies have concentrated on the diagnosis of congenital heart disease (22) and on the process of hospitalization (23), but little attention has been paid up until now to the experience of returning home. All participants surveyed admitted that the feeling of joy that comes from being able to return home transformed into a feeling of uncertainty. This is typical of those who must face a new situation without feeling safe. Just as in studies that investigate the hospital experience of these par-

ticipants (23), the fear of the unknown seems to dominate. The rediscovery of a strong bond with healthcare professionals dedicated to the assistance of their own child may be a theme because of the relationship that is established between parents and hospital personnel during the hospitalization of children (24, 25).

Chronic psychophysical fatigue is a typical experience of primary carers.

These results were also confirmed by the SF 12 scale. The average results of the participants show that these subjects report a perception of quality of psychological condition "below normal"; they having average scores below the level considered normal in the physical state ( Physical Component Summary - PCS) and in psychological state (Mental Component Summary - MCS).

The increase in workload and desire to try to reconcile their private lives with this new role is typical of all participants who found themselves in this position (26, 27). Healthcare providers should identify these issues and offer structured educational programs to help families deal with such situations. In the specific case of heart surgery, the lived experiences of parents post-discharge emphasize the need for educational programs designed to support parents once their children have returned home (10). These programs have also been suggested for parents who feel the constant need to monitor their child's body weight (10). Regardless of whether children have been discharged with or without a device for power, fear related to the possible loss of weight is strongly present in these parents and is a source of stress that has been recognized in previous research (10). It seems that many experiences related to the hospitalization of cardiopathic children continue at home during the period after discharge. At this stage, supportive networks between professionals and parents, or even between parents and parents, seem to be an ideal solution for such situations (10).

This multicenter study showed similar results regardless of the geographical area where enrolled the participants. It seems therefore that the lived experience of parents is similar regardless of the hospital, welfare network, region and local health service. A common request expressed by parents was the desire for information and the desire to be prepared through specific educational programs.

## Conclusion

Understanding the lived experience of parents whose children have recently been discharged after undergoing cardiac surgery for congenital heart disease can direct the design of specific educational programs designed to improve long term welfare outcomes in the dyad of care. The understanding of this lived experience also immediately allows a correct holistic approach to nursing care. Understanding the areas of support sought by parents of children undergone to cardiac surgery and discharged to home will direct nurses to specific areas of intervention and support within the care process.

## Limitations

This multicenter study has the capacity to compare participants' unique experiences of programs of hospital discharge indirectly, however as the discharge programs in this study were not standardized, it is difficult to relate the results with these procedures.

The study's limitation is that it has not distinguished the various CHDs and any assistance issues that have occurred during surgery or during the post-operative period. This certainly could have influenced the experiential experience of the respondents.

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