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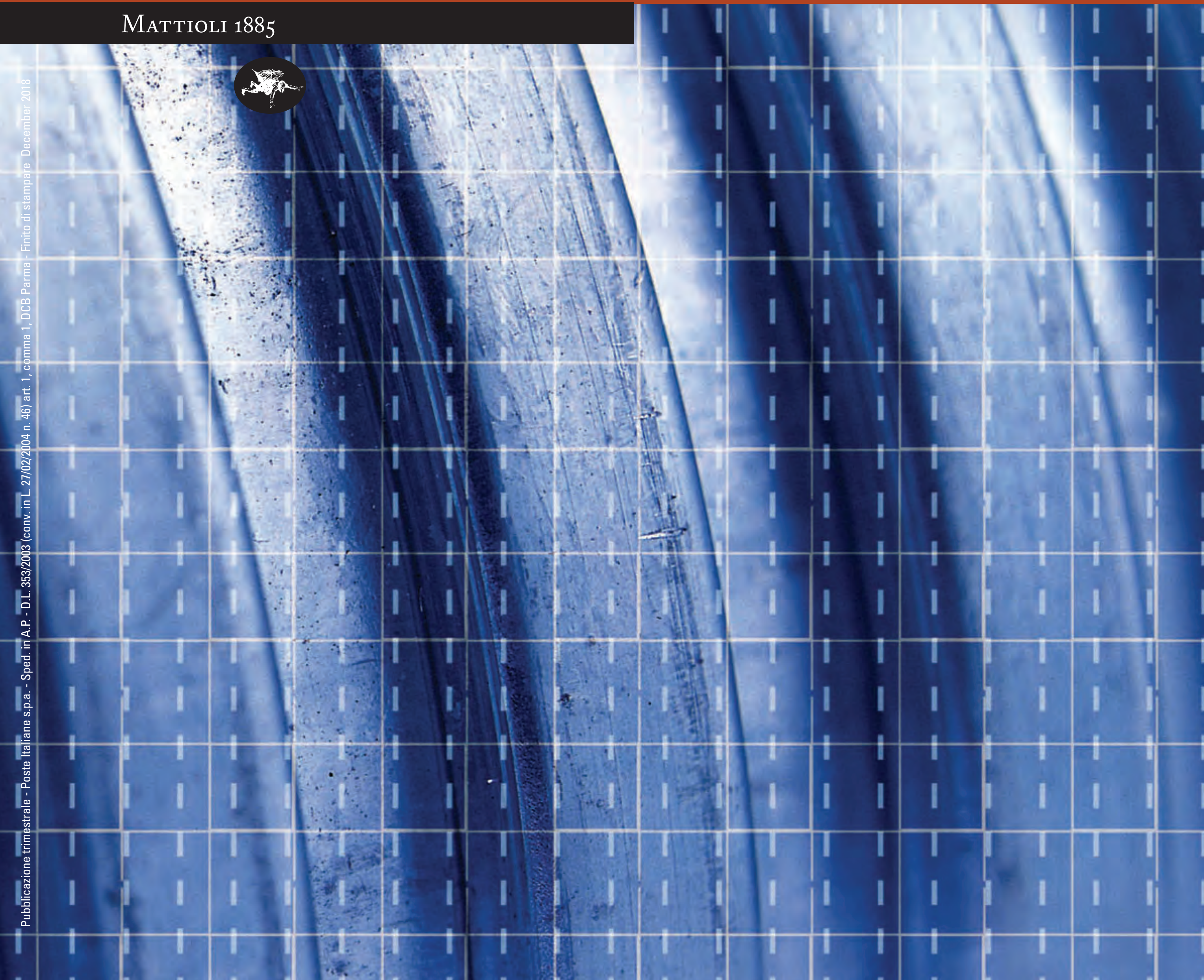

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Special Issue (3-2018)

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ORIGINAL ARTICLE: LOOKING INSIDE THE CARE: THE SUBJECTIVE POINT OF VIEW

ORIGINAL ARTICLE: THE CAREGIVERS' SIDE OF THE CARE

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Foreword

In this supplement of ACTA for health profession, the topics discussed in the various articles highlight the importance of evaluating objective and subjective parameters in the health professions, underlining how the integration of these two approaches, in the health care, leads to the achievement of a high personalized standard of care.

In particular, this issue addresses specific topics related to nursing care: sensitive topics in nursing processes such as the specific nursing skills needed to track ventilatory asynchronies in patients and a retrospective analysis of factors related to unplanned extubations, problems that the nursing professionals are to manage in clinical practice and that still deserve further studies to guarantee an increasingly specific and timely intervention, allowing to increase the patient's safety. Another topic here addressed, always linked to the professional nursing practice, are the healthcare associated injuries among nursing students, analyzing a specific context and trying to identify which factors, even in this case, reduce the risk and increase the safety, this time for professionals.

There are, however, analysis that start from another point of view, linked to subjective experience and personal well-being or malaise, in both professionals working in the healthcare sector (formal caregivers), and in those who have a caregiving function for people close to them, without having a specific profession (informal caregivers).

It is central, in fact, for the Editorial Board of this journal, highlighting how the crucial issues in the health professions are not only related to instrumental and technical skills, but also to transversal skills focused on reading the context, the individual needs of all the actors present in the care system (patients, caregivers, professionals), therefore linked to human and professional skills of understanding and empathy.

For this reason, in this issue there is a contribution that seeks to integrate these technical-human skills in a single approach: the Integrated Narrative Nursing Model (INNM).

This journal has already chosen to embrace this line of investigation that places at the center of the skills of a specialized health professional the ability to train, integrating in a continuous stream of professional and personal growth qualitative and quantitative skills for the evaluation of the person. Specifically, in the contribution present here two specific methods of diagnosis are integrated: the standard and the narrative one. The goal is to demonstrate how these two types of diagnosis can and must be integrated to arrive to an analysis of the person and not only of the pathology. This allows to conceive and co-construct with him/her a truly personalized intervention plan, taking into account the shortcomings, the weaknesses but also and above all, the real and perceived strengths of the person, as an aid to stimulate an active process of care and taking charge of oneself. In this issue, therefore, the focus is linked to the technical and human growth and development, that a health professional can and must achieve, to increase more and more the possibilities of treatment.

Chiara Cosentino
Giovanni Artioli
Leopoldo Sarli

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Original article: Technical skills and tools

Patient-ventilator asynchronies: types, outcomes and nursing detection skills

Enrico Bulleri[1], *Cristian Fusi*[1], *Stefano Bambi*[2], *Luigi Pisani*[3]

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Abstract. *Background:* Mechanical ventilation is often employed as partial ventilatory support where both the patient and the ventilator work together. The ventilator settings should be adjusted to maintain a harmonious patient–ventilator interaction. However, this balance is often altered by many factors able to generate a patient ventilator asynchrony (PVA). The aims of this review were: to identify PVAs, their typologies and classifications; to describe how and to what extent their occurrence can affect the patients' outcomes; to investigate the levels of nursing skill in detecting PVAs. *Methods:* Literature review performed on Cochrane Library, Medline and CINAHL databases. *Results:* 1610 records were identified; 43 records were included after double blind screening. PVAs have been classified with respect to the phase of the respiratory cycle or based on the circumstance of occurrence. There is agreement on the existence of 7 types of PVAs: ineffective effort, double trigger, premature cycling, delayed cycling, reverse triggering, flow starvation and auto-cycling. PVAs can be identified through the ventilator graphics monitoring of pressure and flow waveforms. The influence on patient outcomes varies greatly among studies but PVAs are mostly associated with poorer outcomes. Adequately trained nurses can learn and retain how to correctly detect PVAs. *Conclusions:* Since its challenging interpretation and the potential advantages of its implementation, ventilator graphics monitoring can be classified as an advanced competence for ICU nurses. The knowledge and skills to adequately manage PVAs should be provided by specific post-graduate university courses.

Key words: review, patient, waveform, ventilator, asynchrony, dyssynchrony, intensive care unit, nurses, skill, knowledge

Introduction

Mechanical ventilation represents the main life supporting treatment in critically ill patients. However, it is however associated with various complications (1), such as ventilator-associated pneumonia (2), ventilator-induced lung injury (VILI) (3), ventilation-induced diaphragm dysfunction (4) and patient ventilator asynchrony (PVA) (5).

Technological evolutions in delivering and monitoring of mechanical ventilation has rapidly expanded, currently offering a wide array of tools. The ventilator graphics monitoring is one of the most important instruments available for doctors and nurses. Waveforms monitoring allows a bedside unique assessment of the interaction between patient and ventilator, allowing the prevention or early detection of asynchronies.

Mechanical ventilation is frequently employed as partial ventilatory support in situations where both the patient and the ventilator work together. Ideally, the ventilator settings should be adjusted to maintain a normal level of respiratory muscle activity and

---

For the Triggerlab team (https://triggerlab.org) a harmonious patient–ventilator interaction (6, 7). However, this fragile balance is often altered by many factors able to generate patient ventilator asynchronies (8). PVA can be defined as "a mismatch between patient breaths and ventilator-assisted breaths as well as the ventilator's ability to meet the patient's flow demand" (5). Since this problem is associated with worse outcomes the prompt identification, management and thus reduction of PVAs have been recognized as fundamental actions during both invasive and non-invasive ventilation (NIV) (9, 10).

Nurses can play a key role in the early detection of an improper interaction between patient and ventilator. However, to date there's no clarity about the diffusion of nurses' knowledge and skills related to the ventilator waveforms interpretation and the detection of asynchronies. Moreover, there are a scarce number of handbooks and monographs facing the issue of patient-ventilator interaction from the nurses' point of view. To the best of our knowledge, this kind of issue is rarely included in intensive care nursing educational programs.

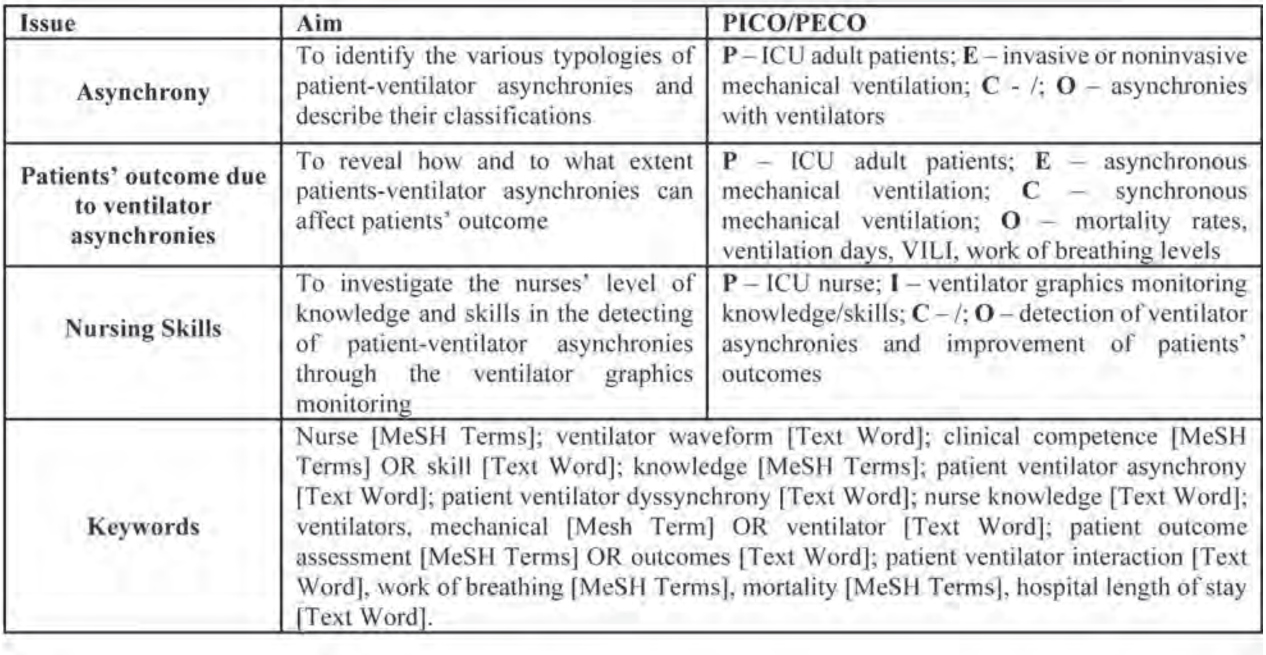
Therefore, we have designed a literature review with the following aims: to identify and classify PVAs during invasive and noninvasive ventilation; to describe how and to what extent their occurrence can affect patients' outcomes (such as mortality, duration of mechanical ventilation, work of breathing, VILI occurrence); lastly, to assess the degree of nursing skills in detecting PVAs through ventilator graphics monitoring.

Methods

A literature review was performed through medical and nursing scientific databases: Cochrane Library, PubMed-Medline and CINAHL. The references of the included full text papers were scanned, and the articles considered pertinent were retrieved and analyzed with same criteria. Three research questions were built using the PICO format (patient population, intervention, comparison- intervention, and outcome of interest) and PECO format when applicable (patient population, exposure, comparation, outcome). The research questions and keywords are reported in table 1.

Studies performed on animals pediatric, and neonatal patients, and trauma patients were excluded. The search was limited to Italian and English languages. No restriction to any study design and no restriction in time was applied in the search, but papers without

Table 1 - Research questions based on the PICO/PECO Format



Issue	Aim	PICO/PECO
Asynchrony	To identify the various typologies of patient-ventilator asynchronies and describe their classifications	**P** – ICU adult patients; **E** – invasive or noninvasive mechanical ventilation; **C** - /; **O** – asynchronies with ventilators
Patients' outcome due to ventilator asynchronies	To reveal how and to what extent patients-ventilator asynchronies can affect patients' outcome	**P** – ICU adult patients; **E** – asynchronous mechanical ventilation; **C** – synchronous mechanical ventilation; **O** – mortality rates, ventilation days, VILI, work of breathing levels
Nursing Skills	To investigate the nurses' level of knowledge and skills in the detecting of patient-ventilator asynchronies through the ventilator graphics monitoring	**P** – ICU nurse; **I** – ventilator graphics monitoring knowledge/skills; **C** – /; **O** – detection of ventilator asynchronies and improvement of patients' outcomes
Keywords	Nurse [MeSH Terms]; ventilator waveform [Text Word]; clinical competence [MeSH Terms] OR skill [Text Word]; knowledge [MeSH Terms]; patient ventilator asynchrony [Text Word]; patient ventilator dyssynchrony [Text Word]; nurse knowledge [Text Word]; ventilators, mechanical [Mesh Term] OR ventilator [Text Word]; patient outcome assessment [MeSH Terms] OR outcomes [Text Word]; patient ventilator interaction [Text Word], work of breathing [MeSH Terms], mortality [MeSH Terms], hospital length of stay [Text Word].	

an abstract were excluded. The upper time limit of this search was settled to June 2018.

All abstracts and full texts of the retrieved records were independently reviewed by two reviewers (the authors EB and CF); any discrepancy resolved collegially.

Results

A total of 1610 records were retrieved through database searches, and an additional 15 records were identified from manuscripts references. A total of 43 records were included in the analysis. Figure 1 shows the flow-chart of the literature review and the overview of included studies.

PVAs classification and types of asynchronies

The papers answering to this research question that were included in this review were 37 (11-47).

The need to identify and understand PVAs has led many authors to search and propose different classification methods.

PVAs have been classified with respect to the phase of the respiratory cycle as: asynchronies of the triggering phase or just "trigger asynchronies" (ineffective efforts/delay triggering, auto-triggering, double triggering and reverse triggering); asynchronies during flow delivery phase or "flow asynchronies" (flow starvation in volume controlled ventilation and insufficient pressurization - rise time too slow in pressure support ventilation-); asynchronies during cycling phase or "cycling asynchronies" (late cycling and premature cycling) (11-16). Some authors have identified a fourth category of asynchronies or "expiratory asynchrony" (shortened expiratory time) (12, 13). This classification can facilitate the diagnosis at the bedside using ventilator's waveforms analysis (12).

Subirà et al. have provided another kind of classification, based on the breathing cycle phase (17). Thus PVAs are distinguished in three groups: generated during the inspiratory period (trigger delay, inspiratory flow mismatching, short cycling and reverse triggering); during the transition from inspiration to expiration (double triggering due to short cycling or reverse triggering and expiratory muscle contraction due to prolonged cycling); during the expiratory period (ineffective inspiratory effort, auto-triggering and expiratory muscle contraction).

Lastly, a new classification of PVAs based on the circumstances of occurrence has been introduced (18, 19) to highlight the fact that PVAs occur primarily in the context of either high respiratory drive or low respiratory drive. As explained by Dress et al., in case of high respiratory drive we must discriminate whether the asynchronies (flow starvation, premature cycling, double triggering/breath stacking) are caused by an insufficient level of ventilator assistance and unmatched needs, or whether they are intrinsic to the patient's acute disease and thus best treated with additional sedation (18). At the other extreme, PVAs associated with low respiratory drive (reverse triggering – resulting in double cycling, delayed cycling, ineffective efforts) may be due to distinct mechanisms as sedation or over-assistance (19).

Ineffective effort and trigger delay

Also known as "ineffective triggering", "missed triggering" or "wasted effort", it is the most frequent type of asynchrony (20, 21), both in the early course of the disease, and during prolonged ventilation (22-24). This asynchrony is defined as inspiratory muscle effort not followed by a ventilator breath. The ventilator fails to detect the patient's inspiratory efforts, which are characterized by an increase in trans-diaphragmatic pressure and/or electrical activity of the diaphragm (EAdi) (12, 25, 26).

The inspiratory triggers are affected by delays due to the intrinsic reactivity of ventilators and their functioning characteristics (27). Nonetheless, there are some situations when there is a considerable delay between the time of respiratory muscle activation and the trigger activation, the so-called "trigger delay" (13-16, 28, 29). Ineffective effort and trigger delay are similar asynchronies because they have the same mechanism although yielding a different result. During ineffective efforts the ventilator does not deliver the inspiratory assistance because the trigger is not activated; conversely, with 'trigger delay' the patient manages to activate the trigger after a considerable time.

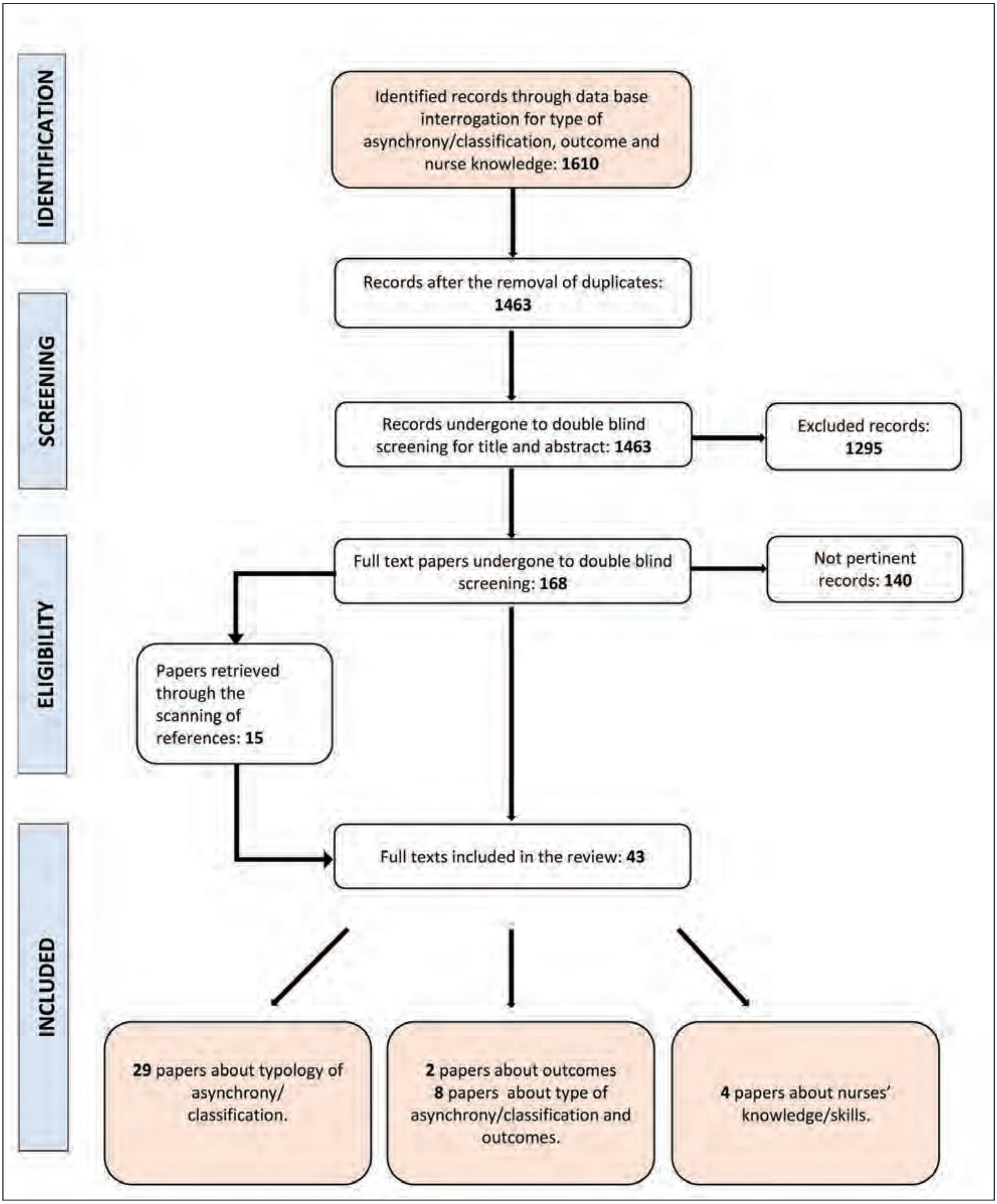


Figure 1. Flow chart of the literature review

Ineffective effort and trigger delay may occur during both the inspiratory or expiratory cycle. It can depend on a variety of mechanisms, such as a weak respiratory drive and/or effort as when these are reduced by ventilator over-assistance (30, 31) and excessive sedation levels (24, 32). They may also occur with a high intrinsic positive end-expiratory pressure (PEEPi), or an excessively low ventilator trigger sensitivity setting (23, 24, 33). The presence of ineffective effort is detected on ventilator graphics by a downward concavity of the flow/time waveform (sign that the expiration is briefly interrupted) with a simultaneous upward concavity of the pressure/time waveform (not apparent in some cases). When a nasogastric tube equipped with electrodes for EAdi recording is inserted, ineffective efforts can be promptly confirmed, i.e. the diaphragmatic depolarization - contraction - is not followed by the trigger activation and the consequent system pressurization (figure 2A).

Premature cycling and double-triggering

Premature or short cycling occurs when the neural time is greater than the ventilator's inspiratory time. The ventilator ends flow delivery, but the patient's inspiratory effort continues (17). Premature cycling describes a condition where the end of the ventilator insufflation anticipates patient's effort termination and it is more frequent in patients with low compliance, such as in Acute Respiratory Distress Syndrome (ARDS), or in case of inspiratory time set too short (34, 35). Moreover, this condition may result in double triggering (36): if the patient's effort exceeds the trigger threshold, it can activate another breath, generating a double-triggering.

The premature cycling occurs at the beginning of expiratory phase. It can be detected by an expiratory flow waveform that start with a peak, but it returns rapidly to a level near to 0 (baseline). The airways pressure waveform (Paw) does not end at the PEEP level but draws a small depression (indicating that inspiratory muscles are still working and depressurizing the system). The patient delays the expiration for few tenths of a second, as the EAdi waveform confirms (figure 2B).

Double-triggering, also named breath-stacking in Assist/Control (A/C) ventilation (37), is characterized by two consecutive ventilator cycles (triggered by the patient) separated by an expiratory time lower than one-half of the mean inspiratory time. The patient's effort is not completed at the end of the first ventilator cycle and triggers a second ventilator cycle (23, 38). On the ventilator's graphic, double triggering is displayed as two breaths very close: as one inspiratory phase has ended, the next one starts immediately. Usually the double triggering is interpreted as a double activation of inspiratory trigger. However, this activation is generated by an only one efforts of respiratory muscles, as confirmed by the EAdi waveform. When the mechanical ventilator cycles to the expiratory phase, an immediate pressure drop occurs, due to the inspiratory muscles that are still in tension and activate the inspiratory trigger, determining a new mechanical insufflation (figure 2C).

Double-triggering and premature cycling can also occur when the patient's ventilatory demand is high and the ventilator inspiratory time is too short (35, 39). These types of asynchrony occur more frequently in patients with severe lung injury and increased respiratory drive (19).

Also, acute respiratory failure patients managed with low tidal volumes (≤6 ml/kg of ideal body weight) can easily develop double triggering. In these patients, the benefits hypothesized by a protective ventilation approach could be vanished when high tidal volumes are delivered due to this asynchrony (40).

Auto-triggering

Auto-triggering also known as "auto-cycling" is defined as a cycle delivered by the ventilator without a prior airway pressure decrease, indicating that the ventilator delivered a breath that was not triggered by the patient (23). The occurrence of auto-triggering can be due to airleaks in the system, or to an excessively high trigger sensitivity. Moreover, changes in airway pressure and/or flow secondary to cardiac oscillations or water accumulation in ventilator tubing can erroneously be sensed as triggering efforts (41, 27, 15).

To detect the activation of inspiratory muscles on the ventilator's graphics, the pressure-time waveform should be observed. A little deflection on the PEEP level immediately before the beginning of the inspira-

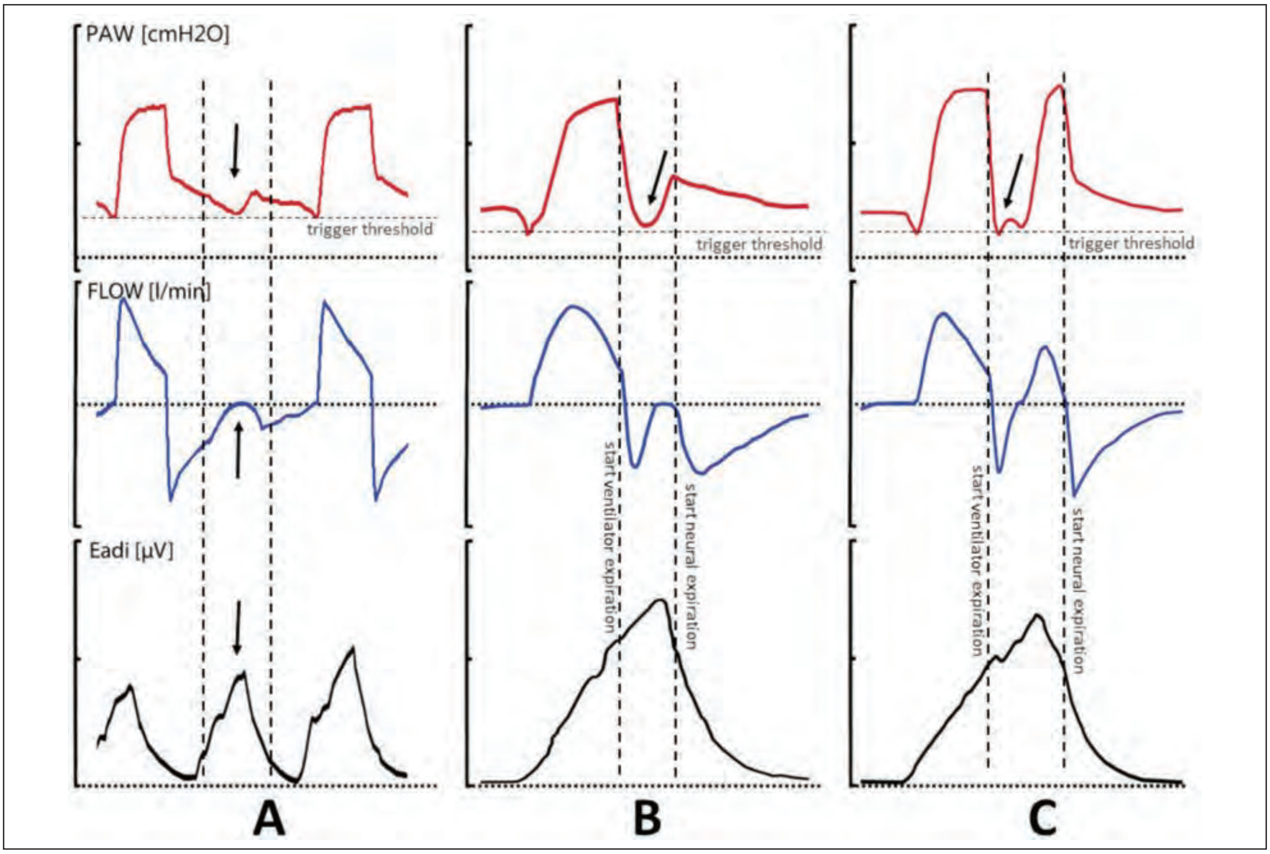


Figure 2. (A) Ineffective effort during pressure support ventilation (PSV). (B) Premature cycling during PSV. (C) Double triggering during PSV

tory phase indicates the presence of trigger activation. Auto-triggering can be spotted on ventilator's graphics by noticing the absence of trigger sign when this is expected (as during pressure support ventilation or assist-control ventilation) and a "passive-like" flow-time waveform. The absence of diaphragmatic depolarization showed by the EAdi waveform confirms the presence of this asynchrony (figure 3A).

Reverse triggering

Akoumianaki et al (42) described this type of asynchrony in acutely ill patients undergoing controlled mechanical ventilation. Ventilator insufflations trigger diaphragmatic muscle contractions through activation of the patient's respiratory center in response to passive insufflation of the lungs. If the inspiratory effort is strong enough, a second breath can be delivered by the ventilator, resulting in breath-stacking. As opposed to double-triggering, during reverse triggering the first breath is triggered by the *ventilator* and is followed by a *patient* inspiratory effort (19). The exact causal mechanism is unknown, but this asynchrony was found in heavily sedated ARDS patients (42) and in brain-death (43). Reverse triggering might result in alterations of measured plateau pressures, increased oxygen consumption, and hemodynamic instability. This may also play a role in ventilator induced diaphragmatic dysfunction (11).

A reverse triggering example is showed in figure 3B. A patient is supported with pressure-controlled ventilation. The ventilator starts the insufflation according to the settled time (no sign of triggering, since the breath is mandatory). After some tenths of second the patient activates his/her inspiratory muscles. This activation is detected by the light deflection on the pressure-time waveform, while the flow-time wave-

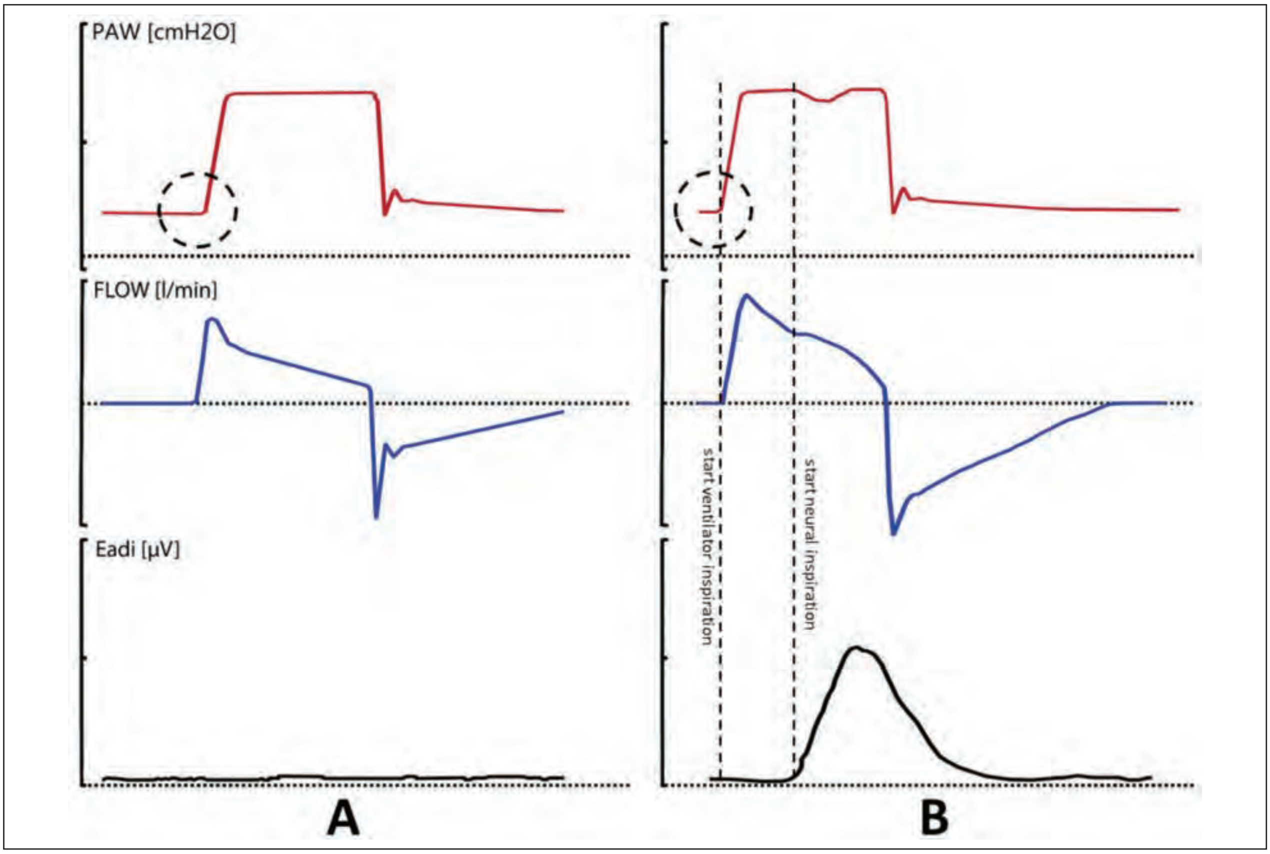


Figure 3. (A) Auto-cycling in PSV. (B) Reverse triggering during pressure-controlled ventilation (PCV)

form shows a light convexity. This kind of assessment on the ventilator's graphics is not easy, and sometimes it's impossible. If an EAdi waveform is available, the diagnosis of reverse triggering is simplified since the discrepancy between ventilator insufflation and the patient neural activation is clearly detectable.

Delayed cycling

When the ventilator inspiratory time exceeds the patients neural inspiratory time, an asynchrony known as late, prolonged or delayed cycling occurs (11). Mechanical insufflation continues after neural inspiration has ceased or even during active expiration. Most frequent causes are an inappropriate timing in cycling setting (17) and airleaks (44, 45). Chronic obstructive pulmonary disease (COPD) and asthma are risk factors for delayed cycling, and the shorter expiratory time contributes to worsening hyperinflation in these patients (46).

An example of delayed cycling due to airleaks caused by a large bronchopleural fistula during PSV is showed in figure 4A. The ventilator displays a delay in the ventilator's cycling as compared to the patient's neural activity. In this case, the flow-time waveform shows a slow decrease and late activation of the expiratory trigger, despite the patient has well began the neural expiration. Simultaneously, the pressure-time waveform records an *increase* in Paw between the end of neural inspiration and the end of the mechanical inspiration. These graphical aspects indicate that the patient truncated the inspiration before the ventilator has ended the inspiratory phase. This is confirmed by the EAdi waveform that displays the mismatch between the diaphragmatic relaxation and the end of mechanical inspiration.

Flow starvation

Gilstrap et al. have defined flow starvation as the PVA that "occurs when gas delivery fails to meet patients' flow demand". Inadequate gas delivery is common when ventilator flow is set inappropriately low, or the combination between V_T and inspiratory time does not result in adequate flow to the injured lung, or when inspiratory flow demands are high and vary from breath to breath (15).

The pressure-time waveform is typically "sucked down" by the patient's inspiratory effort (figure 4B). The delivered flow is markedly lower than patient's demand and excessive muscle loading may occur. When flow starvation is severe, the pressure–time waveform during inspiration can be pulled below the baseline airway pressure by a high patient's flow demands" (15, 16).

Flow asynchronies appear to be more common with ventilatory settings that deliver a fixed flow (flow-targeted breaths) rather than with a flow that can vary with effort (pressure-targeted breaths) (47)

Influence of PVAs on patient outcomes

The papers answering to this research question that were included in this review were 10 (21-24, 29, 35, 40, 44, 48, 50).

Chao et al (22) showed that 10.9% of 174 studied patients experienced ineffective breathing efforts. These patients had lower weaning success rates ($p<0.001$). In fact, the mean time of weaning in patients with asynchronies was 72 days versus 33 days in those well adapted to the ventilator ($p=0.013$).

The asynchrony index (AI, number of asynchronous breaths/total number of breaths X 100) >10% has

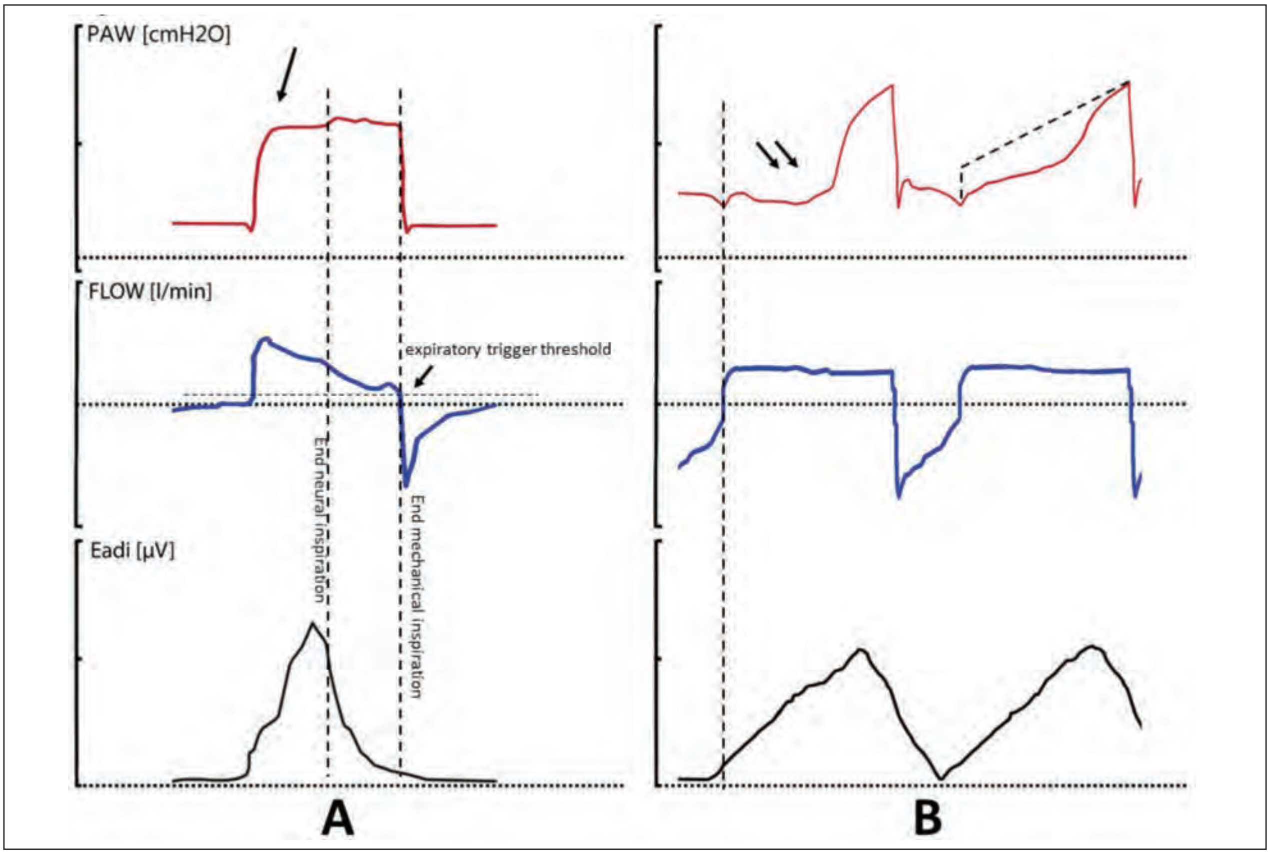


Figure 4. (A) Late cycling during PSV. (B) Flow starvation during volume controlled ventilation. The dot line shows the shape of the waveform in absence of flow starvation

been associated to longer mechanical ventilation duration (p=0.005) and higher incidence of tracheostomy (p=0.007), but not to mortality rates (p=0.36) (23). On the contrary, Blanch et al. found that values of AI>10% were associated to ICU mortality (p=0.011) and hospital mortality (p=0.044), but not to a larger mechanical ventilation duration time (p=0.061) (21).

During NIV the airleaks from the interface can determine a prolonged pressurization of the ventilator, causing an insufficient fall of the flow to reach the expiratory cycling threshold (44). Consequently, the ventilator cycling is considerably delayed, and the work of breathing increases (44), with consecutive decreased patient's compliance to NIV support.

Tokioka et al. (35) evaluated the effects of PSV cycling in patients recovering from acute lung injury, with flow-cycling at 1%, 5%, 20%, 35%, and 45% of peak inspiratory flow. The higher flow-cycling percentages resulted in premature cycling, double-triggering, lower tidal volumes, higher respiratory rate (p<0.001), and higher work of breathing (p<0.001). On the contrary, in patients with COPD higher percentages of expiratory trigger levels seem to decrease the extent of delayed cycling, reduce the intrinsic PEEP level, and the ventilator triggering effort (29).

De Wit et al. (24) found that the increase of ineffective trigger index (ITI, number of ineffective triggers/number of total breaths) was associated to deeper levels of sedation. In fact, lower Richmond Agitation and Sedation Scale scores were associated to higher rates of ineffective breathing efforts (p=0.04). In that study, patients who were awake showed about one-fifth of the total number of ineffective efforts when compared with not-awake patients (p=0.04) (24). The same authors (48) found that ITI ≥10% (if compared to ITI <10%) was an independent predictor for longer mechanical ventilation duration (10 days vs. 4, p=0.0004) and shorter ventilator-free survival (14 days vs. 21, p=0.03). Patients with ITI ≥10% had a longer ICU length of stay (8 days vs. 4, p=0.01) and hospital length of stay (21 days vs. 8, p=0.03). Mortality was similar in the two groups, but patients with ITI ≥10% were less likely to be discharged home (44% vs. 73%, p=0.04) (48).

Vaporidi et al (49) have introduced a new concept of events defined "clusters" of ineffective efforts (IE). These events are defined as more than 30 ineffective efforts in a time period of 3 minutes (about half the number of breaths per minute in a patient with a respiratory rate of 20 breaths per minute). This study showed that the ineffective effort index ≥10% had no correlation with critically ill patient's outcome; the presence of clusters of IE was associated with longer duration of mechanical ventilation (even in presence of IE index <10%) and higher hospital mortality.

In 2000 the ARDS network clearly showed that a lung-protective ventilation strategy can reduce mortality in patients with acute respiratory distress syndrome (ARDS) (50). Moreover, in ARDS patients ventilated in assist-control-volume (ACV) mode, tidal volumes of 4-6 mL/kg of IBW have been recommended to reduce VILI. However, Pohlman et al demonstrated that tidal volumes settled in ml/kg IBW had a strong association with the occurrence of breath-stacking (p=0.007) (40). Therefore, the beneficial effects of lower tidal volume ventilation may be decreased when this asynchrony is present.

Nursing detection skills

The papers answering to this research question that were included in this review were 4 (51-54).

Published studies about nurses' knowledge and/or skills in ventilator's graphics monitoring are scarce. Chacòn et al. in 2012 (51) investigated the level of nurses skills in detecting patients' ineffective breathing efforts through the monitoring of ventilators' graphics. 2 ICU nurses underwent to ad hoc education for monitoring ventilator's graphics, before undergoing a test about ineffective efforts. The answers of nurses were compared to those of 5 expert physicians (reference standard). The results indicate that nurses, if adequately skilled with specific courses, can detect patients' ineffective efforts with the same accuracy of expert clinicians (k=0.92 for the first nurse, and k=0.74 for the second one) (51).

The ability of nurses in detecting patient-ventilator asynchronies through graphics monitoring was confirmed by the before-after study performed by Fusi et al. (52). The authors have assessed the nurses' knowledge before a specific course on ventilator's graphics and after 6 months from its end. They recorded a significant increase in knowledge at the end of the training (p<0.001) which was retained after 6 months (p<0.001) (52).

Lynch-Smith et al. in 2016 (53), evaluated the influence on the mean duration of mechanical ventilation exerted by the education on patient-ventilator interaction performed on nurses and respiratory therapists. The study showed an increase of knowledge in nurses and respiratory therapists (p<0.001), but failed to demonstrate a relevant reduction in duration of mechanical ventilation (53). During the same year, Ramirez et al. (54) performed a survey on 25 hospitals in Chile that was administered to different professional roles in the ICUs with the aim to understand the factors affecting the ability to detect patient-ventilator asynchronies. The authors found that the only significant factor associated with an increased detection of PVAs was to have received previous training in ventilator waveform analysis (p<0.001). The professional role and the experience of the ICU team members did not influence the correctness in detecting the patient-ventilator asynchronies.

Discussion and conclusion

Salient findings of this review are: *1)* PVAs have been classified with respect to the phase of the respiratory cycle or based on the circumstance of occurrence but there is agreement on the existence of 7 types of PVAs: ineffective effort, double trigger, premature cycling, delayed cycling, reverse triggering, flow starvation and auto-cycling; *2)* the influence on patient outcomes varies greatly among studies but PVAs are mostly associated with poorer outcomes; *3)* adequately trained nurses can learn and retain how correctly detect PVAs.

The PVAs classification according to the phases of breathing cycle, has been made with the intent to ease the healthcare professional comprehension and detection through the ventilator waveforms. The classification offered by Dress et al. (18) and Pham et al. (19), based on the circumstances of PVAs occurrence, could simplify the treatment approach to the PVAs. However, there are no published studies showing that the use of PVAs classification methods could improve the detection and fixing of the PVAs. Beyond the diverse classifications, there is agreement on the existence of 7 types of PVAs, even if some incongruencies still persist among the definitions of the single typologies of PVA. This element could generate confusion in the understanding and approaching of PVAs, especially among the less trained professionals. Since the last 20 years, modern ventilators are equipped with continuous respiratory waveform monitoring on their displays useful in the detecting of asynchronies. Pressure and flow waveforms are available in all the modern ventilators, being a fundamental tool to understand patient-ventilators interactions (12). However, they have some limitations: visual inspection of waveforms in search of patient-ventilator asynchronies is objectively difficult (55). Moreover, the healthcare professionals' ability to recognize PVAs can be very low and affected by training in ventilator waveform analysis (54). In addition, some PVA are hardly recognizable if only the pressure-time and flow-time waveforms are used (18). In fact, sometimes the ventilator's waveforms could appear "normal" also when an asynchrony is occurring (56).

Some additional tools to face these limitations are available on the market: esophageal pressure monitoring and EAdi monitoring. The esophageal pressure is a surrogate of pleural pressure, providing useful data for the respiratory mechanics and pulmonary stress evaluation (57). This parameter allows an accurate interpretation of patient-ventilator interactions and asynchronies (6), but the esophageal pressure measurement is often underused in clinical settings due to lack of knowledge (58). EAdi signal allows to measure the size of diaphragmatic depolarization, expressed in μV. The nasogastric tube for EAdi records directly the respiratory drive and it's very accurate in revealing the beginning and the duration of neural inspiration and expiration (32). Its widespread use is limited by the need to have available a specific mechanical ventilator equipped with a patented technology and software.

PVAs are associated to poor outcomes, but it's not still clear if the occurrence of asynchronies is a factor directly affecting these outcomes or if it's an indicator of illness severity. In fact, the predisposing factors for PVAs are often related to the patients' severe clinical conditions, the presence of COPD, the ventilation modes and the changes of ventilator settings (22, 23).

Incidence of PVAs is affected by large variability in case definition, patients' conditions, ventilator modes, time and methods of observation, with studies reporting AI >10% rates ranging from 12 to 43% (21, 38). Among the occurrence of asynchronies, ineffective efforts are those with the highest percentages (20, 49). One of the main and frequent limits in the studies on incidence of PVAs and their effects on patients' outcomes is the short times of observations. In order to overcome this limitation, some researchers have studied the occurrence of asynchronies using adequate software for the continuous recording of the patient-ventilator interaction (21, 49).

The nurse could potentially play a crucial role in the early detection of PVA, since he/she is the professional figure spending the most part of the working time at the bedside. The detection of auto-cycling during brain death assessment is one enlightening example. In fact, the lack of detection of this asynchrony can potentially delay the brain death diagnosis (59) with consequences as longer ICU management times, and increased risk of losing potentially transplantable organs (60). The correct interpretation of ventilator waveforms could improve the multidisciplinary workflow in ICU and the therapeutic interventions (61). The effective early identification of double triggering, cluster of ineffective efforts and asynchronies between neural times and ventilator times could decrease the risk of complications. However, to date only few nurse researchers have faced the complex area of patient-ventilator interaction. In particular there is a lack of studies on the effectiveness of ventilator graphics monitoring performed by nurses.

The few available studies indicate that nurse-led ventilator waveform analysis is a practice rarely performed (13, 20, 54, 61, 62). Potential reasons for this can be found in the complexity of this kind of monitoring, the lack of specific educational courses and shortage of resources and didactic tools (61-63). These findings hint to a wide knowledge-gap in the patient-ventilator interaction domain that should be tackled by the clinical and academic community.

In conclusion, PVA are variously defined and classified, but the achievement of a unique and widely shared definition of the typologies of asynchronies should be desirable. Asynchronies have been associated to ICU and in-hospital mortality, and have the potential to compromise important clinical objectives. However, it's not clear if PVAs represent the root cause or are simply proxies of patients' illness severity level. Monitoring system to detect PVAs are currently available and effective, but scarcely implemented for the lack of skills, shortage of resources and education. Since its difficult interpretation and the potential implication of its implementation, the ventilator graphics monitoring can be classified as an advanced competence for nurses. The knowledge and training to manage adequately this issue should be provided by specific post-graduate university courses.

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A first contribution to the validation of the Italian version of the Behavioral Pain Scale in sedated, intubated, and mechanically ventilated paediatric patients

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Abstract. *Background and aim of the work:* Numerous negative outcomes of inadequate pain management among children have been cited in the literature. Inadequate pain management may be particularly detrimental to children and adolescents facing life-threatening injury or illness on a Paediatric Intensive Care Unit (PICU). It is therefore absolutely necessary that professionals utilize effective and efficient tools in order to evaluate a person's sensations of pain in the most objective way possible. The COMFORT-B scale is recognised as the gold standard in such patients. However, the use of this instrument in the clinical PICU setting is disputed. It requires long periods of observation to ensure an adequate utilization. Boerlage et al. noted that nurses are often impatient and do not always observe the patient for the recommended 2 minutes period. The Behavioral Pain Scale (BPS), instead, is considered to be the gold standard for pain assessment in deeply sedated, mechanically ventilated adult patients. This observational pain scale requires shorter observation time compared to the COMFORT-B. Moreover, BPS three subscales are included in other observational pain scales for paediatric patients. Therefore, the objective of this study was to assess the applicability of the BPS for use with paediatric patients. *Methods:* Firstly, a questionnaire was administered to physicians and nursing staff that work in the units where the study was conducted in order to investigate the actual use of observational pain scales in their units. A second questionnaire was administered to a group of experts regarding the BPS, to assess both face validity and content validity, and to gain opinions on the relative appropriateness of each item. A descriptive, comparative design was used. A convenience sample of non-verbal, sedated and mechanically ventilated critical care paediatric patients was included. 39 observations were collected from 9 patients, all in their first year of age. Patient pain was assessed concurrently with the three observational scales, before, during and after routine procedures that are considered painful and non-painful. *Results:* The data collected through questionnaires for professionals gave a useful insight into pain assessment in the investigated units: only 46% of respondents stated that they assessed patients' pain levels, with an average of 2.8 times per shift; 60% of respondents declared to be unhappy with the observational scales that they utilise. Regarding the observations, internal consistency was $\alpha = .865$. Correlations between BPS and the other instruments were high, demonstrating a good concurrent validity of the test. T test and ROC curves demonstrated a good discriminant validity as well. *Conclusions:* Although the current study is based on a small sample of participants, these first results encourage us to continue working in the validation of the BPS in paediatric patients.

Key words: Behavioral Pain Scale, pain assessment, PICU, paediatric patients

Introduction

The International Association for the Study of Pain (1; 2) in 1979 defined pain as "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." (p. 3). Pain is a frequently experienced problem in critically ill patients in the intensive care unit (ICU). Its assessment in critical patients may be complicated by decreased consciousness, severity of illness, mechanical ventilation, and the use of sedatives in these patients, particularly when high doses of sedatives are administered (3). Although self-report is still the *gold standard* in pain measurement according to the guidelines of the International Association for the Study of Pain (2), a number of ICU patients are unable to communicate effectively. In these cases, the gold standard (that is, the pain intensity reported by the patient) is not possible or is potentially unreliable. This is also a common problem in neonates and children, who are not able to report pain in a reliable manner. However, as IASP reports: "The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain-relieving treatment." (1; p. 3). Indeed, the absence of an adequate pain assessment in such patients interferes with their optimal care management and may provoke grave physiological and psychological damage. Numerous negative outcomes of inadequate pain management among children have been cited in the literature, including long-term behavioural changes, pain-perception impairment, pain-tolerance reduction, physical disability, and emotional disability (4). Inadequate pain management may be particularly detrimental to children and adolescents facing life-threatening injury or illness on a Paediatric Intensive Care Unit (PICU), as well as to the parents of such children and adolescents (4). It is therefore absolutely necessary that professionals utilize effective and efficient tools in order to evaluate a person's sensations of pain in the most objective way possible. Several observational pain assessment scales are available, however, the literature points to an absence of an effective and simple method to evaluate pain in intubated and ventilated children (5). The COMFORT-B scale is recognised as the gold standard in such patients. It can be used in both ventilated and nonventilated paediatric patients and showed to be reliable in pain assessment of 0 to 3-year-old infants allowing professionals to manage the antalgic therapy correctly (6). However, the use of this instrument in the clinical PICU setting is disputed. Studies have demonstrated insufficient correlation between physiologic and behavioural COMFORT items (6, 7). Moreover, it requires long periods of observation to ensure an adequate utilization. In the original validation (6) cut point values for post-operative pain and distress were determined based on a 2-min observation period. Therefore nurses are instructed to observe patients for 2 minutes preceding the actual scoring. However, Boerlage et al. (8) noted that nurses are often impatient and do not always observe the patient for 2 minutes. They tend to reduce the recommended 2-min period – even to 30 secs - this might be understandable in view of the nurses' heavy workload. Thanks to an experimental study, Boerlage et al. (8) concluded that observation for 30 seconds rather than the recommended 2 minutes creates a greater risk of underscoring pain. Therefore, the research suggests an emphasis on the lack of adherence to the requested observation times by professionals, which results in assessments of limited therapeutic use (8).

The Behavioral Pain Scale (BPS; 9), instead, is considered to be the gold standard for pain assessment in deeply sedated, mechanically ventilated adult patients. This observational pain scale requires shorter observation time compared to the COMFORT-B. Moreover, BPS three subscales (i.e., facial expression, upper limb movements, and compliance with mechanical ventilation) are included in other observational pain scales for paediatric patients (e.g., COMFORT-B, and Children's Hospital of Eastern Ontario Pain Scale, CHEOPS; 10).

Therefore, the objective of this study was to assess the applicability of the BPS for use with paediatric patients.

Methods

Approval from the Institutional Review Board (IRB) at the University of Parma and written consent and assent from caregivers was obtained before study recruitment.

Preliminary, a questionnaire was administered to physicians and nursing staff that work in the units where the study was conducted in order to investigate the actual use of observational pain scales in their units. A second questionnaire was administered to a group of experts regarding the BPS, to assess both face validity and content validity, and to gain opinions on the relative appropriateness of each item.

Design and sample

A descriptive, comparative design was used. A convenience sample of non-verbal, sedated and mechanically ventilated critical care paediatric patients was included. Patients excluded from the study were those who were on medication with neuromuscular blockers (Curaro®); patients on muscle relaxants (Dandrolene®); patients with neurological pathologies or head injuries or encephalopathies and patients with drug-resistant epilepsy. Premature babies were also excluded because of their specific and complex characteristics. Refusals to take part in the study on the part of even one parent was also considered an exclusion criterion.

An a priori power analysis, conducted with the software G*Power (11), indicated that we needed to have at least 8 subjects to have 80% power for detecting a medium-sized effect when employing the traditional .05 criterion of statistical significance (12).

39 observations were collected from 9 patients, 5 boys and 4 girls, all in their first year of age.

Instruments

Behavioral Pain Scale (BPS). The BPS is a behaviour rating scale that evaluates three behavioural domains (i.e., facial expression, movements of upper limbs and compliance with ventilator). Each domain contains four descriptors that are rated on a 1-4 scale, and the total BPS value can range from 3 (no pain) to 12 (most pain) (13).

COMFORT-B. The COMFORT-B scale (6) asks observers to consider intensity of six behavioural manifestations: Alertness, Calmness, Respiratory response (for ventilated children) or Crying (for spontaneously breathing children), Body movements, Facial tension, and Muscle tone. For each of these items, five descriptions are provided reflecting increasing intensity of the behaviour in question; these are rated from 1 to 5. Summating the six ratings leads to a total score ranging from 6 to 30. Scores from 17 to 30 are thought to suggest pain or distress.

Numerical Rating Scale (NRS). The NRS is a global pain rating scale that asks to rate pain intensity by number (0 no pain and 10 worst pain) (17). NRS is a commonly used clinical measure of pain, and the gold standard of self-report measures - Patients are asked to indicate the intensity of pain by reporting a number that best represents it. In the use with non-verbal patients, the NRS assessment is intrinsically linked to the COMFORT-B scale and expresses the expert opinion of the nurse to complement the behavioural observation with the COMFORT-B scale. This expert opinion can take patient-related, environmental characteristics into account.

Procedure

This study was conducted over a 3-months period at the neonatal intensive care unit of Parma University Hospital and neonatal and paediatric intensive care unit of Genova Paediatric Hospital "G. Gaslini", two hospitals in the north of Italy.

Patient pain was assessed concurrently with the three observational scales, before (T0), during (T1) and after (T2) routine procedures that are considered painful (mobilization and tracheobronchial aspiration) and non-painful (hematic withdrawal of CVC, CVC medication). The types of procedures to be observed were selected beforehand according to direction provided in the literature (1) but were observed only if they actually occurred during the time the observers were in the unit.

In order to guarantee reliability and objectivity, two independent observers carried out each observation simultaneously. Data were recorded on a data collection form that included a description of the patient and, in addition to the BPS, the COMFORT-B, and the NRS.

Data analysis

All data were analysed with SPSS version 20 (SPSS, Chicago, IL). Internal consistency was assessed with Cronbach's coefficient α using the scores during nursing procedures when the patient was most likely to be experiencing pain. Inter-rater reliability was assessed using Cohen's kappa for two raters. Spearman correlation coefficient was also used to examine the relationship between the BPS, COMFORT-B and NRS scores in order to test construct validity. We hypothesized that a significant correlation would be found between the three scales scores seeing that they were supposed to measure the same concept (pain). The discriminant validation was examined by calculating within-patient differences in scores between the assessments on T0, T1, and T2, using a t-test. We hypothesised that if the BPS reliably measures pain, the BPS scores should be much higher during painful procedures than while the patient is at rest. Receiver operating characteristic (ROC) curves and the area under the ROC curves were calculated to illustrate the relationship between sensitivity and specificity of the BPS and - as a further measure of discriminatory validity - to evaluate the probability of the BPS in correctly identifying patients with controlled and non-controlled pain, as defined by the NRS score.

Results

Questionnaire for professionals

In order to investigate the actual use of observational pain scales in their units a questionnaire was administered to physicians and nursing staff. 146 professionals replied to the questionnaire: 83% of the participants were nurses; 16% were physicians. 50% of those who replied to the questionnaire were from an emergency department; the majority (44%) reported work experience ranging from 0 to 5 years.

The data gave a useful insight into pain assessment in the investigated units: only 46% of respondents stated that they assessed patients' pain levels, with an average of 2.8 times per shift; 60% of respondents declared to be unhappy with the observational scales that they utilise (mainly COMFORT-B and NRS).

In order to assess both face validity and content validity, a group of experts' opinion was also requested regarding the BPS. 40 professionals replied to the questionnaire. 64% of the respondents believed that the BPS is "very clear", compared to 36% ("sufficiently clear"). The scale was also judged to be "easy to use" by 72% of participants whilst 28% that stated it was "sufficiently easy". 64% of the respondents considered the BPS to be very pertinent and 56% were positive towards the idea of adapting it for the use with paediatric patients. It should be noted that no negative responses ("little/none") were registered. With respect to the detailed analysis of the subscales, all the three subscales were greatly appreciated. Only 4% of respondents were unhappy with "upper limb movements" and "compliance with mechanical ventilation" subscales. In the opinion of experts, these last two parameters should require long training and experience for nursing staff to be able to assess them. Moreover, the relationship between compliance with mechanical ventilation and pain may not be clear to the professional, since this is only recently receiving study (9).

Observations

Internal consistency for the BPS was α=.865. The agreement among raters was high (k=.86). Correlations between BPS and the other instruments were high, demonstrating a good concurrent validity of the test: BPS vs COMFORT- B (ρ=.93; p<.01); BPS vs NRS (ρ=.911; p<.01); NRS vs COMFORT- B (ρ=.880; P<.01). There was a statistically significant difference between BPS scores when the patients were at rest (T0: M=3.33; SD=.68), and during painful procedures (T1: M=7.35; SD=2.55) ($t_{(38)}$=-11.778, p<.001); a significant difference was also found between T1 and post procedure measurements (T2: M=3.31; SD=.71) ($t_{(38)}$=11.857; p<.001). The discriminant validation was further examined by calculating Receiver Operating Characteristic (ROC) curves. The area under the ROC curve was .995 (p<.001; e.s.=.007; I.C. 95% [.982;1.009]), including good diagnostic accuracy of the BPS for the identification of critical pain (Figure 1) – an AUC range between .9 and 1 is classified as "Excellent" (13). For a BPS cut-off score between 3 and 4, sensitivity and specificity were 1 and .929, respectively.

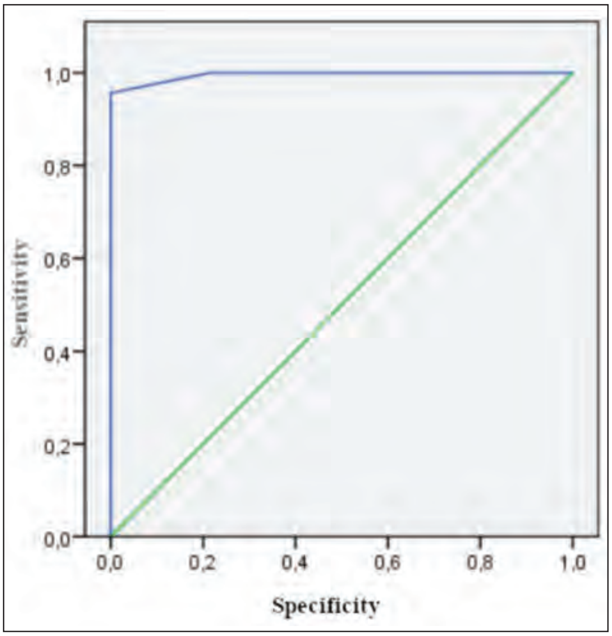

Figure 1. Receiver operating characterisics curves for BPS scores

Discussion

Pain management is an essential component in the provision of high-quality health care to patients. Nurses play an important role in controlling and activating timely pain management interventions in collaboration with other professionals. The scientific literature has chosen the *Behavioral Pain Scale* as the *gold standard* for the evaluation of pain in intubated and non-intubated adult patients. This study aimed to demonstrate the applicability, efficacy and efficiency of the BPS for paediatric patients.

The first questionnaire was designed to investigate the actual use of observational pain scales in the investigated units. The majority of respondents were nurses, confirming what is reported in the literature (e.g., 14): nursing staff provide the most frequent and ongoing assessment of pain and are responsible for reporting any problems or concerns to the physician-led services.

Another interesting finding is that the majority of respondents reported to have a work experience between 0 and 5 years. The emphasis placed on pain management in the last ten years may have influenced professionals whose training is more recent, and thus resulting in a greater awareness on the subject of pain assessment.

However, a less positive element was revealed from questionnaire responses: 54% of nurses working in emergency units state that they do not evaluate pain during their shifts, confirming what was already evidenced in the guidelines issued in 2013 (1). The scant adherence to this practice may be due, amongst other reasons, to the fact that a specific assessment tool for intubated paediatric patients does not exist at present (15). Within the responses to the first questionnaire, the rate of dissatisfaction with the tools that are presently in use in the investigated units amounted to 63%.

The 2013 guidelines on pain (1) outlined the characteristics of a good pain scale. Similar results were confirmed by the questionnaire given to the experts, with greater weight given to efficiency and reliability. The respondents stated that they considered the BPS easy to understand and user friendly: this was reinforced by the fact that no respondent gave a negative opinion of these items. This confirms what has been reported by American and Italian authors in their validation of this scale, in the USA and in Italy, respectively (9, 16). Moreover, more than half of those interviewed believed that that the BPS can be easily used in a PICU setting.

A limitations to this study was the fact that the BPS was administered by the researchers. This decision was inevitable seeing that an increase in their working load would have probably make the nurses to quit the study. However, because of this, no data about the compliance of the professionals to the use of the scale were collected.

Moreover, in the investigated units was common practice for the nurses to concentrate all the assistance activities (e.g., blood sampling, tracheobronchial aspiration, patch change, etc.) in the shortest possible time, usually during the morning shift, in order to reduce the young patients discomfort as much as possible. Most likely, pain evaluation was made at the very end of the assistance procedures. Because of this, the post procedure evaluation of pain was not possible for every single procedure. However, in the original validation of the COMFORT B scale (6) cut point values for distress are determined based on a 2-min observation period before and after the actual evaluation of each potentially painful procedure. Again, this gives an account of the fact that the complexity in the use of this scale does not necessary meet the needs of the operational reality.

On the other hand, a high Cronbach's α index revealed a very good internal consistency, demonstrating a good reliability of the BPS. Further, a good consistency among observational ratings provided by the two independent observers demonstrated a good inter-rater reliability. High correlations between BPS scores and the scores of the COMFORT-B (the current gold standard in PICUs) and NRS (the most utilized self-report tool) demonstrated good construct validity and concurrent validity. The BPS also showed a great capacity to discriminate pain in this sample; it showed high specificity and sensitivity; that is, it showed a good capacity to identify potential false positives and negatives.

Although the current study is based on a small sample of participants, these first results encourage us to continue working in the validation of the BPS in paediatric patients.

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Unplanned extubations in general intensive care unit: A nine-year retrospective analysis

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Abstract. *Background and aim*: Unplanned extubation (UE) in Intensive Care Units (ICU) is an indicator of quality and safety of care. UEs are classified in: accidental extubations, if involuntarily caused during nursing care or medical procedures; self-extubation, if determined by the patient him/herself. In scientific literature, the cumulative incidence of UEs varies from 0.3% to 35.8%. The aim of this study is to explore the incidence of UEs in an Italian university general ICU adopting a well-established protocol of tracheal tube nursing management and fixation. *Methods*: retrospective observational study. We enrolled all patients undergone to invasive mechanical ventilation from 1st January 2008 to 31st December 2016. *Results*: in the studied period 3422 patients underwent to endotracheal intubation. The UEs were 35: 33 self extubations (94%) and 2 accidental extubations (6%). The incidence of UEs calculated on 1497 patients intubated for more than 24 hours was 2.34%. Instead, it was 1.02%, if we consider the whole number of intubated patients. Only in 9 (26%) cases out of 35 UEs the patient was re-intubated. No deaths consequent to UE were recorded. *Conclusions*: The incidence of UEs in this study showed rates according to the minimal values reported in scientific literature. A standardized program of endotracheal tube management (based on an effective and comfortable fixing system) seems to be a safe and a valid foundation in order to maintain the UE episodes at minimum rates.

Key words: unplanned extubation, self extubation, accidental extubation, adverse events

Background and aim

Intensive care units (ICU) are settings with a high risk of adverse events related to patients' interferences with the treatment. Treatment interference is a concept which involves the self-removal of support or monitoring devices at various levels of invasiveness and it can determine clinical consequences with different levels of severity (1). Nurses perceive the burden of responsibility in protecting the patient from injuries and keeping the integrity of the devices, especially arterial catheters, venous catheters and endotracheal tube (1). Concerning the adverse events with endotracheal tubes, there is not only the risk of self extubation (SE), but also of accidental extubation (AE). AE is the extubation caused accidentally by healthcare workers during nursing or medical procedures. SE and AE are phenomena gathered under the whole concept of unplanned extubations (UEs) (2).

UEs are conditions with high relevance for ICU patients' safety issues. A work group on patients' safety of the European Society of Intensive Care Medicine has recognized the UEs as quality care indicators because they are related to high rates of reintubation, increased nosocomial pneumonia incidence, and death (3-5). The AEs are often the result of errors occurred during the change of patient's position, or tracheal tube handling and fixation. The SE, instead, can be due to failure in surveillance of the patients, or to the missed identification of the criteria to start the weaning from mechanical ventilation and subsequent extubation (3, 6).

Overall, the UEs in adult ICU patients show a very floating incidence. A recent systematic review of the literature shows a rate varying from 0.5% to 35.8% (7). In the studies using the incidence density rate to describe the phenomenon, the range is from 0.1 to 4.2 cases every 100 days of ventilation (7). The incidence density rate is the desirable indicator to compare different settings. The SEs characterize the larger part of UEs. In fact their incidence varies from 50% to 100% of all UEs (7).

The most important risk factors for UEs are (in a decreasing order): APACHE II score ≥17, patient's agitation, physical restraints, Chronic Obstructive Pulmonary Disease, use of midazolam, inadequate sedation and altered state of consciousness (7-9). Furthermore, some intrinsic risk factors have also been studied (e.g. age, gender and body mass index), but their role is still unclear (10).

Lastly, although there is no evidence about the superiority of one kind of tube fixation method over others, a weak fixation has also been acknowledged as a risk factor for UEs (10-12).

A survey performed in U.S. has showed that healthcare workers (doctors, nurses and respiratory therapists) considered risk factors for UEs the following conditions: the absence of physical restrain, a nurse patient ratio of 1:3, the trips out of ICU, light sedation, bedside radiographies and the night shift (13). The night shift seems to be an influential risk factor for UEs (Odds Ratio: 6.0-95% CI: 3.65-10.03), according to a case-control study carried out on 690 patients in Chorea (14).

The UE complications occurrence varies from 14% to 35% and can be related to problems concerning airway management (difficult laryngoscopy, esophageal intubation), respiratory system (tachypnea, hypoxemia, Ventilator Associated Pneumonia) and hemodynamic (tachycardia, hypertension, hypotension) (2, 3, 15).

The negative consequences of UEs can determine the increase of ventilation days, and the ICU and hospital lengths of stay (2, 3, 15). In scientific literature there are some ambiguous data about mortality related to UEs. An observational study on SE patients showed a difference of 22% in mortality rates of patients who had a UE compared with those who underwent to a well-planned extubation ($p<0.01$) (16).

The SE patients undergo to reintubation in a range from 0% to 63%, while those who experienced an AE can be reintubated up to 100% of the cases (3, 17). However, reintubation is an event which generally occurs immediately after the UE. In fact, 74% of the cases it is accomplished within an hour from the time of UE (3).

The need of reintubation is not different between medical and surgical patients (respectively 3.4%-74% and 22.6%-88%). Instead, there are lower reintubation rates in patients during weaning from mechanical ventilation (max 30%) when compared with those who are under a full ventilation support at the moment of UE occurrence (max 81%) (3).

Nevertheless, reintubation after UE is strongly associated to the rise of hospital expenses consequent to the increase of ventilation days and ICU length of stay (18).

Currently there are no data about UE from Italian ICU settings, except for a recent qualitative study exploring the phenomenon (19). For these reasons, a study to analyze the incidence and risk factors of UEs was performed in an Italian general ICU.

Material and methods

Study design and aims

An observational retrospective study was designed. The primary aim was to record the incidence of AE and SE. The secondary aims were to identify the outcomes of UE patients and the risk factors.

Sample

All the intubated patients in the general ICU of the San Gerardo Hospital in Monza were enrolled from the 1st January 2008 to the 31st December 2016. This ICU admits patients from the emergency room and operating theatre; moreover, it is an Italian referral center for Acute Respiratory Distress Syndrome and Extracorporeal Membrane Oxygenation support.

The UEs events were distinguished into: self extubation (SE) and accidental extubation (AE).

The endotracheal tube fixation in the enrolled patients was made according to the well-established local ICU procedure. In orotracheal intubated patients the fixing system is performed using a 5 cm tape (Durapore®), cut as shown in figure 1. Under the tape, the nurse applies a thin hydrocolloid film (Duoderm extrathin®) to protect the patient's face skin, preventing the occurrence of pressure ulcers. This dressing is changed every 12 hours (at 8 am and 6 pm) and, simultaneously, the endotracheal tube is moved from a mouth side to the other. In nasotracheal intubated patients the fixing system is performed through of the utilization of a 1 cm tape (Durapore®) and the application of a thin hydrocolloid film (Duoderm extrathin®) to protect the skin of the patient's nose and the nostril. This dressing is usually changed every 24 hours. In these patients the oral care is carried out three times a day.

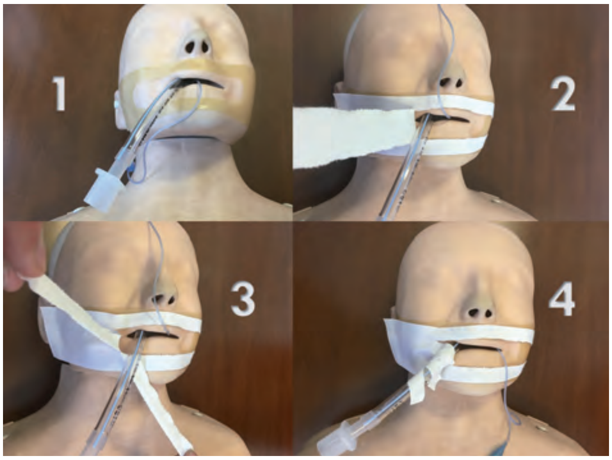

Figure 1.

Data collection

The study data were collected from a dedicated section of the electronical clinical documentation. The collected respiratory parameters, ventilation settings and administered medications were those recorded one minute before the occurrence of UE. The electronic integrated clinical documentation system records patients' data every 60 seconds. The analysis of patients' sedation levels was performed using the Richmond Agitation Sedation Scale (RASS) (20), as routinely done in the studied ICU. RASS evaluates the patient's level of consciousness, sedation or agitation. The score varies from 0 (alert and calm) to +4 (combative) for awake patients. If the patient is not awake, the score varies from -1 (drowsy), to -5 (unarousable) (20).

During the study period RASS was measured every four hours. The last value of RASS scale before the UE was recorded.

Statistical analysis

Data were collected and transposed on an xls file, and analyzed by the software SPSS ver. 22.0 for Windows©. The variables were analyzed as mean, standard deviation and range or median and interquartile interval, according to the type of statistical distribution. The comparison among groups was performed through non-parametric tests (Mann-Whitney test). A value of $p<0.05$ was considered statistically significant. The study was submitted to the Local Ethical Committee and approved by the act number 874 on 15th May, 2018.

Results

In the studied period 3422 patients underwent to endotracheal intubation. The patients with an intubation duration time higher than 24 hours were 1497 (43.7%). The mean age of the patients was 66.12±20.22 years, with a mean ICU stay of 5.57±10.30 days (median 2, Q1-Q3: 1-5 days). The admission diagnosis was medical in 46% (n=1574) and surgical in 54% (n=1848) of the patients. The UEs were 35: 33 SEs (94%) and 2 AEs (6%). The UE incidence on the 1497 patients with an intubation duration time higher than 24 hours was 2.34%. The percentage of UE decreases to 1.02% if calculated on all the intubated patients' population. For the years 2014, 2015 and 2016 we could estimate the incidence density of UEs. In these three years the density incidence was 0.31 for 100 ventilation days. Table 1 summarizes the cases of UE divided for years of occurrence. At the time of the UE occurrence, the patients had a median RASS of 0 (Q1-Q3: -2/0), a mean propofol dosage of 84.2±140.9 mg/h (in 7 patients), a mean midazolam dosage of 2.1±1.1 mg/h (in 4 patients) and a mean fentanyl dosage of 34.9±35 mcg/h (in 16 patients). A physical restrain by wrists lock was present in 17 (48.6%) patients. The other 18 (51.4%) UE patients were not restrained at the time of the event. At the time of the UEs, the ventilators settings were: Volume Controlled Ventilation in 2 (6%) cases (AE events – pediatric patients, events occurred during hygienic care); Pressure Support Ventilation with sigh in 15 (43%); Pressure Support Ventilation in 8 (23%); Continuous Positive Airway Pressure in 10 (29%). Table 2 summarizes the ventilation settings at the time of the UE events. Only 9 patients (26%) were reintubated. Eight patients were reintubated within an hour from the UE occurrence, while one patient was reintubated after 11 hours. In the 26 patients who were not reintubated, the respiratory supports used after the UE were: oxygen reservoir mask - 1 (4%), Venturi mask - 12 (46%), and helmet CPAP - 13 (46%).

In order to identify specific risk factors for reintubation after UE occurrences, an analysis of the differences in the parameters between the non-reintubated

Table 1. Events per years

Year	SE	AE	Total UE	Intubated patients	(Patients >1 day mechanical ventilation)	% UE	Ventilation days	UE rate every 100 days of mechanical ventilation	Reintubated patients	
									n.	%
2008	6		6	273	204	2.20			1	17
2009	5		5	470	179	1.06			1	20
2010	3	2	5	389	248	1.29			2	40
2011	2		2	402	219	0.50			1	50
2012	1		1	372	198	0.27				0
2013	2		2	318	213	0.63			1	50
2014	3		3	361	236	0.83	1410	0.2		0
2015	7		7	407	264	1.72	1505	0.47	2	29
2016	4		4	430	171	0.93	1506	0.27	1	25
Total	33	2	35	3422	1497	1.02		0.31	9	26

Legend: AE: accidental extubation; SE: self extubation; UE: Unplanned extubation

Table 2. Respiratory parameters before unplanned extubations events

Parameters	Average (SD)	Range
Sigh Frequency rate (15 pts)	0.8 (0.3)	0.5-1
Sigh Pressure – cmH_2O (15 pts)	29.9 (11.0)	25-36
Pressure Support Ventilation cmH_2O (24 pts)	9 (3.3)	4-14
PEEP cmH_2O	7.6 (2.9)	4-15
RR	19.2 (5.8)	9-33
FiO_2	0.4 (0.1)	0.3-1
$PO_{2\,mmHg}$	108 (112)	62-208
PO_2/FiO_2	264 (112)	62-693
$SpO_{2\,\%}$	97.4 (1.7)	94-100

Legend: FiO_2: Fraction Of Inspirated Oxygen; PEEP: Positive Ending Expiratory Pressure, PO_2: Partial Pressure Of Arterial Oxygen; RR: Respiratory Rate; SpO_2: periferical oxygen saturation

Table 3. Comparison between non-reintubated patients versus reintubated after unplanned extubation events

		No Reintubated Patients N=26	Reintubated Patients n=9	P value
Age		63.7 (16.5)	47.1 (30.9)	0.054
Intubation Days		4.9 (4.8)	4.6 (3.9)	0.875
Mode Of Ventilation	CPAP	10 (38%)	2 (25%)	0.986
	PS	5 (19%)	3 (38%)	
	Sigh+CPAP	2 (8%)	1 (13%)	
	Sigh+PS	9 (35%)	2 (25)	
Sigh		6 (26%)	6 (75%)	0.434
PS		9.2 (3.0)	8.5 (4.0)	0.647
PEEP		7.1 (2.0)	8.2 (2.8)	0.241
RR		18.0 (5.2)	24.2 (4.5)	0.005
pO2		156 (214)	98 (18)	0.455
FiO2		0.43 (0.7)	0.41 (0.7)	0.571
P/F		281(121)	240 (53)	0.365
SpO2		97.6 (1.6)	97.0 (1.5)	0.355
RASS		-0.3 (1.3)	-2.1 (0.75)	0.004

Legend: CPAP: Continous Positive Airway Pressure, FiO_2: Fraction Of Inspired Oxygen PEEP: Positive End Expiratory Pressure, P/F: PO_2/FiO_2 ratio, PS: Pressure Support, PO_2: Partial Pressure Of Arterial Oxygen, RASS: Richmond Agitation Sedation Scale, RR: Respiratory Rate, SpO_2: Periferical Oxygen Saturation,

patients and the reintubated patients was performed. The respiratory rate (RR) before the UE event was higher in the reintubated patients' group than the non-reintubated group (24.2±4.5 vs. 18.0±5.2 breaths/min. – p=0.005). Besides, the reintubated patients had a lower mean RASS value (-2.1±0.75 vs -0.3±1.3 – p=0.004).

We did not find statistically differences between the ventilation settings, the oxygenation levels and ventilation days in the two compared patients' group. Table 3 summarizes all the investigated variables in the two subgroups. No episode of death related to UE was recorded in the 9 years observed.

Discussion

The incidence of UEs reported by this study (1.02%) is similar the lowest UE values reported in literature (range from 0.5% to 35.8%). According to the international literature, in the studied sample most of the UEs were caused by the patients (94.3%), while only 5.7% was provoked by the healthcare workers.

The low incidence of the UEs found in this study could be affected by the appropriate nurse to patient ratio (1:2), kept as a constant work standard 24 hours a day (21). Moreover, the use of a protocol for endotracheal tube management shared by the whole staff (22) which has an efficient fixing system could have been a protective factor. These two variables probably allowed a sufficient level of patient's direct surveillance, and the prevention of the loss of the stability of the endotracheal tube.

No UEs happened during the oral care performance or during the change of the tube fixing system. These data confirm the safety of the recommendation to carry out these nursing procedures more than once per day. However, in order to accomplish this task maintaining a good control of the risk for the patient, it's mandatory to follow the procedure using an adequate level of attention. The patients with the highest risk of UE complications are those at the beginning of the respiratory weaning. In fact, at the time of the interruption of the sedation infusions, the patients could be agitated and confused and trying to self-remove the devices, since their presence can provide discomfort and pain.

However, the AEs remain the potentially most dangerous events because the patient often doesn't show an efficient respiratory drive to provide a valid spontaneous breathing. In fact, 2 patients (100%) were reintubated within an hour from the time of the event. On the contrary, the SE patients were more awake and with lower ventilator support parameters (6, 12); therefore, only 21.2% was reintubated. About SE events, there were no sufficient data to demonstrate the occurrences of some delays in the identification of extubation citeria (success predictors of spontaneous breathing trial).

The physical restrain is a tool with ambiguous effectiveness in preventing SEs because half of the patients (48%) succeeded in removing the endotracheal tube. In the literature the usefulness of physical restrain systems as preventive measures for the removal of medical devices is still discussed (15, 23).

Concerning the issue of patients' surveillance, the studied ICU is an open space type. This design could have exerted an influence on the low incidence of SEs, allowing an immediate awareness of the impending danger of SE and the consequent prevention of this kind of event. Currently, this consideration should deserve empirical demonstration, because there are no published studies comparing open bay ICUs and single box ICUs in terms of UE occurrence rates.

This study showed statistically significant differences in the mean RASS (p=0.004) score and in the mean RR (p=0.005) between UE patients undergone to reintubation versus those who were not reintubated. In fact, the reintubated patients had higher RR and lower RASS scores. These elements confirm the need of paying adequate attention to clinical evaluation (level of consciousness, breathing) immediately after the UE, besides the instrumental data which sometimes can be misleading. For example, patients during hypoxemic respiratory distress can maintain appropriate oxygen saturation values, at the cost of large increases of their RR.

Limitations

This study has some limitations. First of all the retrospective design didn't allow systematically to gather some potentially important data such as the number of nasotracheal intubated patients, even if we can affirm that they were surely the minor part of the studied sample. Besides, there was not the possibility to know the number of physical restrains implemented in the patients who did not undergo to UEs, thus limiting the possibility of making statistical comparisons. Lastly, the very low incidence of the UEs probably affected the level of statistical significance for the comparison of the subgroups of patients with AE versus SE, and reintubated versus no reintubated.

Conclusions

The incidence of UEs in the studied setting showed rates according to the minimal values reported in scientific literature. Furthermore, no episodes of death related to UEs occurred. Patients with lower RASS values and higher respiratory rates are likely to be reintubated after a UE event. A standardized program of endotracheal tube management (based on an effective and comfortable fixing system) seems to be a safe and a valid foundation to maintain low rates of UE episodes.

The results of this study seem to indicate that the patient's surveillance cannot be substituted by the utilization of physical restrains in order to prevent SE events.

The study was performed at General Intensive Care Unit of S. Gerardo Hospital, Monza (Italy).

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The efficacy of interprofessional simulation in improving collaborative attitude between nursing students and residents in medicine. A study protocol for a randomised controlled trial

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Abstract. *Background:* Effective collaboration among health professionals is an essential component to ensure quality of care. Many adverse events experienced by patients are attributed to misunderstanding or poor communication among members of the interprofessional team. Interprofessional simulation is a learning strategy used to improve collaboration and facilitate communication between medical and nursing students. *Aim of the work:* To determine the efficacy of educational program based on high-fidelity interprofessional simulation aimed at improving collaborative attitude. *Method:* For this purpose, a protocol for a planned single-center, non-blinded and Randomized Controlled Trial (RCT) was chosen. The present has been approved by the Ethics Committee of Area Vasta Emilia Nord (Italy) (n° 479/2018). All students attending the second and third year of nursing and all resident physicians in anesthesia, reanimation, intensive care and pain management of University of Modena and Reggio Emilia, will be recruited and randomly assigned to two groups. The Experimental Group (EG) will receive an educational intervention based on high-fidelity simulation and the Control Group (CG) will attend a traditional classroom lesson. Jefferson Scale of Attitudes toward Physician-Nurse Collaboration (JSAPNC) and Readiness for Interprofessional Learning Scale (RIPLS) will be administered before and after the educational program in both the EG and CG. *Conclusion:* Expected outcomes is that, at the end of the study, nursing students and resident physicians who participated in the interprofessional simulation show significantly higher levels of interprofessional collaboration compared to the CG, evaluated through the JSAPNC.

Key words: high-fidelity interprofessional simulation, interprofessional collaboration, educational program, nursing student, resident physician

Introduction

Effective collaboration among health professionals is an essential component to guarantee safety and quality in health care (1-5). According to several authors, many errors and adverse events are frequently correlated to poor quality of communication between the members of the interprofessional team and to poor teamwork skills (6-13). In contrast, the Interprofessional Collaborative Practice (ICP) promotes the reduction of care-associated infections, hospital readmissions and patient mortality (14-17). Recent studies highlight that highly efficient teamwork among health care professionals is associated with increased patient satisfaction, with reduced costs for the healthcare system and with a lower turnover of health staff members (13, 18-21). The ICP can be defined as a decision-making process between two cooperating roles, such as physician and nurse, characterized by interdependence, trust, respect, open communication and shared responsibilities in order to promote and improve patient care (22-26). In the healthcare settings, where patient outcomes are influenced by effective communication and interprofessional collaboration, there is a need for better interdisciplinary teamwork preparation of future professionals (3, 27, 28). Despite the fact that physicians and nurses work together, their academic courses are separate and the training in effective strategies of communication and care participation is often postponed to the future professional practice (29, 30). On the contrary, Inter-Professional Education (IPE) is considered by important international organizations [Institute of Medicine (US), World Health Organization, Joint Commission (US), Agency for Healthcare Research and Quality (US)] as an essential educational requirement in the health professional curricula (31-34). IPE has been defined as occasions "where students from two or more professions in health and social care learn together during all or part of their professional training with the object of cultivating collaborative practice for providing improved quality of care" (35, 36). According to the literature, students trained to use the IPE approach more likely become members of collaborative teams where the autonomy and the role of each profession are recognized (2, 37). In addition, IPE programs prevent the development of negative attitudes and prejudices and increase the importance of teamwork both in physicians and nurses (4, 5, 37-43). Medical students scored lower on readiness for IPE than nursing students, but they presented higher need for collaboration (44).

The use of simulation or standardized patients in IPE had a positive effect on readiness for IPE (45).

Clinical simulation is an interdisciplinary teaching strategy that can be used to facilitate the ICP and to improve communication skills between medical students and nurses in a skill lab context (13, 46-48). Simulation is an activity that allows replication of clinical care in a safe environment for students, without the pressure and the complexity of a real care environment, improving the integration of theory and practice (49-53). Traineeship and competency development are essential parts of clinical teaching (54) and realistic simulation can be an effective training method, especially if it is supported by the presence of trained instructors (55, 56). The simulation environment is therefore a controlled and low-risk pedagogical context, where the students, supported by a tutor, can feel free to learn without putting patients at risk (48). The necessity to guarantee reliable and safe treatment to the assisted people means that the simulation has acquired an increasingly important role in university education (57, 58). Being actively involved in the simulation process can provide a learning integration, which combines the theoretical foundations with clinical practice, favoring critical and thoughtful thinking in the students (59-63). In the simulation laboratory, students can develop technical and communication, problem solving and decision making skills (53, 61, 64-68). The benefits of the simulation procedure were analyzed by a meta-analysis and a systematic review, which showed that, compared to traditional learning methods, simulation improves students' knowledge, skills and behavior and, consequently, patients' treatment and care (66, 69). The scenarios planned for the simulated health activities create the conditions favoring teamwork and integration among professions in order to improve care programs and paths (70). Although some authors report cases of efficient interprofessional simulations, many questions are still open about the feasibility, acceptability, efficacy and changes in attitudes of the students who participate in simulations (71). Moreover, in many cases the effectiveness of these educational interventions has been evaluated without the necessary psychometric assessment (72). Since the interprofessional simulation requires a significant use of economic and human resources, its adoption can be justified only if trainers implement valid and reliable outcome measures (73). An integrative recent review (2018) on the use of interprofessional learning and simulation in undergraduate nursing programs concluded that the IPE and simulation, used together, show a positive impact on the development of communication skills and collaboration of nursing students (74). The authors concluded that, although among the eight included research studies none were randomized and controlled, meticulous methodology of studies could have minimized biases, predominantly due to the use of convenience sampling. Also the systematic review of Rutherford-Hemming & Lioce (2018) suggested that more studies with rigorous designs are needed to compare outcomes of IPE (75). Finally, Labrague et colleagues conclude their review by observing that an important aspect that warrants attention is the lack of RCT studies, 96% of the studies were not RCTs, therefore, one may question whether the interprofessional simulation caused significant improvement in interprofessional competencies or such changes were caused by other factors (76).

In the 2016-2017 Academic Year (A.Y.), a sample composed of three student groups of the University of Modena and Reggio Emilia 108, nursing students, 18 students of obstetrics and 20 residents in the School of Specialization in Pediatrics, participated in an interprofessional training program aimed at developing collaborative attitudes (77). The training intervention consisted of a preparatory meeting, a high-fidelity simulation “Reanimation of a new-born infant in a neonatal island” and a debriefing. The effects of the simulation was measured through the Jefferson Scale of Attitudes towards Physician-Nurse Collaboration (JSAPNC) (78), which showed a significant increase in the attitude of interprofessional collaboration only among nursing students but not in the other two groups of participants. The results of this study, which reports one of the first Italian experiences of simulated interprofessional didactics, suggest the value of simulation in improving interprofessional cooperative attitude, even though the low number of obstetric students and resident physicians may have influenced the lack of significant results (77).

In line with the literature, which promotes the research of strong experimental evidence of the effect of IPE combined with simulation activities (79), the aim of the present study is to evaluate the attitude of collaboration between nursing students and resident physicians in anesthesia, reanimation, intensive care and pain management, through an interprofessional simulation. The assumption is that, at the end of the study, nursing students and resident physicians in specialist training who participated in the interprofessional laboratory based on a high-fidelity simulation, show significantly higher levels of collaborative attitudes than the group of nursing students and resident physicians who participated in the standard education.

Method

Study design

This study protocol describes the design of a single-center, non-blinded, parallel-group RCT (1:1 ratio). A randomized, controlled, monocentric study will be carried out, involving two parallel groups of students, the Experimental Group (EG) and the Control Group (CG): in both groups, the interprofessional collaboration will be measured before (T0) and after (T1) their education session based on high-fidelity simulation for EG and traditional classroom lesson for CG. The study will be conducted at the Advanced Training and Medical Simulation Center of the Faculty of Medicine and Surgery of the University of Modena and Reggio Emilia and will last 12 months, starting from 1 October 2018.

The study protocol is consistent with the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) and conforms with the Consolidated Standards of Reporting Trials (CONSORT) statement for reporting RCTs (80, 81).

Study population

The students attending the 2nd and 3rd year of the nursing course and the resident physicians of the school of specialization in anesthesia, reanimation, intensive care and pain management, of the University of Modena and Reggio Emilia, during the 2018-2019 A.Y., will be considered eligible and invited to participate in the study. All members will be informed of objectives and methods of the study. Their participation will be voluntary. All participants will be asked to sign an informed consent.

Inclusion criteria

- Enrollment in the second or third year of the nursing course for nursing students in the 2018-2019 A.Y.,
- Enrollment in one of 5 years of the specialization school in anesthesia, reanimation, intensive care and pain management in the 2018-2019 A.Y.

Exclusion criteria

- Irregularity in the payment of university fees for both nursing students and residents,
- Refusal of written informed consent.

After having agreed to participate in the study, nursing students and residents will be allocated to one of the two groups (EG and CG) through a randomization list generated by software (Figure 1). The study will be conducted in the 2018-2019 A.Y. (from 1-10-2018 to 30-9-2019).

Randomization and allocation concealment

The randomization list, stratified by gender and study course attended, will be generated by software (R v3.5.1), in order to randomly assign the participants to the intervention group and the control group, in a ratio of 1:1. Randomization will be performed by an external statistician, not involved in training or data collection. Student recruitment will be completed before randomization. The allocation will be sealed on an envelope and held by a study assistant who is blinded to the subsequent allotment.

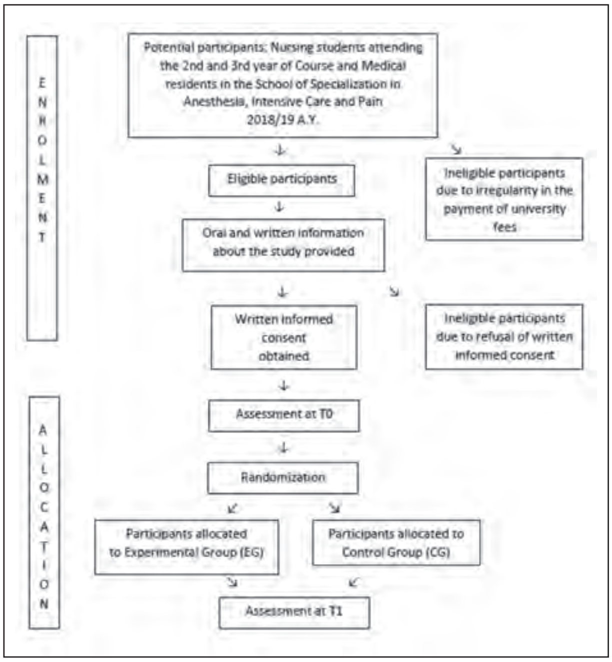

Figure 1. Diagram of the protocol (planned)

Intervention

The EG will participate in an experimental intervention based on high-fidelity simulation at the Advanced Training and Medical Simulation Center, realized by Faculty facilitators who are experts in this methodology. The members of the EG will be 6 nursing students and 2 residents. Before the simulation, the topic of interprofessional collaboration will be introduced and, afterwards, this group will be divided into two further subgroups, the first consisting of second year nursing students and residents attending the first three years of specialization, the second one consisting of third year nursing students and residents attending the last two years of specialization. All EG participants will receive an interprofessional training session in the laboratory using high-fidelity simulation, which provides two different scenarios, one after the other, in which the two sub groups will be involved. The first scenario, addressed to the first sub group will simulate the conditions of a patient admitted to a surgery unit who, after a surgical operation, presents a modification in his mental state, showing symptoms of acute cognitive deterioration. General clinical conditions, vital parameters and laboratory tests will suggest the evolution of a septic state. Nursing students should be able to recognize changes in mental status of the patient and in his vital signs and alert the medical doctor and, on his indication, take a blood sample. In the same simulation, the residents must be able to formulate a first diagnostic suspicion. After having formulated the diagnosis, the residents will prescribe a therapy and transfer the patient to the Intensive Care Unit (ICU). Following this first scenario, a Faculty facilitator will implement a debriefing session in both subgroups in order to deal with the issues highlighted by this first simulation.

The second subgroup, after having observed the first simulation described above through a video link, will participates in the debriefing session and, afterwards, accept the patient in ICU and provide him with intensive monitoring and supportive therapies for vital functions, after having considered the necessity of mechanical ventilator support. Nursing students and residents will take into consideration the aforementioned procedures and treatments in accordance with their professional competency. The handover between the two subgroups will have to take place in a standardized way, including a "patient" evaluation through the Confusion Assessment Method in ICU (CAM-ICU) and a passage of information through the Situation, Background, Assessment and Recommendation (SBAR) instrument.

At the end of the second simulation, a new debriefing session will be conducted by the same Faculty facilitator of the first session with all the participants in the two scenarios of simulation.

Control

The CG will receive a standard training intervention, consisting in a traditional classroom using lectures and powerpoint presentation lesson on the topic of interprofessional collaboration.

Questionnaires

To measure the attitude in interprofessional collaboration, the following scales will be administered to the participants of both groups before and after the training:

1. Jefferson Scale of Attitudes toward Physician-Nurse Collaboration (JSAPNC) (78, 82), a self-report questionnaire already validated in a sample of Italian medical doctors and nurses with a Cronbach alpha of 0.70 (83). The most recent version of JSAPNC consists of 15 items with answers concerning participants' degree of agreement/disagreement on a 4-point Likert scale (from 1 = strongly disagree to 4 = strongly agree). The score ranges from a minimum of 15 to a maximum of 60 points; the higher the score, the greater the attitude of collaboration. Items in each of the four factors are as follow:

a) Shared education and collaboration (1, 3, 6, 9, 12, 14, 15);

b) Caring versus curing (2, 4, 7);

c) Nurse's autonomy (5, 11, 13);

d) Physician's authority (8, 10).

2. Readiness for Interprofessional Learning Scale (RIPLS) (84), validated and adapted to the Italian educational context by Sollami and Colleagues, with a Cronbach alpha of 0.92 (85). This questionnaire has been widely used in literature to measure the readiness and attitudes of students in health professions towards the IPE. This scale consists of 10 items with a Likert 5-point scale (from 1 = strongly disagree to 5 = strongly agree).

3. A short anonymous questionnaire to investigate few socio-demographic variables (age, gender, high school diploma, year of university course).

At the end of interprofessional simulation, the Educational Practices Questionnaire (EPQ) will be administered only to the participants in the EG in order to evaluate perceptions of educational best practices' presence and importance in simulation (86). The Italian version of this scale presented a Cronbach alpha of 0.95 (56). It consists of 16 items to which the participants respond through a Likert 5-point scale (from 1 = strongly disagree to 5 = strongly agree). The questionnaire is divided into the following sub-scales: "Active learning" (10 items) measuring opportunities for active learning and participation in simulation; "Collaboration" (2 items) measuring opportunities for working together during simulation; "Learning diversity" (2 items) measuring opportunities for learning material in simulation and "High Expectation" (2 items) measuring objectives and expectations presented during simulation (86). Higher scores represent greater recognition of best educational practice in simulation.

Data collection procedure

To guarantee anonymity in completing the questionnaires and to allow a comparative analysis of the data, the students will be invited to put on the questionnaires a code known only to themselves. All participants will be asked to anonymously complete the investigative questionnaires, before and after the simulation. Anonymity regarding the pre- and post-test will be guaranteed by assigning a code. The operator who inserts the data of the questionnaires in the file for analysis will not be aware of the groups to which the nursing student and resident physician belongs.

Expected outcomes

The expected primary outcome is that, at the end of the study, nursing students and residents who participated in the interprofessional simulation show significantly higher levels of interprofessional collaboration compared to the CG, evaluated through the JSAPNC.

The secondary outcomes are represented by an improved readiness for interprofessional education, evaluated by RIPLS, in the EG compared to the CG and, only for EG, the effectiveness of simulation training, evaluated by EPQ.

Sample size and statistical study power

In accordance with the data collected in a pilot study focused on pre-post intervention, without a control group, performed in the same training context (Nursing students and resident physicians of the University of Modena and Reggio Emilia in the 2016-2017 A.Y.), with an identical primary outcome (77), we expected to detect a difference of 2 points in the mean JSAPNC scale scores between the EG and CG. Assuming a minimum difference between the EG and CG of 2 points in the mean JSAPNC scale scores, on the average total value of the JSAPNC scale, and a variance of 35, with an alpha error of 0.05 and a power of at least 0.80, the minimum sample to be enrolled in the present study is 153 students per group.

Data collection, management and analysis

The analysis of JSAPNC and RIPLS score variation will be conducted within the EG and CG at T0 and T1; from this comparison, it is expected that the difference between EG and CG at T0 is not present or is not statistically significant, while at T1 it is statistically significant. Descriptive statistics such as frequency, mean and standard deviations will be used to summarize the socio-demographic characteristics of the participants and the JSAPNC, RIPLS and EPQ scores. Statistical comparisons between T0 and T1 of both JSAPNC and RIPLS mean scores will be applied using the Student's t-test or the ANOVA, when appropriate. The comparison of categorical variables between groups will be performed through the chi-square test or Fisher test, when appropriate. Results will be calculated by software R v3.5.1 (87). A $p<0.05$ value is defined statistically significant. All randomised participants will be included in the intention to treat analysis.

Ethical considerations

This study has been approved by the Ethics Committee of Area Vasta Emilia Nord (Italy) (n° 479/2018) and will be conducted in agreement with the Helsinki declaration. Informed consent will be obtained before the students' and residents' participation in the study. All eligible participants will be informed of the purpose and characteristics of the study and of the proposed teaching interventions and will receive a clear informative written document, explaining the design, aims and procedure of the study. The investigator will present the study to the students and answer any questions. Each student will be given the opportunity to discuss the study with other people and will have at least one day to reflect before giving informed consent. The students and residents who sign the consent will be informed that participation in the study is voluntary and that they can withdraw their consent to participate at any time they wish and this will not affect training. The data collected will be reserved and used in compliance with the current legislation on the protection of sensitive data and privacy regulations. The investigator is the data processor, pursuant to EU Regulation 2016/679. The investigator will guarantee, at every stage of the study, monitoring, verification, review by the Ethics Committee and regulatory authorities, providing direct access to both the data and the original documents.

Strengths and limitations of this study

- This study addresses an important gap regarding utilizing of robust methods of research and reliable assessment methods.

- Randomised controlled trial design minimizes risk of selection bias.

- The power of the study was calculated in order to reach a potential statistical significance.

- Single-center study design may limit the generalizability of the study.

- Owing to the type of intervention, blinding of the nursing students and residents physicians is not possible.

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Incidence and type of health care associated injuries among nursing students: an experience in northern Italy

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Abstract. *Background and aim of the study:* Nursing students are at high risk of injury while on clinical placement. The incidence of injury is three times higher in comparison to other healthcare workers, with a prevalence ranging from 25% up to 33,2%. Lack of knowledge and of experience in delivering nursing care, anxiety and unfamiliarity with the clinical environment all represent risk factors for injury. This study describes the number and type of injuries occurring in an organizational setting where nursing students are trained in simulation laboratories before being exposed to a real clinical environment. *Methods:* An eight year retrospective observational study (2009 to 2017) was conducted on a non-probabilistic population of 1,403 nursing students from a university in the north of Italy. Incident reports were anonymised and entered in a database. *Results:* Overall the percentage of students who reported an injury (6,2%) was much lower than the one reported in the literature. *Conclusions:* The nursing programme curriculum of the above mentioned university consists of frontal lectures, group works, simulation based sessions and supervised clinical practice designed to equip students with all the necessary knowledge and clinical skills to prevent health care injuries. Despite the encouraging results of this study, further actions in order to protect first year students, who are more subject to risk of injuries, are recommended.

Key words: nursing students, incidents, biological risk, occupational injuries, simulation, nursing tutoring

Introduction

The safety of health workers is paramount. Nursing students, while on placement, are considered to be at high risk of Healthcare Associated Injury (HAI) during clinical placement. In an Australian study, 13,9% out of 319 students reported a needle or sharp injury during the first two semesters of their nursing course (1). On the contrary, another study performed on 2047 students reported only 135 injuries (6,6%) (2). An Italian study compared the incidence of students' injuries within the nursing population over a period of 11 years and found 171 out of 909 biological HAI in nursing students (18,82%) (3). It is interesting to notice that whenever anonymous questionnaires were used to collect the HAI data, the results showed higher percentages than the retrospective studies in which written reports were used, with incidence rates of 25,2% (4) and 32% (5).

The level of knowledge of the procedures, the lack of experience in delivering them, and the first impact with the professional environment are factors that are directly associated with HAI during the period of clinical training (1). Therefore, the acquisition of preventive strategies including the proper use of safety devices is essential in order to minimize the incidence of HAI in the clinical setting (6).

The greatest risk factors for student injuries are stress, haste, inadequacy, inexperience and a low level of training. The risk of injury is higher in the initial semesters and lower in the last university year. In fact before completing their studies, undergraduate nursing students may benefit of a comprehensive theoretical and clinical learning experience and therefore they will be able to participate more actively and consciously in delivering patients' care. Furthermore they will learn how to properly use safety devices which are also considered as an effective measure of prevention to lower the number of injuries (3, 7). Furthermore, simulation and hospital based clinical training, which promote the proper use of safety devices, is proven to reduce the risk of injury in nursing students and to provide a better patients' care (8). In addition to the proper use of safety devices, first aid recommendations should be provided in case of an incident, according to the different types of injury and all incidents must be systematically reported (1) Furthermore, it is well known that in different clinical settings, where clinical training is carried out, safety devices are randomly used due to lack of time or to the unavailability of the devices. This scenario is further worsened by the frequent inattention of students in using security devices and the lack of reporting of any incident occurred (1).

Needle and cutting injuries are a significant risk for the transmission of infectious diseases, including Hepatitis C Virus (HCV), Hepatitis B Virus (HBV), and Human Immunodeficiency Virus (HIV). The World Health Organization (WHO) has estimated 16,000 cases of hepatitis C, 66,000 cases of hepatitis B and 1,000 cases of HIV as a consequence of needle injury (9). Moreover, percutaneous exposures account for 75% of all biohazard exposures reported by nurses (10).

Needlestick injury appears to be the most frequent incident, and usually occurs during the clinical procedure or immediately after while discharging the needle. In 19,9% of cases the injury occurs when using butterfly needles, in 18,6% when using standard needles, in 15,2% when using insulin needles and in 3.4 % when using blood lancets. The syringe needle determines 37% of injuries (4).

The areas most affected by the injuries are the hands (83,4%), specifically the fingers of the hand opposite to the dominant one (11). The mucocutaneous contacts with biological fluids are prevalent with 62,2% of exposures, with a 66,6% localization in the face and 91% in the ocular area (12).

During clinical training, nursing students perform a set of procedures at high risk of percutaneous and mucocutaneous exposure to blood potentially infected with pathogens. This risk decreases as students' clinical skills improve, as students' awareness of the biological risk is developed and as preventive measures are correctly applied. This suggests that the development of simulation laboratories for nursing practice, the presence of tutors during clinical placement, the elimination of unnecessary punctures and the implementation of industrial research for the development of safe technologies can improve working conditions while reducing the risk of occupational diseases in healthcare (7).

Students claim that "doing" rather than "reading and writing" aids learning in preparation for clinical training and practice. Studies show that those students who attend simulation laboratories acquire safe and controlled knowledge and skills. Moreover, tutors' clinical experience during laboratory activities is a vital as this contributes in making students' placement safer (8).

However, several studies show a lack of awareness of HAI risks and how these are underestimated by clinical tutors (registered nurses working in the clinical setting) and lecturers in clinical placement and simulation laboratories (13). This sparks a careful consideration of the organizational model of nursing degree courses, where university tutors are directly responsible for the management of simulation laboratories and clinical placement (8, 14).

The Italian Study on HIV Risk Occupational (SIROH) reported changes in knowledge among nursing students, before and after the first year of their degree course. Students in the first two years of nursing courses use gloves when handling needles, mainly as a self-protection procedure, especially during blood collection and intramuscular injections. However, this concept of self-protection has practical inconsistencies. In fact, it has been reported that a large percentage of students have maintained the habit of recapping the needle after use. This practice is considered one of the main causes of incidents (13). Since students underestimated the HAI risk a consistent training during all the university course is necessary together with and a tight cooperation between the university and the health agency staff (14).

Aim

The objective of this study is to describe the number and type of injuries occurred to students attending the nursing degree in a university in Northern Italy that has activated simulation laboratories and professional activities preparatory to the clinical placement.

Materials and methods

A retrospective observational study was conducted in which clinical placement injuries occurring to a cohort of nursing students were recorded and investigated.

The students enrolled in the present study received a modular and consecutive learning experience consisting of a mandatory attendance in the simulation laboratory, in-depth seminar activities, nursing science classes, safety courses and specific activities carried out with tutors.

The professional activities were delivered by university nursing lecturers, by clinical skills tutors, by members of the prevention and safety service of the health authority and by university tutors. The apprenticeships involved were the medical areas for the first year, the surgical areas, paediatric and operating room for the second year, critical area, psychiatry and home / family care for the third year.

The sample, of a non-probabilistic type, consists of students from all three years attending the nursing degree program who carried out the clinical placement from 2009 / 2010 to 2016 /2017. The study was carried out for a period of 8 academic years.

Data were collected in a database. Any personally identifiable information was removed from data sets and a numerical code was used for each subject. The following data were recorded: academic year, genre, training period, vaccine coverage for HBV and tuberculosis (TB), unit or ward, the day and time of the incident, training time preceding the incident, dynamic and prognosis. Data collection was authorized by the local Bioethical Committee.

The analysis was conducted with SPSS Version 24. For cardinal variables, univariate (ANOVA) and descriptive analyses were performed, calculating mean (M) and standard deviation (SD), with a confidence interval (CI) of 95%.

The categorical variables were evaluated through the non-parametric chi-square test. A value of $p < 0,05$ was considered statistically significant.

Results

1403 students took part in the present study; 481 (34,28%) were enrolled in the first year, 451 (32,14%) in the second year and 471 (33,57%) in the third year.

The planning of the internship activities is described in the materials and methods section. Daytime presence was 7 a.m. to 9.30 p.m. with a 7-hr and 15-min daily duty. Overall 87 (6,2%) clinical placement injuries were recorded; 41 (41,1%) occurred in the first year, 13 (14,9%) in the second year and 33 (37,9%) in the third year.

The non-parametric calculation shows no statistically significant differences ($X^2 = 12,309$, $P = ,581$) on the total number of incidents occurred for each Academic Year (AY). However, as shown in Table 1, the first-year and third-year students have a higher number of incidents than the second-year, especially in the Academic Year 2009/10 and 2015/16.

Gender does not show substantial differences ($P=,393$). However, as expected by the predominant representation in course degree, the female population was the most affected (n = 28, 68,29%).

There are no differences regarding the times in which the incidents occurred ($P = ,957$); however, the most sensitive segment would seem to be from 10:00 to 14:00 with an average percentage of incidents > to 9,5% (figure 1).

On the dynamic characteristics and the anatomical sites affected by injury, there are no differences re-

Table 1. Overall distribution of injuries occurring to nursing students during clinical practice

Number of injured students	Year 1 n=41 n	Year 1 n=41 %	Year 2 n=13 n	Year 2 n=13 %	Year 3 n=33 n	Year 3 n=33 %	Total N=87 N (%)	X²	P
Academic year								12,309	,581
2009-10	8	19,51	2	15,38	5	15,15	15 (17,24)		
2010-11	5	12,20	3	23,08	2	6,06	10 (11,49)		
2011-12	6	14,63	2	15,38	4	12,12	12 (13,79)		
2012-13	3	7,32	1	7,69	6	18,18	10 (11,49)		
2013-14	2	4,88	3	23,08	4	12,12	9 (10,34)		
2014-15	3	7,32	1	7,69	4	12,12	8 (9,20)		
2015-16	8	19,51	1	7,69	6	18,18	15 (17,24)		
2016-17	6	14,63	-	--	2	6,06	8 (9,20)		

lated to the years of the course. Needle-stick injury shows a higher percentage (n = 45, 51,72%); injury mostly occurred (n = 57, 65,52%) during medication administration, mostly affecting the hand / finger area (n = 62, 72,09%) (Table 2).

Table 3 describes the trend of incidents during the eight academic years considered and demonstrates that needle injury significantly occurs during the procedure (P = <,0001).

It is interesting to note that the percentage of injury occurring during needle disposal (n = 9, 60%) in the 2009-10 AY almost halved in the following years. However, needle injury remains steadily high during the administration technique.

ANOVA analysis on the days and hours of clinical placement were injuries did not occur (Table 4) demonstrates that the incident-free interval is inversely proportional to student's year of study; in fact, this interval is shorter in first-year students than in students' enrolled in other years of their course: 211,20 ± 130,38 hours, followed by second-year students with 311,71 ± 209,39 and from third-year students with 391,45 ± 230,82, P = <,0001. Similar values are obtained when the number of days spent on clinical placement before

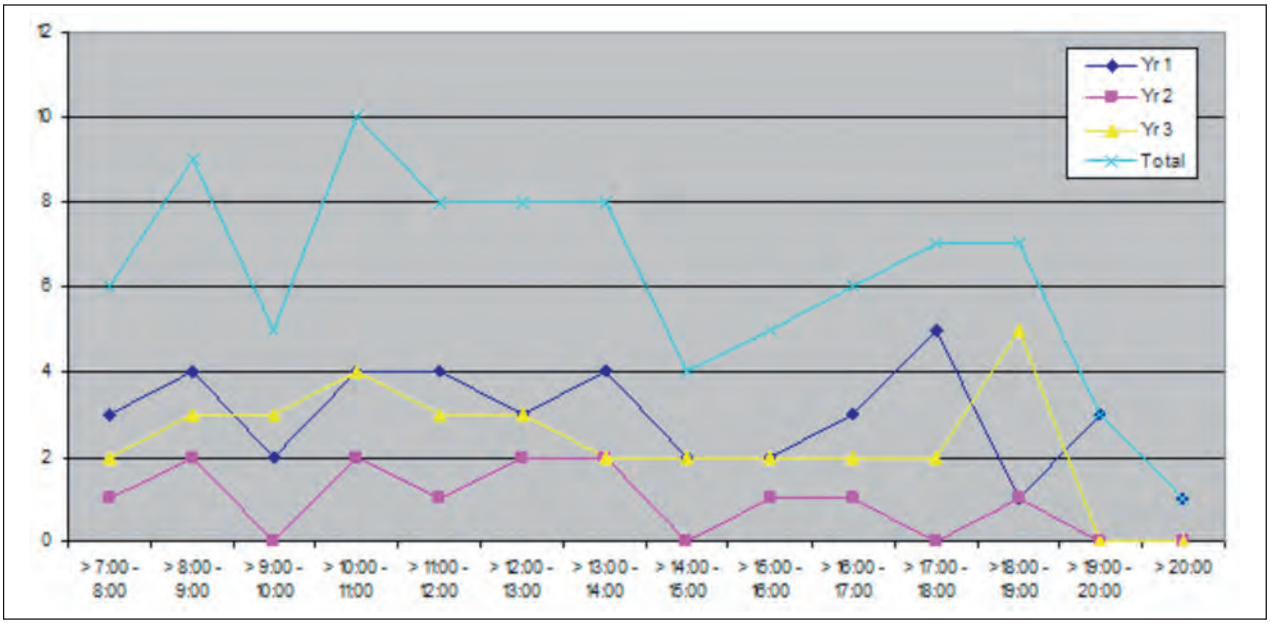

Figure 1. Distribution of injuries according to working hours

Table 2. Time and type of HAI

	Yr 1 n=41		Yr 2 n=13		Yr 3 n=33		Total n=87			
	n	%	n	%	n	%	n	%	X^2	*P*
Time									15,033	,957
>7:00-8:00	3	7,32	1	7,69	2	6,06	6	6,9		
>8:00-9:00	4	9,76	2	15,38	3	9,09	9	10,34		
>9:00-10:00	2	4,88	--	--	3	9,09	5	5,75		
>10:00-11:00	4	9,76	2	15,38	4	12,12	10	11,49		
>11:00-12:00	4	9,76	1	7,69	3	9,09	8	9,2		
>12:00-13:00	3	7,32	2	15,38	3	9,09	8	9,2		
>13:00-14:00	4	9,76	2	15,38	2	6,06	8	9,2		
>14:00-15:00	2	4,88	--	--	2	6,06	4	4,6		
>15:00-16:00	2	4,88	1	7,69	2	6,06	5	5,75		
>16:00-17:00	3	7,32	1	7,69	2	6,06	6	6,9		
>17:00-18:00	5	12,2	--	--	2	6,06	7	8,05		
>18:00-19:00	1	2,44	1	7,69	5	15,15	7	8,05		
>19:00-20:00	3	7,32	--	--	--	--	3	3,45		
>20:00	1	2,44	--	--	--	--	1	1,15		
Type of injury									9,181	,515
Needlestick injury	22	53,66	6	46,15	17	51,52	45	51,72		
Blood exposure	6	14,63	1	7,69	5	15,15	12	13,79		
Exposure to other body fluids	7	17,07	3	23,08	6	18,18	16	18,39		
Muscle skeletal injuries	--	--	2	15,38	2	6,06	4	4,6		
Sharps injury	5	12,2	1	7,69	1	3,03	7	8,05		
Other	1	2,44	--	--	2	6,06	3	3,45		
Type of dynamic									3,766	,439
Needlestick injury while preforming the procedure	29	70,73	7	53,85	21	63,64	57	65,52		
Needlestick injury at needle disposal	11	26,83	4	30,77	8	24,24	23	26,44		
Not specified	1	2,44	2	15,38	4	12,12	7	8,05		
Anatomic site of injury									7,386	,287
Head/face	11	26,83	3	23,08	8	25	22	25,58		
Hand/fingers	30	73,17	9	69,23	23	71,88	62	72,09		
Trunk	--	--	--	--	1	3,13	1	1,16		
Foot	--	--	1	7,69	--	--	1	1,16		

Table 3. Mode in which injuries in the academic years studied occurred

	2009-10 n=15		2010-11 n=10		2011-12 n=12		2012-13 n=10		2013-14 n=9		2014-15 n=8		2015-16 n=15		2016-17 n=8		Total		
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	N (%)	X^2	*P*
Needlestick injury while preforming the procedure	6	40	8	80	10	83	8	80	2	22,22	6	75	12	80	5	62,5	57 (65,52)	30,4	,007
Needlestick injury at needle disposal	9	60	2	20	--	--	1	10	4	44,44	2	25	3	20	2	25	23 (26,44)		
Not specified	--		--		2	17	1	10	3	33,33	--	--	--	--	1	12,5	7 (8,04)		

Table 4. Days and hours free of injury

	Yr 1 n = 41	Yr 2 n = 13	Yr 3 N = 33	Total n = 87		
	M±SD				F	*P*
Days of traineeship	30,76±18,5	45±29,97	56,28±32,89	42,41±28,66	8,448	,000
Hours of traineeship	211,2±130,38	311,71±209,39	391,45±230,82	293,46±201,27	8,554	,000

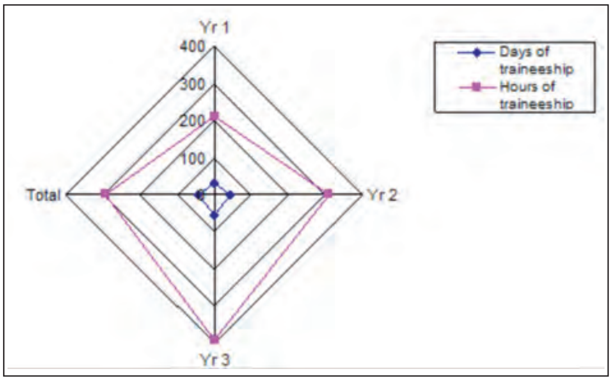

Figure 2. ANOVA analysis on the days and hours of traineeship spent free of injury

an incident are considered; 30,76 ± 18,50 for first-year students, 45 ± 29,97 for second-year students, 56,28 ± 32,89 for the third-year students, P = <,0001.

In figure 2, it is evident that the time spent in training before the incident report for second-year students, overlaps the total average of the days and hours of all three years of the nursing course.

Discussion

Overall the percentages of Healthcare Associated Injury (HAI) occurred to students in the eight academic years taken into consideration, were lower than reported in the literature (6,20%). (1, 3) However, these results could underestimate this phenomenon. In fact, it has been reported that half of the injured students tend not to report the incident (1, 15) and this explains the higher rate of injuries detected through an anonymous questionnaire administered to students (2, 4, 5).

The results of the study could be influenced by educational and organizational factors. Before going on clinical placement, students attended and passed the exams in the simulation laboratories where they applied the procedures and techniques learned during nursing classes. This allowed a possible knowledge consolidation related to the correct use of Personal Protective Equipment (PPE). The first-year laboratory activities have been supplemented by 16 hours of frontal teaching compliant with the 81/2008 Legislative Decree, dealing with health workers safety. Furthermore, in-depth seminars delivered during the nursing degree program also supported skills laboratory and clinical placement activities.

The need to evaluate the relationship between the number of skills laboratory hours and the number of exposures is already considered an important element that needs to be further explored in literature (2). The percentage of HAI detected, albeit low, does not prove that the adopted educational approach is better than other approaches currently in place in other universities. In fact, it is not possible to compare the number of students injured during the course of study with the number of HIA occurred in a previous teaching model, in which laboratory activities were not delivered. For this reason, it was not possible to evaluate the direct relationship between simulation and accident reduction during clinical placement.

The nursing degree program has developed specific teaching material preparatory to the clinical placement, which consist of topics integrated by theoretical and practical activities. Tutors' supervision of practical activities have fostered student critical thinking in care planning in pre, intra and post-training phases The organizational model, in accordance with the literature (2, 3, 5, 13), has allowed to reduce the risks of exposure, making students more aware and proactive during their time in the clinical setting.

The laboratory activities were carried out by expert clinical tutors, which actively collaborated with the university nursing lecturers, responsible for the teaching processes, in order to reduce the gap between theory and practice, favouring access to clinical placement. Most of the laboratory tutors supervised students during their clinical placement. This favoured a strong integration of clinical tutors in the university setting. According to Smith et al. (2), this dual function of laboratory tutors allowed students to prevent injuries and at the same time to have a solid and consolidated clinical training. In this regard, Stefanati et al. (3) support the important role of the clinical tutor integrated with the university system. Nursing professionals who supervise students must foster and increase trainees' awareness towards the biohazardous incidents and the correct and responsible use of the PPE.

Although the study does not highlight statistically significant differences between the number of injuries in the academic years taken into consideration, first-year students were more subject to incidents despite laboratory tests, safety courses, and tutoring. The number of injuries, although very small, depends on the student's individual difficulty in perceiving risk (17) within an organizational context in which the student has no previous experience (7). Another factor that can affect this result is the area in which the injuries occurred. In fact, first-year students spent 420 hours of training in the medical areas. This supports previous findings by Giuliani et al. (17) who showed that 63,7% of incidents occur in medical departments.

Another relevant figure is the percentage of incidents in third-year students (37,9%) that differ from percentages reported in the literature (7, 13). Possible explanations could include the clinical complexity encountered in the clinical area and the use of advanced techniques and complex devices, despite the fact that available studies suggest the adoption of less complex procedures, which might expose students to a higher risk of injury (7, 18).

The time slots in which there is a rate of incidents > 10% are 8 to 9 a.m. and 10 to 11 a.m. From this time onwards there is a progressive reduction interrupted by an afternoon peak > 8% in the slot from 5p.m. to 7 p.m. In this survey the students were exposed in time slots not confirmed by the literature (11); however, the current dynamism of the organizational and welfare models has affected the workplans of the operative units with consequent shifting of risk into different time slots.

Regarding the dynamics and the characteristics of the injury, the needle injury is the most frequent injury (51,72%). This occurs during the administration phase (65,52%); with 26,44% of injury occurring in the disposal phase. The most affected anatomical site is the hand / fingers with a 72,09%. The results are in accordance with those provided by previous studies (4, 11, 16).

This study also tried to map the average time spent by the student in training before the incident report. The results are in line with research carried out in this field (7) and provide valuable indications for establishing appropriate and effective teaching planning for tutors. Considering that the incidence of injury is higher in first-year students when compared to their second and third year colleagues, specific sessions were designed and carried out by the university tutors to tackle this phenomenon. These sessions could promote and strengthen the safety culture, in which students, clinical and / or university tutors, would no longer underestimate the risks of HAI, as highlighted by Bergamini et al. (13).

Students following injuries report negative feelings such as anxiety, fear, anger, worry, low self-esteem, insecurity, frustration and perception of insecurity (15). These feelings could lead students to drop out of their course, especially in the first year (19). From the analysed data none of the injured students dropped out. All students exposed to biological fluid risk followed the occupational medicine recommendations. This result contrasts with results reported by Almeida et al. (16), which recorded a drop-out rate of 32,8%. This discrepancy could reflect the activity of university tutors that met the injured students in one-on-one meetings or in small groups in which the internship experiences are re-elaborated together. This practice is essential and it will have to be implemented in the future. It is also very important to collect data on how incidents occurred in order to develop strategies to be shared in safety courses and simulation laboratories before the beginning of clinical placement.

Conclusions

The percentages of Healthcare Associated Injury (HAI) occurred to students in the eight academic years taken into consideration were lower than reported in the literature (6,20%).

The university has favored a model in which the training is planned and valued with preparatory and introductory professional activities. Students were engaged in a learning process consisting of simulation laboratory classes, in-depth seminar activities, nursing science classes, safety courses and dedicated tutoring activities. Professional activities were delivered by university nursing lecturers, clinical laboratory tutors, members of the prevention and safety service of the health authority and university tutors.

This model requires a close collaboration between the university and the healthcare regional system institutions. The activities described above were managed by clinical staff who were supported and supervised by university tutors, responsible for the teaching and learning process. The clinical placement was monitored by university tutors through meetings with small groups of students. These meetings took place throughout the academic year with the purpose of promoting students' self-reflection on care planning, sharing good practice and enhancing critical reasoning.

Limitations of the study

Students recruitment limited to a single campus in a university with multiple campus and the small sample size represent the limitations of this study.

Given the importance of the topic, it is advisable to conduct a cross-sectional study involving students from different nursing degree programs throughout the national territory. This would allow to compare different teaching and organizational models and to indicate what could further limit the incidence of HAI.

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Original article: Looking inside the care: the subjective point of view

"I would like to tatoo the illness on my arm". The Integrated Personalized Nursing Diagnosis (IPND)

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Abstract. *Background and aim*: The nursing diagnosis can based on two different approaches: the standard diagnosis, searching for regularities that can fall within pre-existing categories identified by the nurse, as the expert of the disease; the narrative diagnosis, based on personal meaning attributed to the illness, of which only the patient is the expert. The aim of this work is to underline the usefulness of integration between standard diagnosis and narrative diagnosis, through the Integrated Personalized Nursing Diagnosis (IPND). *Methods*: A 31 years old man, suffering from leukaemia, is welcomed at an Italian Oncological Day Hospital, by a nurse trained in the IPND approach. She used the Gordon functional models on objective data, and collected a narration about patient's experience, which has been analyzed with a Grounded Theory methodology. *Results*: The narrative revealed critical issues and the priorities that patient assigns, which would not have been obtained from a standard diagnosis. From the standard diagnosis, however, emerge several aspects that the patient has neglected to narrate and that does not directly address in his story. The diagnostic integration allowed the nurse to define a conceptual map of problems and resources in a personalized manner. *Conclusion:* The IPND not only gives importance to the priorities of the patient, but also underlines the dynamic path, in which not only the static analysis of needs becomes significant, but also the changes that occur in attributing new meanings to the life experience, as well as the evolution of the person him/herself in this process.

Key words: integrated, personalized, nursing diagnosis, patient, engagement, leukaemia, Oncological Day Hospital

Background

The evolution of the care and assistance system has underlined the need for a global approach to health problems, as highlighted by numerous studies (1-5). The experience of the disease includes, in fact, the bio-physical dimension (disease), the psychological-perceptive (illness) and the socio-relational profile (sickness).

Charon has been analyzing narratives in the clinical setting and she has been using narratives to improve practice, in the light of a new awareness reached thanks to the study of narrative theory (6). Narrative medicine does not represent a different type of medicine, but it is the same practice performed with narrative skills (7). We can identify four situations where narrative skills can be implemented: sympathetic involvement in the physician-patient relationship; a reflexive approach of healthcare professionals with themselves; the relations of healthcare professionals with their co-workers; the physician-society relations, based on mutual trust.

In the perspective of the humanistic narrative approach, the integration model proposed by Silva and Charon (8) aims to integrate the Narrative Medicine with the Evidence-Based Medicine. Also in nursing, the recently proposed Integrated Narrative Nursing Model (INNM) (9) addresses the person as a unit, consisting of a plurality of dimensions (bio-physiological, psychological, socio-cultural, and spiritual). The model integrates the traditional model based on the disease, with the narrative one based on illness and sickness. It therefore considers health in both the bio-clinical and the psycho-social dimension. Its objectives are to solve problems, but also to understand the person and the family, accompanying them when the problem can no longer be solved. It becomes therefore a shared problem between the sick person expert in his internal life and a professional expert in empathy.

In agreement with Sakalys (10) a restructuring is necessary in patient-nurse relationship during the nursing process, which must pass from a monological meeting to a dialogic approach, encouraging the patient's voice in an interdependent, mutually respectful care process. In this dialogical encounter, shared meanings are developed between professionals and patients.

Starting from these epistemological assumptions, the methodological process that derives from this model has been analytically described, which, rather than breaking up and parceling, integrates the data in order to arrive to an integrated assessment or INNA (11), and at personalized patient education or INNE (12). The model uses both quantitative methodologies and instruments, deriving from the natural sciences (e.g. clinical and instrumental exams, scales, measurement tests), and qualitative ones typical of the human sciences (e.g. interview, narration and patient's agenda).

This methodology requires a training of the nurse to the flexibility and to the specific assessment of the situation, including the context and the person, as well as the knowledge of effective protocols in the treatment of the disease. Thus, a critical and reflective thinking and a relational awareness help the nurse to organize data efficiently in a dynamic way, establishing the main needs, as well as the welfare priorities and the educational goals, choosing the most suitable methodology based on personal characteristics and situation, inside the particular and unique framework of the assisted person in his/her history of illness.

The aim of this work is to offer further development to the INNM model and the INNA model through the Integrated Personalized Nursing Diagnosis (IPND).

As well as the model from which it originates (INNM), nursing diagnosis is also characterized by the integration of information coming from two different approaches applied to the diagnosis of the same person. Using a terminology typical of the psychological debate on the assessment of the personality and the individual, the first approach is represented by the standardization of nursing language (13, 14) and is characterized by being nomothetic, monosemic and centered on the detection of laws and rules common within the population.

In the individual, the effort is the search for regularities that can fall within pre-existing categories, be they statistical, diagnostic or symptomatological. This type of nursing diagnosis therefore leads to the formulation of a judgment concerning the responses of a person to health problems, real or potential, which is based on hypothetical-deductive thinking. This method adopts a defined set of areas of possible impairment of the patient, ranging from the physiological, to the psychological, social and spiritual one, from time to time selected based on the pathology and risk taking place in the specific case.

The other approach, represented by the narrative diagnosis, is instead an idiographic and polysemic one, which is centered on the detection of the unique and unrepeatable characteristics of the individual, implying a deep analysis of the single narrated story, and on an interpretative, analogical and associative type of knowledge. Referring to the methodology of the Grounded Theory (15, 16), the diagnosis uses the "raw" material provided by that particular patient. According to this perspective, it is not the nurse theoretical model that guides the path, but it is the material shared by the patient himself or herself.

The standard diagnosis, duly known by the professional, comes to be integrated to "give voice" to the patient and his/her experience. The narration is understood and analyzed as a unitary material, as it is aimed at reconstructing the complex and idiosyncratic meaning attributed to the experience of illness and sickness, of which only the patient is the undisputed expert (17).

Narrative uses active listening, empathy and active participation of the person in the diagnosis as well as in the whole process of assistance, through the patient engagement (18).

It is then integrated with the standardized assessment that is expressed by the professional, as the undisputed expert of the disease.

The basic approach is therefore oriented towards the support and co-construction of shared meanings. Person and nurse, according to this approach, provide a joint judgment on real and potential problems, as well as on the resources that can be put in place.

As recently argued in the clinical-care setting (11), the evaluation and understanding of the free patient narratives makes use of a professional who collects the story and develops a strong professional competence in identifying the words and key concepts that emerge from that specific narration. This is combined, in this case, with the competence related to the knowledge and applicability of the standard diagnosis, quantifying the trend of the salient thematic categories.

In summary, the combination of these two diagnoses, one in depth, dynamic and ideographic and the other objective, defined and nomothetic, allow to return a personalized, unique and unrepeatable evaluation framework for every person who experiences illness.

Method

The purpose of this work is to integrate diagnostic information from both a nomothetic and an ideographic evaluation of the same person, in order to be able to make a personalized diagnosis

The case analyzed in this paper is that of Paul, 31 years old, suffering from acute myeloid leukaemia and afferent at the Oncological Day Hospital (DH) in a city in Northern Italy.

Paul is at the first access to the service and he is welcomed by Diletta, a nurse duly trained in the assessment of the person with the IPND approach. The nurse offers a first nursing evaluation based on the Gordon functional models (14) and on objective data related to the patient's health status together with an overview of the main problems reported.

Subsequently, the nurse decides to collect a narration of the person about his own experience of illness, starting from a question: "Would you tell me about your experience of illness?" which is followed only by brief questions of clarification. The narration collected with the written consent of the person, has been recorded and entirely transcribed.

Subsequently, three independent judges analyzed the free narration, with a Grounded Theory methodology. This research approach involves the progressive identification and integration of meaning categories deriving from the information collected. The method places the emphasis on the identification of the categories and the relationships that exist between them, to create an explanatory context concerning the investigated phenomenon. The categories emerge from the grouping of narrative components that share the central characteristics (19).

In this study, the three independent judges decided not to use descriptive or analytical labels to identify the categories, but to use the salient words of Paul himself. Therefore, from the analysis of the narrative, some thematic areas emerged that have been integrated and defined, starting from the contents themselves. We then proceeded to the structuring of the categories with the addition of the same extracts of the narrative composing them. The main active role of who collects a history of illness is characterized by the use of soft skills, such as empathy and active listening that, in clinical practice, translates into an advanced competence in identifying the central themes that emerge from the story. Since the latter is a free production characterized by logical and temporal jumps, recursion and "generative chaos", the nurse limits herself to ordering and aggregating the data, without interpreting them, increasing the comprehensibility of the words also in the eyes of Paul himself.

The personalized diagnosis, which emerges from this type of analysis, is therefore a joint and dynamic judgment on the current, potential and personal resources of the person, which takes into account the patient's voice, directly collecting the meaning that he attributes to his story.

Results

1. Standard Diagnosis

Paul, 31 years old, is being treated at the oncological Day Hospital, with a diagnosis of acute myeloid leukaemia after allogeneic transplantation from a consanguineous donor.

Currently he is in good general condition.

Paul shows slight loss of appetite with significant weight loss outcomes. He currently weighs 70kg and his BMI index indicates a slightly underweight (BMI=18).

Paul is quite worried about excessive weight loss, even admitting signs of embarrassment and shame. He also shows slight signs of fatigue and intolerance to daily activity.

He finally complains about some adverse effects of cortisone therapy, such as fluid retention and increased blood sugar levels.

The assistance problems emerged are displayed in Table 1.

There is also a potential problem, which is the risk of complications due to the adverse effects of adrenocorticosteroid therapy.

2. Narrative Diagnosis

The following seven topics emerged from the patient's narration.

1. "I was an invincible type as a person"

Before the onset of the illness, Paul describes himself as an active, dynamic and proactive person on a social, work and recreational level, as emerges from the following extracts.

"It was always me who gave a help to others […]"It was the first time I needed someone, although I never acted like I needed" (Extract 36).

"Having a very strong character, to avoid disputes I used to do things. I have done relatively little wrong, but because I have always studied the work choices I have made" (Extract, 52).

"I was doing a job that ... There are 150 phone calls a day, 40,000 km a year, that is ... so you're always there, full all day, completely always at high stress level" (Extract 12).

"I've always been on holiday alone, every year, 10-15 days, to see if I could handle stress, if I managed to handle a lot of things" (Extract 11).

"Until just before the discovery ... […] being quite young, I have always done many sports activities.. Just before getting sick I did a 3,000 m long trek, four mountain peaks 25 days before. On Monday we had a game of soccer […] after a few days I had a bit of trouble breathing and […] basically everything started there" (Extract 2).

2. "Like a bolt from the blue"

In this image of independence, strength and performance, the disease broke out in a sudden and overwhelming way, with repercussions on Paul's identity and on his management of everyday life.

"*They are all very sudden discoveries, so they do not give you much warning" (Extract 1).*

"Everything is completely sudden, you do not have time to prepare at all" (Extract 3).

"In a few hours everything was involved: professional activity, offices, and employees. You get up one morning and you have to close. I had commitments and it was very complex" (Extract 4).

"As long as I was alone in the rooms it was always better […] because I had my rhythms, my times, my thoughts, and my dynamics with my partner. It was terrible" (Extract 100).

Table 1. Paul's assistance problems according to Gordon's diagnosis

Gordon's functional health patterns	Nursing diagnosis
Self perception/self concept	Fatigue related to increased metabolism, organism-to-nutrient neoplasm competition, anemia, and tumor-related stressors Body image disorder related to changes in appearance secondary to disease
Nutritional metabolic	Unbalanced nutrition: lower than the need related to increased caloric needs and difficulty in assuming a sufficient quantity of nutrients secondary to cancer
Role relationship	Impairment of the role due to discontinuance of relationships

"For me it was an abstract stuff, a physical condition in my life that was impossible to happen, of any kind. And as long as one does not live it, he can not understand it. You do not understand how much the legs can be important […]the legs keep you standing, there's nothing to do" (Extract 65).

"One says <the hospital steps?> Yes, the hospital steps were the daily obstacle. [...] when you are destroyed" (Extract 66).

"In the morning I can hardly get up, it hurts a bit, my legs. I feel a little slobbering everywhere. I take some paracetamol and then I pull it forward and the next day I get up" (Extract 80).

"I realize that I have physically deficiencies compared to before, but I also see that I can recover. I know that something will follow me for the rest of my life. I have dysfunctions, but I hope not "(Extract, 60).

3. *"I never cried"*

In an attempt to maintain an image of strength, autonomy and combativeness, it is not surprising that Paul's attitude is oriented towards "forgetting" pain and suffering, while he was conscious of living a particularly serious and complex clinical situation.

"The doctors said <<look at this guy ... he will have about two or three months of life, not more>>" (Extract 23).

"Even the doctors at the beginning said [...] that I dealt with this thing blandly, that I did not realize what was happening to me, because in the morning I put the music. I have never cried, except for two or three times for painful situations [...] for six months long, I have faced it like this" (Extract 22).

"I have always gone beyond the expression of pain. Always, it was something that I wanted to manage" (Extract 37).

"I felt pretty good, even if everyone was talking about pain. I was dealing with it pretty well, so I did not feel super problematic, even though I was. And anyway I was well aware of the survival rates of the type of illness I have, that was very low" (Extract 28).

"So sharing my pain or things could not help me. I had the strength to handle this and so I always did it. It seemed like a right path, here" (Extract 38).

"There are some aspects that I do not remember, because in my opinion they do not lead me to anything, such as physical pain. That is to remind me how painful it was, it is useless" (Extract 43).

"Hearing my partner saying < you do not tell me the truth, you do not tell me how bad you feel >yes it is true. But that's okay, in the sense that she helps me in another way. It's not like I'm here to tell her <I feel awful. I can not stand up, I can not get the shopping bag, but I do it, I feel as though a truck had passed over me> I would get nothing. I would only get her to focus on a worry that does not lead to any kind of advantage, whereas now peace can help me instead" (Extract 39).

"And then in the post-transplant phase, everyone feels very bad, even I was very sick. And hearing <"you could even die from here to tomorrow> are things that do not have to touch you too much" (Extract 42).

4. *"I have faced it completely"*

Paul never took a self-pitying attitude, but showed instead a rational and conscious approach to the disease, combined with an active and problem focused coping.

"It is a general thought that a person can go crazy ... that he can not sleep anymore. Actually it was not like that for me, it has never been like that" (Extract 7).

"I'm not an atheist ... but if I felt the need to pray and face the disease from the spiritual point of view in my path, no, no! This was in strong contrast with the rational aspects. It was just the opposite. I was focusing on to deal with it. I had to understand how a protein reacted or why the chromosome had changed like that, or how a medicine had effect on my body" (Extract 98).

"But if you commit to this, in the end you have nothing to do, you can understand certain things. There are many university theses, which explain many paragraphs to you in a usable way, so that you can understand the mechanisms. If one begins to understand, he also understands the directions doctors are taking. Because in the phase of chemotherapy the patient basically does not think he can decide anything. These are really technical things and you can not decide how much medication you can take or not. What chemotherapy to take or not. No. One can only know how he feels" (Extract 13).

"I was able to concentrate completely on this thing, because I made a choice. I chose to focus on this disease. Not to let it slip away, without knowing. And so I also managed to take away many thoughts from my mind, which

I've always had. So it also was a diversion. More than just a diversion, it helped me" (Extract 6).

"The disease ... I tackled it as all other things in my life" (Extract 8).

"To do this you have to know everything, even the bad, be aware of what you study" (Extract 41).

"During my days there were physical obstacles. There were times that I had difficulty pulling the clutch with my foot. But I have always driven, no one has ever accompanied me, despite telling me << I accompany you? >> No, never ever" (Extract 66).

"I was carrying a backpack with me, with useless water inside, but that was a weight to train me. Although I had legs that did not get up" (Extract 67).

"I was always diligent, because caring for me takes effort and steadiness. And it's not simple" (Extract 69).

5. "I was not a patient who does not trust, but who wants to understand"

The desire to know, understand and decide autonomously, has negatively conditioned the establishment of a relationship of trust with the doctors, at least in the initial phase.

In this relationship of incomplete trust Paul confirmed his desire to understand the mechanisms of illness, treatment and to self-determinate his own path.

"In that phase [...] I had not yet found the right balance with the doctors of the department, because there was still a lack of information" (Extract 21).

"They tell you not to look on the internet, not to see situations [...] but then it is right that one chooses alone" (Extract 9).

"They suggested that I avoid going too far into things. But then from there to about 10 days, almost immediately, I decided to investigate very precisely all things and see. Because I am always measured in life [...] appreciating the things you can measure" (Extract 10).

"One thing that I did not appreciate was [...] that they explained to me the things about the transplant, the risks of the transplant, in a phase in which I could not decide. I did not like this thing. Nobody liked it. So this kind of meeting must be done abundantly before" (Extract 70).

"I would have liked a more open discussion on these aspects. I had to create this discussion with a bit of violence, studying, trying to have talks with the doctors up to what they represented, of the profession they had, in my limits of course, because I graduated, I understand things, to give me the opportunity to set some situations under my responsibility" (Extract 72).

"How does the doctor evaluate the benefit? Who is it? How can you afford? Based on what? Does he know how bad I feel? No!" (Extract 77).

"I've been a very troublemaker patient! Very, very, very! But in the end, it is my life and I respect it. Therefore where I can decide, I decide for myself. Where I can do it, I entrust myself. But I still rely on a minimum of knowledge. Not completely by chance" (Extract 84).

The relationship with the doctors has however evolved over time, given the widening of his knowledge and having received clearer and more direct information from the doctors: *"When they started to explain things, in all the terms it started to be more balanced, then more trustful" (Extract 26).*

"But with the studies, deepening things, I realized that probably, the chosen strategy created virtuosity in my immune system, which was favorable to fight the disease. So, in the end, I think the strategy was right. At the beginning I did not understand this thing well" (Extract 34).

6. "Today my time has a different value"

Paul's illness had great impact especially on his time management: *"If today I had to say << but what did you understand, what's important? >> The time is important! [...] a condition that people do not value. Even I did not valued it so much. The freedom!" (Extract 46).*

"Today I use my time. If I want to stay a little longer with my partner and a little less to work, I do it" (Extract 47).

Paul claims to have reached a more harmonious relationship with work.

"Fortunately, this has happened in a trend of my personal decisions, to free myself from many things, including just work commitments" (Extract 4).

"I'm trying to do a job, but differently" (Extract 12).

"I'm re-starting a little bit to work, but with a totally different stress management" (Extract 59).

Paul also describes a change in his social and family relations, in terms of a greater awareness of past investments and their current downsizing.

"I have made a life very dedicated to others. [...] Helping often takes up your time. You can also learn many new things by contacting people. I've always been a kind

person like that… So it was important for me, but it was a job, among many jobs. It was a social aspect that I took care of, over many years, that has repaid me. Under the hospital window, every day someone came. For my birthday, they made a banner and they came in 50. So I've always had a lot of people doing a lot of things. It was important. At the same time, however, I understood who was really there, in these moments" (Extract 49).

"Above all, those left behind in my family made me understand this. I've always been a child who has supported and been close to my family for many years. So, I realized that in reality their presence was due more to exculpation to them, or to an action that had to be done. And so in the hospital you had to come on that date, at that time" (Extract 51).

"But in reality they were not really there to help me" (Extract 53).

The romantic relationship with the partner takes on even greater importance in Paul's path.

"On the other hand, my partner, who unfortunately slipped into this situation, after a very short time that we had met, has learned what kind of commitment meant this thing. But now we are together, we live, soon we will get married. She is a rather tough woman, a person I have never had by my side in my life. Thanks to her I understood things in my life did not go well. I worked too much; I wasted too much energy for things that were not essential or important" (Extract 54).

"Before the illness [...] I did not realize that I was unhappy. I devoted time to an unattainable family ideal" (Extract 88).

7. *"I would like to tatoo the illness on my arm"*

Finally, personal considerations regarding the overall sense that the disease has taken in Paul's life are represented. The disease is symbolically associated with an indelible mark, which at the same time takes on the positive connotation of a life teaching.

"Understanding the energies I put into dealing with things, remembering certain things, in my opinion is positive. So [...] tomorrow I would like to tatoo the illness on my arm [...]. I have another tattoo for me very important on the right, which is my father who committed suicide ... I would not be afraid to write it down. It's not that if I see it every day I remember the pain and the suffering ... I remember the ability to face the thing, the enthusiasm, the smile of every day, the fact that today I am here"(Extract 45).

"I do not want to forget anything at all. I want it to stay in my mind so clear" (Extract 94).

"I know that something will follow me in the course of my life" (Extract 61).

"I could almost say that a path of illness made of sacrifices can somehow be a fortune for a lifetime. Because [...] I think that these things put you in front of situations to see life in technicolour. Before I saw life more or less in black and white, only sometimes I saw it in technicolour. I used to see the technicolour when I bought something, or because I was on vacation […] things like that. So only in flashes it became technicolour. While this type of path gives you the opportunity to see it in full technicolour" (Extract 56).

"The possibility that today I have been given the opportunity to face life in technicolour is not a trivial matter; it is not to be underestimated [...].Currently I do things in this way" (Extract 58).

"In reality, my mood, already during the hospital, but even more so today, has definitely improved and it is all connected to the fact that I currently see life in technicolour" (Extract 89).

"So it's like that. I'm better now. I'm worse physically, but mentally I'm better. I do not give more value to the money I gave before; it does not mean that I think I'm going to die tomorrow, but I think the future is uncertain, it's right to realize it" (Extract 90).

Discussion

As emerged from the diagnosis, we are facing a person who has developed a serious condition such as leukaemia, which involved transplantation. From the narrative diagnosis emerged several critical issues in the history of Paul's illness and especially the priorities that he assigns to these problems. In fact, the results reveal personal critical issues, which Paul has chosen to share with the nurse, which would not otherwise have been obtained from a standard diagnosis.

From the standard diagnosis, however, emerge several aspects that Paul has neglected to narrate and that does not directly address in his story. For example, the fatigue and the body image, although greatly modified by the disease, as well as an unbalanced nutrition, do not seem to take on particular importance for Paul.

Thus, the personalized diagnosis (IPND) was a process of integration between the standard diagnosis and the narrative diagnosis which led the nurse to the following considerations.

The set of diagnostic data converges towards a coherent configuration, which describes a task oriented person, who tries to stay in control over his life, and to face difficulties with commitment. This is highlighted in the social-relational life, in which in the past the person has assumed the role of caregiver, in the work experience, in which he has always strenuously committed, as well as in the context of his challenging sporting activities.

The self-image is therefore highlighted as a strong, independent, active, proactive and dynamic person, whom the disease has partially affected. In this configuration it is not surprising that he avoids everything associated with weakness, pain and suffering, as they affect the image of the performance strength of his social role. Facing the challenges that the disease has placed before him, he declares, his choice to tackle them completely, as he has always done in his life. This is also confirmed by the rationalizing style with which he approached the illness path, being perfectly informed about mechanisms, progress, treatment and complications of the disease. Wanting to know every detail, to be able to decide in a completely autonomous way seemed to be the motivational drive that also affected his relationship. This self-determination of the treatment process has therefore slowed down, at least initially, the establishment of a relationship of complete trust in the professionals.

In general emerges a person unwilling to rely on faith, and who, far from showing a victimized attitude, underlines the positive aspects of the experience, even though aware of the seriousness of his clinical condition. In this challenge that life has placed before him, considering the sense of the experience of illness in his life, Paul suggests that it is not the disease that has won: if the disease has taken away the physical forces, internally it made him even stronger and this is what he seems to want to remember about his experience.

Considering the dynamic process that takes into account the two different ways of making a diagnosis, the following six aspects emerge.

1. An impetuous event

At first, the disease has been experienced as unexpected, and obstructive. It has been experienced with physical dysfunctions that Paul partially denies or holds in low consideration.

2. Hide the pain

After this he showed the tendency to hide pain and suffering, even though he is aware of his complex clinical situation.

3. Personal resources

Paul showed a defensive attitude during clinical treatments, but thanks to his resources he faced the disease, trying to understand it. He also acted effectively on his condition, thanks above all to his high resilience.

4. Change priorities

There is an important evolution in the disease, linked to the new meaning that Paul attributes to interpersonal relationships, work and in general to the management of his time.

5. An indelible mark

At the current time the disease is experienced as an indelible mark that no longer goes away. It is not useful to remind him of pain and suffering, but his strong ability to deal with leukaemia, just as he has faced other events in his life.

6. Give other meanings

Paul does not talk about spirituality, rather he denies it. However the disease offered Paul the chance to give a better meaning to life.

This diagnostic integration is illustrated by the conceptual map represented in Figure 1.

Conclusion

As we tried to highlight, through the presentation of a clinical case, the purpose of this work was to underline the richness of integration between standard diagnosis and narrative diagnosis, through the Inte-

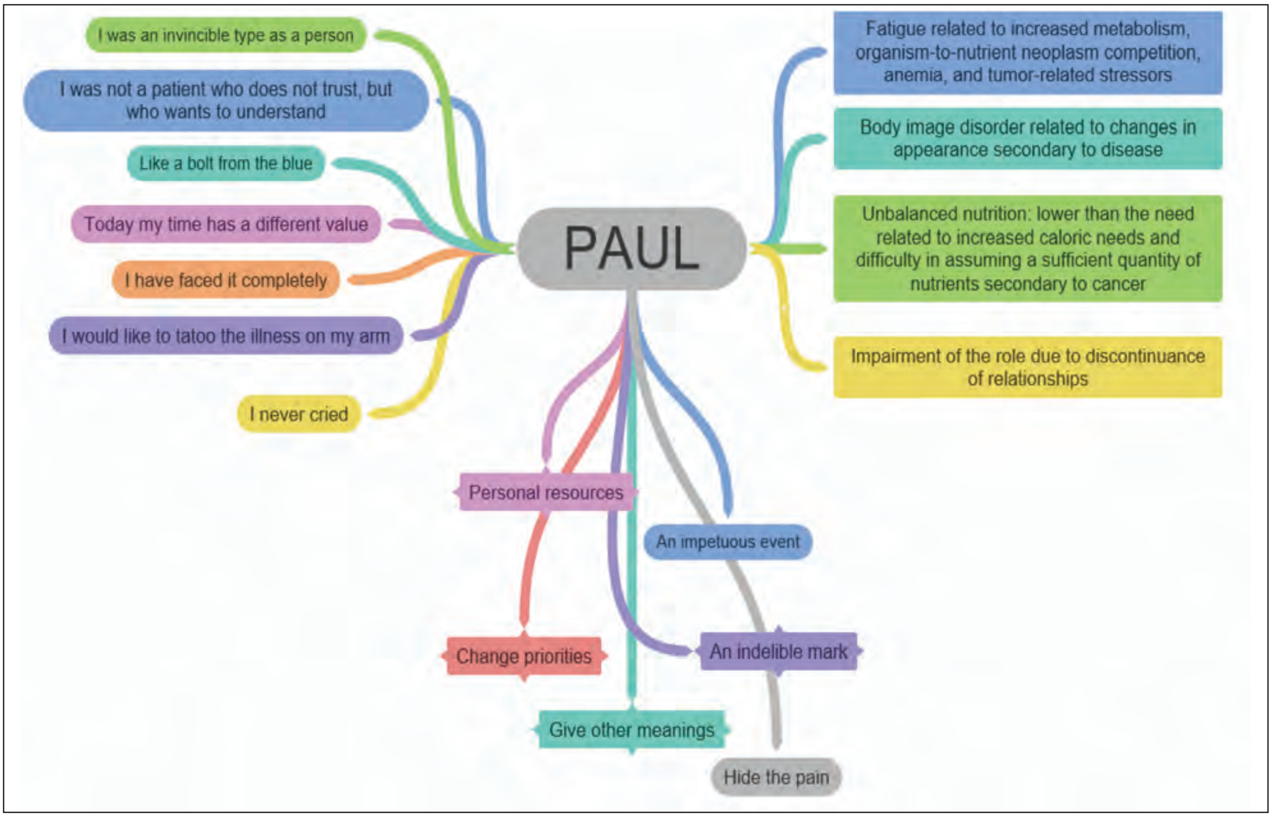

Figure 1. Integrated Personalized Nursing Diagnosis of Paul (conceptual map)

grated Personalized Nursing Diagnosis (IPND). The diagnosis made by the professional (traditional diagnosis), which is of an interpretative nature, is complementary to the introspective one derived from the person (narrative diagnosis), which highlights the priorities of the person.

As we have argued, the active participation of the person in the treatment process is based on the patient's engagement, which allows highlighting current and potential problems and individual resources, which are of great importance and which must be analyzed and used by the professional for schedule a personalized assistance plan.

The two approaches, one of a top-down type (in the case of the standard diagnosis) and the other of a bottom-up type or data driven (in the case of narrative diagnosis) certainly have both limitations and advantages. In the first approach, the advantages lie in the possibility of sharing the diagnostic categories in the scientific community and in the transversal scientific language used to describe the person's criticality and resources. The disadvantages lie instead in the simplification process, which uses the categories already possessed by the professional to describe the person.

In the second approach, the advantages lie instead in the accuracy and personalization of the diagnosis in which the expert is the assisted person. The individual highlights certain aspects of the experience of illness, neglecting others. The disadvantage, instead, is being a more expensive process, which requires specific training in empathy, active listening and recursive and critical thinking. The methodological process is therefore based on the attention paid to the person's own words, without interpretations and without pre-established categorizations. Integration and comparison between different reading lenses, perspectives and languages is therefore fundamental.

The patient's engagement can enrich data already detected in the standard diagnosis, can detect aspects not obtainable from the latter or even integrate aspects that only the professional can highlight. The use of both approaches therefore justifies the complexity of the assisted person: from their successful integration it is possible to reach a richer, more articulated and completely tailored diagnosis based on the uniqueness of the person.

The Integrated Personalized Nursing Diagnosis (IPND) not only gives primary importance to the priorities expressed by the patient, but also underlines the dynamic path, in which not only the static analysis of needs becomes significant, but also the changes that occur in attributing new meanings to the life experience, as well as the evolution of the person him/herself in this process.

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Original article: Looking inside the care: the subjective point of view

Factors associated with and impact of burnout in nursing and residential home care workers for the elderly

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Abstract. *Background and aim of the work:* Numbers of elderly people worldwide continue to grow. Increasingly these individuals require nursing and residential care to meet their needs. Nursing is an occupation associated with burnout amongst its workforce, associated with increases of emotional exhaustion, depersonalisation and decreases in personal accomplishment. This review of literature provides a more detailed picture of the associations and predictors of burnout within this setting, and also considers the implications this holds for patient care, before providing recommendations for managers of such settings. *Methods:* Literature searches were conducted across a range of academic databases with a series of relevant keywords. *Results:* Examination of search results suggested several factors relating to staff burnout including occupational aspects, types of setting, staff perceptions, coping strategies, education and training and the impact of burnout on care delivery. *Conclusions:* Studies from across the globe suggest that burnout is prevalent amongst staff working in nursing and residential homes caring for elderly people, with implications for the patients, staff and home-care providers. Factors associated with burnout appear to include perceptions of job stress and occupational aspects, as well as the types of coping mechanisms staff employ. Managing grief associated with death of patients at work, as well as staff perceptions of both clients and their illnesses also appear related to burnout as well as the specific type of healthcare setting.

Key words: nursing, residential care, older adults, staff burnout

Introduction

As the numbers of elderly people requiring nursing or residential care increase the wellbeing of nurses and care workers employed in this setting grows in importance. Nursing is inevitably a demanding and stressful job in a complex organizational setting and it has been widely regarded as one of the most stressful occupations, associated with high levels of staff turnover, absenteeism and levels of burnout (1). Burnout can be described as a syndrome of three facets: emotional exhaustion (EE), depersonalisation (DP), and reduced personal accomplishment (PA) (2). Emotional exhaustion occurs when the level of emotional resources becomes depleted such that individuals feel unable to give anymore of themselves emotionally. Depersonalisation describes feelings of cynicism towards clients, whilst reduced personal accomplishment refers to forming a negative evaluation of one's work ability (2). Whilst burnout impacts negatively upon staff members, research has suggested that quality of care is impacted, with levels of patient satisfaction lower in hospitals where nurses experience high levels of burnout (3). Furthermore, burnout in nursing has been associated with poor patient outcomes (e.g., 4). It is reported that nursing and residential homes represent one of the largest and most rapidly growing areas to provide care for the elderly (5), as such a greater knowledge of burnout of staff within these settings is important in terms of stress prevention, health promotion and indeed patient care. This article aims to review articles examining burnout within workers in nursing and residential care for the elderly, to obtain a more detailed picture of the associations and predictors of burnout within this setting, and to also consider the implications this holds for patient care. Recommendations will be given based on the findings.

Method

Searches were conducted across academic databases Academic Search Complete, MEDLINE with Full Text, and Psychology and Behavioural Sciences Collection. Subject terms (SU) used were 'nursing home' or 'long term care' or 'residential care' or 'nursing homes' AND SU 'elderly' or 'aged' or 'older' or 'elder' or 'geriatric' AND SU 'burnout'. Limiters were placed by publication type to return academic journals only, peer-reviewed journals only and only articles written in English; only publications from the year 2000 to present were included in the analysis, in order to permit an account of the literature of this topic from the last century. This resulted in 30 hits. After removal of duplicate items and those which did not encompass the review criteria (did not consider burnout amongst those working with elderly people in nursing or residential homes) 14 items remained. These are summarised in Table 1.

Results

Research has suggested that nursing care aids working within nursing homes have high levels of job efficacy (a facet of burnout) but also hold a moderate risk for burnout domains of EE and cynicism (6). This would suggest that whilst care home workers place value and importance in the work that they do, they also have a risk for developing a cynical attitude and levels of emotional EE. It is concerning to note that studies have reported how time worked at a nursing home negatively predicts PA, a burnout factor (7). That is, the longer that staff worked at a nursing home, the lower their level of satisfaction and accomplishment around their work.

Occupational aspects

Research surveying Registered Nurses, assistant nurses, and nurse aides has suggested that those who perceive that they have been exposed to violence at work have higher burnout scores than staff who state they have not experienced violence at work (8). Other aspects of the work may also play a role. For example, (9) noted how staff who perceive the care that they give to residents to be person centred are seen to have high levels of PA, whilst those who feel they did not give person centred care have higher levels of EE and DP.

A further workplace based element can be noted, namely emotion rule dissonance. A study of nurses, orderlies and nursing aides working within nursing homes or outpatient care organizations provided measures of their levels of emotion rule dissonance (the extent to which their true emotions tallied with those required to be displayed at work) and followed them up at a later date. A high level of emotion rule dissonance (a high level of difference between actual and displayed emotions) was associated with both EE and DP at follow up (10). However, it was also observed that role complexity was an important and protective factor for burnout: Those who had high levels of emotion rule dissonance but had high levels of job complexity were less likely to suffer EE and DP than those colleagues who had a role which was not as complicated.

Types of setting

In an examination of public and private nursing homes in Sweden (11) suggested that there exists similarity in terms of the experiences of the workforce and that variations in the workplace (private or public) holds little difference on these variables. That is, similarities in the factors associated with burnout were largely similar. It was reported that 'Stress of Conscience', (the frequency of stressful situations and extent to which they bother the respondents' conscience), 'having to deaden ones conscience to work in healthcare' and levels of EE and DP were associated in both settings, and levels of burnout were comparable. There were however additional factors associated with burnout within the public organisation with an additional role in burnout found for the perception

Table 1. Studies considering staff burnout within elderly care settings identified in the literature review

Authors	Setting	Staff	Location	Study details
Hunter, Hadjistavropoulos, Thorpe, Lix and Malloy, (2016)	Two large rural long-term residential care facilities	Nurses, nurse assistants, managers, professional staff, recreation staff, dietary staff, and housekeeping) extended beyond nursing staff	Canada	How burnout facets predict extent to which staff report delivering certain aspects of dementia centred residential care
Estabrooks, Squires, Carleton, Cummings and Norton, (2015)	Thirty six Long term care homes	Healthcare aids	Canada	Burnout characteristics of workers, how this differs between type of facility
Narumoto, Nakamura, Kitabayashi, Shibata, Nakamae and Fukui, (2008)	Two nursing homes	Nurses, nursing assistants,	Japan	Personality and coping style influences on burnout
Isaksson, Graneheim, Richter, Eisemann and Åström, (2008)	Three nursing homes	Registered Nurses, assistant nurses, and nurse aides	Sweden	Exposure to violence at work and impact on burnout
Anderson, (2008)	Twelve nursing homes	Certified nursing assistants (CNAs)	USA	Predictors of burnout in relation to different types of grief following resident death
Abrahamson, Anderson, Anderson, Suitor and Pillemer, (2010)	Nursing homes for the elderly	Nursing assistant and nurses	USA	Role of conflict with relatives in burnout
Mandiracioglu and Cam, (2006)	Six nursing homes	Healthcare workers, Office employee Nurse's aides, Social workers, psychologists, Cleaners, Others	Turkey	Associations of burnout e.g. gender, violence, elderly and organisational issues
Åhlin, Ericson-Lidman, Norberg and Strandberg, (2015)	Two residential care units for older people	Registered Nurses and nurse assistants	Sweden	Individual difference variables role in burnout. Differences between types of home
Passalacqua and Harwood, (2012).	A for-profit long-term care facility specialising in memory issues (namely AD and other dementias)	Caregivers	USA	Contribution of dementia communication training intervention on burnout
Hillman, (2006)	Nursing home care unit	Registered Nurses, Licensed Practical Nurses, Certified Nursing Assistants	USA	Association of staff perceptions of problematic resident behaviour, staff view of the residents displaying this behaviour and burnout

(continued)

Table 1 *(continued)*. Studies considering staff burnout within elderly care settings identified in the literature review

Authors	Setting	Staff	Location	Study details
Martínez, Suárez-Álvarez, Yanguas, and Muñiz, (2016)	56 residential care homes for the elderly	Care assistants, professionals from a range of disciplines	Spain	Correlations between perceptions of person centred care delivery frequency and burnout
Shinan-Altman, Werner and Cohen, (2016)	Nursing homes and hospitals	Social workers and nurses	Israel	Staff perception of AD and associations with burnout
Kubicek and Korunka, (2015)	Nursing homes and outpatient care organizations	Nurses, orderlies, and nursing aides	Austria	Role of emotion rule dissonance in burnout
Hillman, Skoloda, Angelini and Stricker, (2001)	Nursing home	Registered Nurses, Licensed Practical Nurses and Nursing Assistants	USA	Role of burnout in staff negative perceptions of problematic resident behaviour

of one's conscience as too strict and having a troubled conscience as a result of being unable to achieve one's own standards (11).

Public and private nursing homes as well as voluntary ones were compared in Canada and revealed that the majority of burnout facets did not differ by type of home, with comparable levels of EE and efficacy. However those healthcare aids in private facilities reported higher levels of cynicism, and medium size homes had higher levels than small or large homes (6). As such it may not just be the type of nursing home which requires consideration (that is, if it is public, private or voluntary) but also the size of the home and the number of residents it provides care for. Perhaps even, related to the client group themselves. It has been reported that burnout levels are highest amongst those had complaints relating to the elderly, namely considered by the participants as 'the characteristics of the elderly', 'the increase in the expectations of the elderly clients and the decrease in their appreciation', and 'lack of communication with them, the elderly' (12). As such then, perceptions related to older adults and indeed the illnesses from which they frequently suffer may also play a role in burnout.

Staff perceptions

In the study of Shinan-Altman and colleagues (13) it was found that the perception staff have of AD acts may influence levels of staff burnout. Qualitative interviews with staff (social workers and nurses) caring for elderly people with dementia suggested that workers experience EE and DP, in part because of the reductions in ability to communicate in advanced AD, and decreases in PA as a result of these negative feelings, as well as seeing continued deterioration in patients (e.g., failure to recognise previously known others) (13). Others have suggested that staff who have low levels of burnout (assessed here as perceptions of fulfilment and satisfaction with the caring role) were more likely to have positive evaluations of patients and the frequency of problematic behaviour displayed by residents did not influence this (14).

Burnout can also reportedly be associated with staff perceptions of a particular type of illness. For example, Shinan-Altman et al. (13) in their study of nurses and social workers noted that negative connotations of AD correlated with a number of facets of burnout. For example, perceiving AD as caused by psychological attributes (e.g., 'stress or worry') risk factors (e.g., heredity, diet) accident or chance (e.g. 'chance or bad luck') or who held beliefs about a lack of control of the disease (e.g., 'There is very little that can be done to improve AD') had higher levels of EE and DP. Those who held negative emotional illness representations (e.g., 'AD makes me feel angry') had higher EE, DP and lower PA. Further, a direct association was observed between specific cognitive illness representations (the way in which individuals perceive illness) and different burnout facets: Perceiving AD as attributable to risk factors was negatively associated with EE, whilst believing AD to have a cyclical timeframe was associated with lower levels of PA.

Coping strategies and grief

Within the study of Shinan-Altman and colleagues (13) coping strategies were also relevant: whilst not all coping strategies were associated with burnout, emotion focused coping strategies (focusing on the management of the emotional aspects of the difficult situation) were associated with high EE, DP and lower PA. It was also notable that emotion focused coping strategies were seen to have a linking role between emotional illness representations and all of the burnout facets. Similarly, Narumoto et al. (15) reported that use of emotion-oriented coping predicted EE in nurses and nursing assistants. There was also suggestion that the personality of the individual may be a predictor of burnout. Level of neuroticism (the extent to which an individual responds to events with negative emotions) was seen to positively predict depersonalization in staff. Perhaps most notable however is that the role neuroticism has on burnout is via a specific coping type: Findings suggested that the effects that neuroticism had on DP was a result of emotion-oriented coping, as such, the use of emotional orientated coping enables neuroticism the negative impact on burnout.

Use of coping strategies to manage events within the workplace may not be the only individual difference variable to impact upon burnout. Anderson 7 considered the role of grief within the workplace setting following the death of a resident, and assessed the impact that this has upon certified nursing assistants (CNAs) burnout levels. Anderson (7) uses a distinction between different types of grief. Grief was defined as either Complicated Grief, associated with maladaptive and problematic outcomes as a result of the grief, or as Personal Growth. Personal growth from grief can be defined as associated with gains in levels of tolerance, compassion, forgiveness and hope as well as personal growth (16). Complicated grief as well as race, was seen to predict DP in Anderson's study (7). It was suggested that those who were Caucasian or who had high levels of complicated grief were more likely to experience DP. However, experiencing grief positively had a different impact. PA was seen to be by personal growth from grief, as was religious affiliation and job satisfaction.

Education and training

One way of increasing staff's knowledge of the role that various aspects of themselves and indeed their work can influence their susceptibility to burnout may lie within education and training. Indeed Shinan-Altman et al. (13) demonstrated that staff who perceived themselves as having a low level of knowledge around AD, (that is the extent of their illness coherence) was associated with EE. As such, providing staff with more training and education around the different illnesses they encounter within their role may act to decrease the likelihood of EE. Indeed, Passalacqua and Harwood (17) provided caregivers with a dementia communication training session based on person centred care. At follow up it was found that the levels of DP displayed by staff towards residents had decreased, demonstrating how adequate training may have a role in reducing facets of burnout. The themes of education and training will be discussed more in depth in the Implications for practice session.

Impact of burnout on care delivery

Hunter, Hadjistavropoulos, Thorpe, Lix, and Malloy, (18) in their work with residents experiencing dementia, noted how elderly care staff who have high levels of PA were more likely to report giving care which focuses on empathy and respect for those with disabilities. EE approached significance in negatively predicting the provision of comfort care and support for relationships of residents, that is, supporting the emotional and physical needs of patients and supporting relationships amongst residents, families and staff.

Discussion

From the findings, it is shown that burnout amongst staff employed in nursing and care homes for the elderly is a significant problem reported across the globe, with implications for the wellbeing of patients, providers and staff. In the interest of patients, it is important to recognise and to address the high rates of staff burnout in practice settings. Moreover, given that burnout can result in serious health risks for staff and their families, it must also be recognised as a significant occupational health problem warranting the attention of employers, unions, policy makers, and the community of occupational health professionals.

There appear to be a number of factors related to the syndrome, such as perceptions of job stress and types of coping mechanisms employed, to occupational hazards such as grief, the perceptions staff have of the patients that they care for and the illnesses from which they suffer, as well as some variation within type of healthcare setting.

The first issue noted from the articles was the one concerning with what aspects of the role might be associated with facets of burnout amongst nursing care workers. As highlighted in the results, in the study of Isaksson, Graneheim, Richter, Eisemann & Åström, (8), violence is a fact of working life for nurses and care staff, and being exposed to violence at work was seen to be linked with a higher level of burnout. However, this finding is far from consistent, with other researchers studying nursing home workers reporting that levels of violence at work was not associated with burnout (12). Physical violence appears not to be the only consideration; it appears that experiencing conflict with the relatives of patients is seen to lead to an increase in burnout and decrease in job satisfaction. Burnout levels peaked quickly and remained constant regardless of the type of continued interaction with the relatives (19). Roche and colleagues (20) have also seen that perceptions of violence were related to adverse patient outcomes through unstable or negative qualities of the working environment. Moreover, perceptions of violence affect job satisfaction. A quantitative review of the nursing violence literature including a total of 136 articles providing data on 151,347 nurses from 160 samples (21) revealed that around a third of nurses worldwide indicated exposure to physical violence and bullying, about a third reported injury, whilst a quarter experienced sexual harassment, and around two-thirds indicated nonphysical violence. In geriatric facilities the most prevalent was physical violence.

Martínez, Suárez-Álvarez, Yanguas and Muñiz (9) also took into consideration another aspect of the work that may play a role: they noted how staff who perceive the care that they give to residents to be person centred are seen to have high levels of PA, whilst those who feel they did not give person centred care have higher levels of EE and DP. As such it may be suggested that there are aspects within the workplace that may act to prevent the provision of person centred care. Similarly, research with nurses and social workers suggested that high levels of role conflict, role ambiguity and role overload were associated with burnout, specifically increased levels of EE and DP, as well as lower levels of PA (13). Research has also reported burnout levels to be highest amongst those who had organisational issues within the homes in which they worked, such as lack of equipment and personnel, low salaries, workload, administrative mechanisms and bureaucracy (12).

In the study of (10) a further workplace based element was identified in emotion rule dissonance. Emotion role dissonance refers to the difficult state whereby the self required to be displayed within the workplace is in disconnect from the true feelings one holds. Staff within elderly care settings are required to express a wide variety of emotions during their interactions with patients. They have to switch between keeping a certain emotional distance toward their patients to secure a professional attitude on the one hand, and showing a caring, compassionate attitude on the other. Also, they are faced with situations, such as death, illness, and violence – as it was seen - that trigger emotional reactions, while their professions may require them to inhibit or suppress the emotions that normally occur in reaction to these situations. In the aforementioned investigation was found that high level of emotion rule dissonance was associated with both EE and DP at follow up (10). However, it was also observed that role complexity was an important and protective factor for burnout: Those who had high levels of emotion rule dissonance but had high levels of job complexity were less likely to suffer EE and DP than those colleagues who had a role which was not as complicated. These findings suggest that nurses who feel a discrepancy between the emotions they need to show and their true emotions deplete their energy resources and eventually become cynical towards their patients and their work. This may be disastrous for their performance: they may no longer achieve the objectives of their work, that is, providing high-quality care to patients.

Considering further role complexity, it was investigated whether the level of complexity in a role varies by workplace, and as such may impact upon staff burnout levels. Åhlin et al. (11) found additional factors associated with burnout within the public organisation with an additional role in burnout found for the perception of one's conscience as too strict and having a troubled conscience as a result of being unable to achieve one's own standards. This may suggest that there is some aspect particular to a specific type of nursing home environment which adversely influences staff in terms of their ability to achieve their own standards of care and the impact upon their conscience. The standards staff place upon themselves can be linked to staff perceptions, which are also seen to link to burnout in other ways. The results of a study by Shinan-Altman et al. (13) suggested that the perception staff have of Alzheimer's disease (AD) influence levels of stuff burnout. Alzheimer's disease (AD) represents one of the most common neurodegenerative diseases and is the most common dementia amongst the elderly (22). Hence, it is very frequent for nurses to deal with these patients in geriatric facilities. In the aforementioned study, qualitative interviews with staff (social workers and nurses) caring for elderly people with dementia suggested that workers experience EE and DP, in part because of the reductions in ability to communicate in advanced AD, and decreases in PA as a result of these negative feelings, as well as seeing continued deterioration in patients (e.g., failure to recognise previously known others) (13). Indeed research suggested that burnout seems to have a vital role in the extent to which certain resident problem behaviours (described as 'annoying or attention seeking behaviours' e.g. complaining or whining) were associated with a negative perception of the resident by staff. When the level of burnout was statistically removed certain annoying or attention seeking problem behaviours were no longer associated with a negative perception of the resident (23). Further, in another study taken into consideration in this review, Hillman et al. (14) have suggested that staff who have low levels of burnout were more likely to have positive evaluations of patients and the frequency of problematic behaviour displayed by residents did not influence this. This suggests that burnout is an important factor in both how annoying behaviours are perceived to be, and that in those with low levels of burnout more positive perceptions of residents are observed regardless of the frequency of problematic behaviours.

Among other recurring themes, grief and coping seems to be also relevant. Grief is, at its essence, a form of stress. Coping is the process of responding to stress or, more specifically, the thoughts and actions that individuals use to manage the external and internal demands of stressful situations. This process is complex and coping with grief is influenced by a great number of intrinsic and extrinsic factors. Shinan-Altman et al. (13) found that emotion focused coping strategies, in particular, were associated with high EE, DP and lower PA. Also, Narumoto et al. (15) reported that use of emotion-oriented coping predicted EE in nurses and nursing assistants. The other individual difference variable that was found to have an impact upon burnout is, as we said, grief. Anderson (7) considered the role of grief within the workplace setting following the death of a resident, and assessed the impact that this has upon certified nursing assistants (CNAs) burnout levels. In this study, grief was defined as either Complicated Grief, associated with maladaptive and problematic outcomes as a result of the grief, or as Personal Growth. Personal growth from grief can be defined as associated with gains in levels of tolerance, compassion, forgiveness and hope as well as personal growth (16). Results from these studies suggest that the types of grief elicited in the individual from patient deaths at work can adversely or positively impact upon an individual's level of burnout. It is nonetheless true that relationships with residents are one of the primary reasons why nursing home staff remain on the job (24). Yet despite the intimacy of the relationships between staff and residents, many institutions continue to view these relationships as primarily functional in nature and fail to acknowledge the depth of the grief that results when residents die (25). In addition, care in nursing homes also tends to focus on prolonging life and death is often a viewed as a taboo subject. Residents who are close to death are isolated from other residents and, upon death, residents' bodies are often removed through back entrances in order to conceal this element of long-term care from residents and staff (26). Staff who are not at work when deaths occur may return to work the next day to find rooms empty or occupied by new residents. The failure to acknowledge the relationships between nursing staff and residents and the denial of death in nursing homes may preclude nurses from effectively moving through the grief process.

The last theme identified was the impact of burnout on care delivery. The study of Hunter and colleagues (18) illustrates that elderly care staff who have high levels of PA were more likely to report giving care which focuses on empathy and respect for those with disabilities. EE approached significance in negatively predicting the provision of comfort care and support for relationships of residents, that is, supporting the emotional and physical needs of patients and supporting relationships amongst residents, families and staff. This may mean that, whilst burnout can have a profound impact upon the staff that experience it, it also impacts the quality of care given to the patients with whom they work. Moreover, this might mean that staff who are experiencing the negative aspects of burnout e.g. EE are less likely to provide specific aspects of care to their residents, but conversely that the positive effects of PA, a feeling of pride within one's role can act to increase the likelihood of providing care which is emphatic and respectful. This also may suggest that some aspects of burnout are more influential on care provision than others.

Conclusions and implications for practice

The concept of burnout is not new to nurses and researchers. However, despite the large amount of studies conducted in an attempt to investigate and predict the related factors of burnout, no conclusive data could be drawn. This is might be due to the fact that the health care system is in constant change. The factors that relate to burnout will present different relative significance with the changes. Despite this, the related factors to burnout could generally be classified as both organisational and personal related. Therefore, to inform best practice, burnout intervention programmes should be multidimensional consisting of work-related as well as personal directed approaches.

Evidence-based strategies must be implemented aimed at reducing the likelihood of nurse burnout. Based on the findings of this review a number of care management recommendations are made. First it is suggested that nurse managers and administrators in care homes for older adults should carefully examine the working conditions of their nurses. More specifically they should look to understand the sources of stress from the perception of the workforce and be proactive in ways of tackling it in collaboration with their staff. This should also include an analysis of the complexity of the role workers are asked to do. Complexity of work appears to be a protective factor against burnout, so managers should work with staff to ensure that their role includes adequate levels of challenge.

Moreover, findings from this literature review indicate that providing staff with more training and education around the different illnesses they encounter within their role may act to decrease the likelihood of EE. Hence, nurse burnout might be reduced by ensuring their staff have a good level of knowledge around common diseases amongst older people. Specifically education and training of staff should extend to consider in more depth the process and origins of disease processes often associated with their elderly client groups (such as dementia). Increasing an understanding of the condition may assist in decreasing burnout risk. Staff should also receive training in the types of coping mechanisms which are most adaptive for their caring role and guidance and support in their application, as some types of coping act to encourage burnout, whilst others may offer a preventative role. Perceived coping efficacy, the belief that one can respond well and perform successfully in the face of adversity and stress is a central element of the stress and coping perspective. It is generally regarded as a resource factor for individuals, one which mitigates the impact of stress (e.g., 27).

The challenges of grief should also be considered by managers, perhaps by allocating time to reflective learning sessions, to examine the different types of grief, and how grief can be channelled more productively. Studies analysed in this review (i.e., 7) have underlined that failure to acknowledge the relationships between nursing staff and residents and the denial of death in nursing homes may preclude nurses from effectively moving through the grief process. Indeed, studies of nurses and long-term care staff indicate that many providers – often half or more – report at least one grief-related symptom in response to the death of a patient (e.g., 28). Common symptoms included sadness, feeling upset when thinking about the patient, and feeling numb. A smaller number of health care staff, up to about ten per cent, reported that they experienced more intense emotional and physical responses (e.g., 29). The possible consequences of providers' repeated exposures to loss and the deaths of patients also include burnout and occupational distress (e.g., 30).

From a practice perspective, several avenues that facilities can take to help to enfranchise the grief of nurses may be identified. Nursing homes typically do not have facility-based memorial services to mark the death of residents, nor are there commonly any other forms of remembrance (e.g., pictures, wall plaques) for deceased residents (25). As suggested by Anderson and Gaugler (24), facilities may choose to initiate something as simple as a memorial board where the staff can read death announcements and brief statements about the lives of recently deceased residents. Other facilities may elect to hold brief memorial services on the unit in which the death has occurred which not only acknowledges the loss, but also allows for validation and mutual support. Through such simple and cost effective measures, facilities may be able to accentuate the positive aspects of grief and add to the well-being of their front line staff, and more importantly, encourage personal growth.

Nurses and care staff will continue to be confronted with physical and emotional suffering, illness, and death, sometimes also dealing with aggression form patients' relatives – as said before. Because it was seen (i.e., 10) that emotional dissonance coincides with burnout and reduces in-role performance, it seems important for management to consider ways to reduce the impact of emotional dissonance. Again, further training in managing their emotions could be necessary. Company training with regard to emotion work generally focuses on teaching employees skills to regulate the emotions of recipients. However, include training on how to deal with their own emotions in a healthy manner may be also beneficial. Employees might be taught how to respond to the emotional demands of their work while staying true to their own feelings. In addition, the organizational rules regarding emotional display of frontline employees and the style of supervision may need revision. Allowing employees to express their true emotions may seem undesirable for recipients, but the current research suggests that in the long run this approach may be positive for both clients and organizations (31). It is without doubt that providing safe and high quality care in a context of nurse burnout and severe nursing shortages is very challenging. Developing, testing, and implementing intervention programs to reduce burnout may produce a variety of beneficial effects, including keeping nurses in clinical positions, and maintaining or raising quality of care.

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Original article: The caregivers' side of the care

Mapping Caregivers' Health Assets. A self-care project using Salutogenesis and Mindfulness

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Abstract. *Background:* Thousands of caregivers around the world take care of impaired people, with negative repercussions on their physical, psychological, social and economic resources. The need to promote caregivers' wellbeing is internationally recognized, thus reducing health inequalities. Mindfulness is a powerful tool, directly related to the reduction of stress, able to increase skills and attitudes promoting well-being. The basis of this project of community development based on active health, is the self-care achieved through mindfulness. *Aims:* The overall aim of this project is to improve the caregivers' health and quality of life through community mapping strategies and mindfulness. *Methods:* According to the salutogenic model, and to the model of community development based on active health (ABCD) we will create a map of the caregivers' internal and external health assets. The project will have a participatory action research methodology, and it will go throygh five different phases, with mindfulness as a central tool. *Results:* At the end of the project, results will be analyzed referring to structures, processes and objective and subjective outcomes. *Conclusions:* At the end of the project, we will evaluate if the Salutogenic ABCD methodology along with Mindfulness, will be able to reduce health inequalities improving caregivers' wellbeing.

Key words: assets, caregiver, Mapping party, Mindfulness, Salutogenesis, self-care

Introduction

All over the world, thousands of people need continuous assistance, and thousands of people have to take care of them. These are the caregivers, and it is estimated that there are 225,000 only in Spain, almost always women with an average age between 50 and 70 years. The evidence shows the negative repercussions on physical, psychological, social and economic resources that caring for others can have on these people. However, social, cultural, economic factors and factors such as gender are, in this case, much more relevant and determinant in the health disparities of the caregivers' population (1). Different strategies at national and European level recognize the need to promote care for caregivers. The caregiver must take care of himself to guarantee a good level of care for another person but above all to maintain his health and well-being. But to take care of himself he must be able to ask for help, and request support from professionals and from his networks. The term Mindfulness taken from the Pali language, meaning full awareness or conscious attention to the present moment (2), is considered as one of the most powerful "tools" for understanding one's own thoughts, emotions, and body signals, directly related, not only with the reduction of stress levels, but also with the increase of skills and attitudes (empathy, self-awareness, calm, concentration, attention, kindness) that promote well-being in people who practice it (3).

Mindfulness is also a lifestyle. A way of "being" against the "doing" way, continuously activated in the West countries. In other words, Mindfulness is a life philosophy. Practicing Mindfulness in a continuous way, encourages the development of this philosophy, and so, over time, can become a stable characteristic making the person "Mindful", that means with an attitude of (4-5): curiosity for mental contents, acceptance of the present moment, openness to mental contents, no judgment towards the present experience, detachment, and kindness / love / affection. Therefore, an attitude of self-care and self-acceptance in the present moment, without which it is really difficult to develop full awareness.

Specifically, Minfulness is based on the practice of exercises (or meditations), centered on three fundamental pillars: Samatha (attention, concentration, calm), Vipassana (contemplation, mental clarity) and Metta (loving kindness).

At the beginning of Mindfulness practice, people perform Samatha exercises, to learn to keep their attention on a specific point in a quiet state, becoming aware of what happens. Subsequently Vipassana is practiced, including the contemplation of mental contents (thoughts, emotions) with an attitude on letting them flow freely. However, Metta is the prerequisite of the whole practice, as Mindfulness implies a person being always in a state of loving kindness, goodness, affection, and benevolence towards himself.

The different meditation exercises (fully shown in in table 1) can basically be divided into:

1. - Formal meditations.

a) Sitting practices: meditations linked to the breath, to internal and external stimuli, to thoughts and emotions (Tonglen, Metta, Body-Scan)

b) Standing practices: walking meditations or conscious walking including "sensory", "synupodal rhythm" and "bodily movements and sensations".

2. - Informal meditations

Practices carried out taking advantage of any action put into practice during the day, being fully aware as brushing teeth, eating, listening to someone

3. - Mini-meditations.

Very short exercises (usually focused on breathing) performed at different times of the day.

Practicing Mindfulness can change the relationship of a person with himself, also learning to respond in a different way to stressful situations, encouraging adjustment. This process of empowering one's resources in favor of a better adjustment is extremely close the "salutogenic model" (6), which shows how people who are able to adjust to stressful situations can maintain a good health. Antonovsky identifies among the characteristics underlying the ability to promote health, the sense of coherence, as "a person's view of life and capacity to respond to stressful situations. It is a global orientation to view as structured, manageable, and meaningful. It is a personal way of thinking, benefit and use, and re-use the resources at their disposal "(7). We can therefore find a great affinity between this characteristic and the awareness of rising from practicing Mindfulness. Awareness seems to offer people the resources and opportunities to move towards the health pole on the Antonovsky's continuum (figure 1).

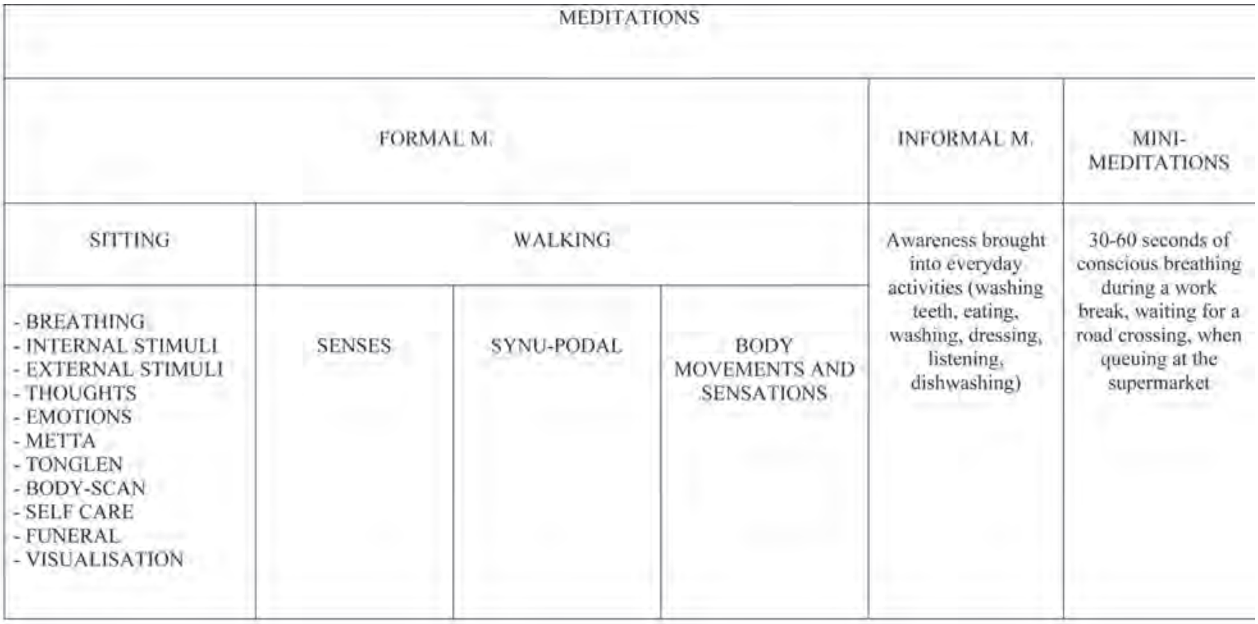
Furthermore, Mindfulness also seems to have a direct connection with the health-related conceptual framework of health developed by Morgan and Ziglio (8). According to this framework a health asset is "any factor or resource that increases the capacity of individuals, communities or populations to maintain health and well-being". According to Botello and col., health assets can be connected to people, organizations and associations, institutions, economy, culture and available infrastructures (9). However, in the ABCD "Assets Based Community Development" methodology, the first basic component of assets is the individual one given by capacities, abilities and gifts of every single person (10, 11). Mindfulness can be central in the identification of these characteristics, which require self-awareness, together with a self-care attitude that allows to identify the best decisions and actions for oneself moment by moment.

As previously mentioned, the task of taking care of others is a complex activity. It requires dedication, often exclusive, so that the person treated is in the best physical, emotional and environmental conditions. This requires caregivers to use a multitude of resources and skills, psychological, behavioral, and attitudinal. These resources can be more or less developed in each caregiver, and require a great awareness of himself and of his own state, to prevent the onset of burnout related to his role (12-13).

But far more important, the caregiver needs to learn how to take care of himself.

On a **cognitive level** (thoughts), self-care means being able to identify thoughts accepting them, with

Table 1. List of Mindfulness Meditations



MEDITATIONS					
FORMAL M.				INFORMAL M.	MINI-MEDITATIONS
SITTING	WALKING			Awareness brought into everyday activities (washing teeth, eating, washing, dressing, listening, dishwashing)	30-60 seconds of conscious breathing during a work break, waiting for a road crossing, when queuing at the supermarket
- BREATHING - INTERNAL STIMULI - EXTERNAL STIMULI - THOUGHTS - EMOTIONS - METTA - TONGLEN - BODY-SCAN - SELF CARE - FUNERAL - VISUALISATION	SENSES	SYNU-PODAL	BODY MOVEMENTS AND SENSATIONS		

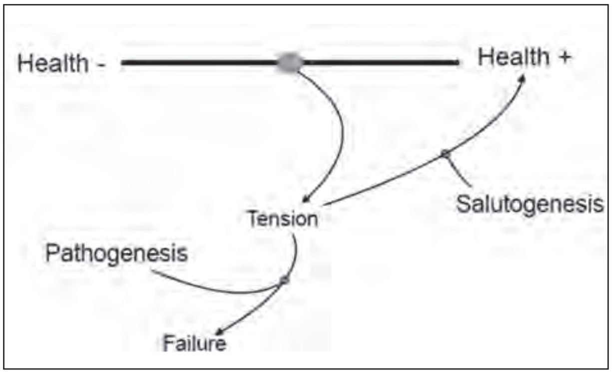


Figure 1. Antonovsky's continuum

the awareness of not being the thought itself. On an **emotional level** (emotions), self-care involves the identification of the emotion in the body, giving it an origin (internal and / or external) and labeling it. This can allow the person to find out which behavior is triggered by this emotion and the consequences it could have, from a perspective of acceptance and benevolence towards any kind of emotion. On a **social level**, self-care means being able to reconnect with one's own, personal priorities. Exactly in this aspect, the practice of Mindfulness can lead to a significant improvement in life and in carrying out of the role of caregiver. So the basis of this proposed community development project, focused on the identification of health assets, is self-care.

Aims

Overall aim

The main aim of this project is to improve the health and quality of life, real and perceived, in caregivers, through community mapping strategies and Mindfulness.

Specific aims

- Identifying and enhancing individual and environmental resources that can be health assets for caregivers;
- Including caregivers in their salutogenic empowerment;
- Developing Mindfulness skills in caregivers;
- Encouraging and developing higher levels of personal self-care in caregivers;
- Strengthening the caregivers' sense of coherence;

-Promoting networks and relationships, among caregivers providing mutual assistance, aid, and empowerment;

- Identifying elements that can be improved in the community and in the caregivers.

Methods

Starting from the salutogenic model, and using the tool of health assets mapping (according to the ABCD model of Kretzman & Mcknight), we will map the population, environment and logistic assets needed to promote this work perspective (14-18). The project proposed here, uses a participatory action research methodology. The target population will consist of female caregivers working the same environment (i.e. same neighborhood) and recruited in health houses, hospitals, palliative care structures, home care services. The project, clearly complex, needs several successive phases for a correct implementation.

PHASE 1 Definition of the Promoting Group (PG)

In this phase is defined the promoting group of the project and, subsequently, the group of targeted caregivers. This phase consists of three moments:

Moment 1: Searching for the PG

The PG will consist of health professionals directly connected with caregivers. These people may be part of the health staff of different clinics, health houses, hospitals, nursing homes, public and private non-profit organizations, entities that are dedicated to health care. The PG will be directly responsible for recruiting participants and monitoring the process.

Moment 2: Organization and training of the PG

Once the PG has been identified, the project will be explained in detail and the different roles will be defined. The fundamental principles of salutogenesis and of Mindfulness will be presented. At this moment of Phase 1 the GP will have to: participate in a Mindfulness course to learn the basics of full awareness (underlining the aspects of care and self-care), and acquire the minimum theoretical and practical knowledge to follow the project. Mindfulness exercises and full practices will be held by expert practitioners, preferably psychotherapists.

Moment 3: Recruitment and configuration of the Caregivers Group (CG).

The projects considers only one PG that will be in charge of recruiting the caregivers who will be part of the project. Once the CG has been identified, a session will be held to present and explain the project, the aims, the Mindfulness and the fundamental principles of salutogenesis. The CG will then begin to perform various Mindfulness practices (19) with a subsequent deepening of Samatha and Vipassana. Subsequently we will introduce practices related to relationships, gratitude and self-care, with Metta and Tonglen meditations. Finally, different types of walking meditation (of the senses, of the synupodal rhythm and of body movements and sensations) will be introduced.

PHASE 2: Organization and planning

In this phase the caregivers' baseline levels of sense of coherence, perceived burden, quality of life, self-compassion and mindful attitude will be traced. An organizational agenda will also be defined, to finally proceed to the delimitation of the area to be mapped.

Moment 1: Test.

Compilation of questionnaires: Sense of Coherence (SOC; 20), Zarit Scale (ZS; 21) or Caregiver Burden Scale (CBS; 22), Cuestionario de Calidad de Vida de los Cuidadores Informales (23), Self-Compassión Scale (SCS; 24) and the Five Facets of Mindfulness Questionnaire (FFMQ; 25).

Moment 2: Actualizing resources and agenda.

We will specify which resources (materials, time, and physical spaces) will be used to implement the project, together with a time schedule related to the conclusion of the project.

Moment 3: Delimitation of the Map.

We will define the internal and external areas that will be mapped:

1) Internal or personal resources promoting health: skills, abilities, characteristics, profiles, leisure time, passions, interests, personal relationships, defined using Mindfulness sessions and group therapy.

2) Existing external resources promoting health: organizations and associations, institutions, local economy, local culture, infrastructures and physical spaces, area (of the city, of the country, ...) where they will identify the external resources .

At this stage, the CG will continue to perform different Mindfulness exercises specifically designed to facilitate the identification of internal resources. To increase the participants' familiarity with the maps, in this phase will be introduced formal and informal dynamic exercises of Mindfulness applied to the maps reading. At this stage, in order to allow participants to be more aware of the external resources, specific walking meditations will be practiced to facilitate the mapping party.

PHASE 3: Mapping party

This phase will be dedicated to the real mapping of the internal and external resources of each participant.

Moment 1: Practice of conscious walking (Walking Meditation).

This phase will begin with the realization of the three walking meditations directly related to the mapping party.

The walking meditations will be followed by general exercises of Samatha and Vipassana, by relational exercises of Metta and Tonglen to strengthen the emotional bonds and group cohesion, and by general self-care exercises.

Moment 2: Mapping party.

To help participants perform the actual mapping, several Mindfulness exercises will be performed immediately before the start of walking meditation, adapted according to the characteristics of the group.

Thereafter, the caregivers will be invited to go out together to the previously identified area (Phase 2, Moment 3) together with the PG. Once the identified area is reached, they will practice a conscious walk, identifying the different external health assets through observation of the context. This process will be videotaped for later analysis. The walking meditation session will also be an opportunity for caregivers to be more aware of some of their internal characteristics (skills, attitudes, interests, resources). Participants will be asked to share verbally or in writing what has emerged during the practice and they will be videotaped.

Moment 3: Identification of Assets.

At this point, the external resources identified (actual and potential) will be classified into six different types: individuals, associations and organizations, institutions, local economy, local culture and physical infrastructure and spaces (9).

After the implementation of the Mapping party, a meeting including PG and CG will be held, to share what happened during the walking meditation, with the visualization of the video realized and the sharing of the identified external assets. Finally, the external assets will be inserted in the map along with the other potential external resources that need to be improved in order to become proper assets.

During this meeting, the personal assets will be determined, identified not only during the walking meditation but also during the whole project through the various exercises proposed and the experiences lived in everyday life. These internal assets will be tracked in what we will call "Mindful Map" (Figure 2).

A heart-shaped illustration divided vertically into two quadrants or "petals" of the heart. A petal refers

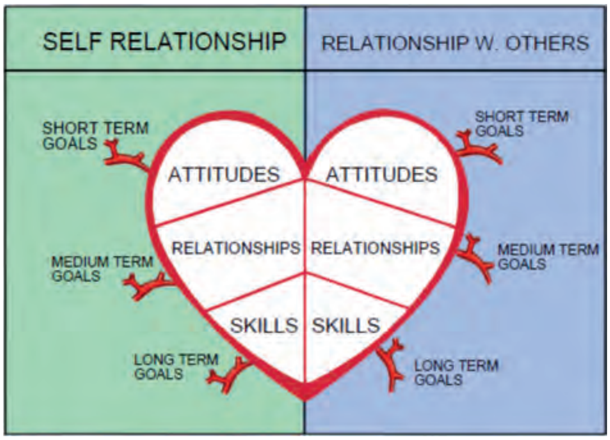


Figure 2. Mindful Map

to the self relationship and the other petal refers to the relationship with others. Each petal of the heart in turn is divided into three other quadrants or shelters. These three shelters indicate the new attitudes, skills and relationships developed during the project. At the same time, the "Mindful Map" indicates the new objectives, interests, in the short, medium and long term, emerged during the project. These goals are reflected in the arteries or natural branches that leave the heart.

PHASE 4: Visibility

This phase will be centered on the diffusion and visibility of the effects that emerged from the whole project. This role will be played by the PG with the help of the CG.

We will use paper material with the maps of external and internal assets, distributed to associations, institutions, shared through the municipal council website, on local radios, in the local press, in posters, and electronic advertising.

We will also create online contents (e-Health site) not only to increase the visibility of the project, but also to continue to support, in an interactive way, the working group. It is assumed that CG and PG will continue to perform Mindfulness exercises regularly.

PHASE 5: Strengthening the relationships between the different parts of the community

According to the results of the mapping process, the interventions needed will be prioritized and modified according to their potential.

The map of assets created during the project will allow the health care context to choose strategies that centralize the local strengths, in order to address health issues appropriately, to define new actions in health policies and to favor a service orientation towards the promotion of health.

In addition, an informal sharing session will be organized to qualitatively evaluate the experience of the participants. Finally a final report will be drawn up on the health of this community, which will be delivered to local policy makers.

Also in this phase Samatha and Vipassana exercises will be practiced and specific exercises related to breathing will be added with the aim of generating greater mental calm, thus facilitating mental clarity, encouraging creativity and improving decision making, not neglecting, not even at this stage, self-care exercises. Finally, in this phase the CG will be asked to fill the same questionnaires filled in Phase 2, Moment 1.

Results analysis

Once the project is finished, a quantitative and qualitative assessment will be carried out using structure, process, outcomes and quality indicators. In particular:

1) Structure: every material and organizational element necessary to guarantee the correct execution of the project (human, physical, technical and financial organizational resources);

2) Process: procedures, activities, methods and organization suitable for the development of the project, best number of participants and activities that should be fulfilled;

3) General and specific aims that have been achieved;

3) The pre-post scores in the questionnaires administered to caregivers: SOC, Zarit, Burden and the Quality of Life.

4) The assessment of technical and organizational quality, as: effectiveness and efficiency (objective evaluation), acceptability and satisfaction of the assisted persons (subjective evaluation).

Conclusions

The project presented here is an innovative model to be implemented in health policies in the context of primary care.

The main objective of this project is not to identify the internal assets only during the mapping party, but throughout the entire project.

We are aware that Mindfulness has its limitations: it is an excellent tool to manage a multitude of stressful situations, but it is not a tool that by itself can solve psychopathological problems or symptoms already in progress. On the other hand, being able to be aware of the present moment by moment, is an important challenge in the current Western cultural approach, and represents a great space for growth. As Jon Kabat-Zinn states: “put awareness into your life and the changes will come by themselves” (2).

Given the lack of homogeneity in the management of health issues, the ABCD methodology with a salutogenic orientation reinforces and emphasizes the development of policies and activities based on the skills, abilities and resources of the less favored people and territories (11). It is an opportunity to promote active citizen participation and cooperation to achieve a sufficient level of empowerment to reduce these inequalities, thus maintaining an adequate level of health not completely influenced by social determinants.

Working with caregivers, with such a powerful tool as Mindfulness, is an opportunity that should not be left aside because of the idiosyncrasy of Mindfulness itself. The cross axis of this philosophy of life revolves around an indispensable pivot: remember people to take care of themselves, even when they are taking care of others.

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Original article: The caregivers' side of the care

Application of palliative care in demented patients: the caregivers' point of view

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Abstract. *Background*: The 38/2010 law has widened the supply of palliative care for patients with chronic and degenerative illness. Dementia is a chronic and debilitating illness and it requires specific, complex and constant assistance, involving the health professionals' community and family, and should also benefit from palliative care. But what do the caregivers of these patients think about it? *Aim*: To explore the point of view of caregivers accompanying dementia patients regarding palliative care and the accompaniment of the medical team. *Method*: A qualitative method with phenomenological approach: 29 semi-structured interviews have been submitted to caregivers of patients suffering from dementia. The interviews were submitted to analysis of thematic content. *Result*: In the majority of cases the caregiver is a member of the family and holds this position because of the affective relationship he/she shares with the patient. They too live the illness of the relative as if it were theirs. The caregiver doesn't know about palliative care or has only heard of it, but is resistant to the application of this care, especially when its correct meaning and use are explained. At the same time, the health professionals" role is important when it comes to taking decisions: caregivers rely completely on the team's competence and on their judgement. *Conclusion*: A correct sharing of knowledge is fundamental. The healthcare professionals must be trained in palliative care in order to correctly inform caregivers and to avoid false beliefs about or resistance to the application of these useful pathways.

Key words: caregiver, palliative care, dementia, health care professional, interview

1. Background

The first important definition of palliative care, given by the World Health Organization (WHO), highlights the patient's central position, the observation of the multifaceted nature of the human condition and the identification of the quality of life as a final goal. Palliative care indeed promotes a complex and holistic approach, identifying and satisfying the complexity of the patients and of their physical, psychological, socio-relational and spiritual needs. Palliative care was created precisely to provide global assistance to patients affected by a disease that does not respond to specific treatment. WHO (1) defines this condition as terminal, a non-reversible state, even with the use of therapies, and which is characterized by a gradual decline of autonomy, by the manifestation of physical and psychological symptoms, which involve both family and social relationships. In this stage of the illness, the medical team suspends all recovery attempts, restricts the therapies to taking care of the symptoms and soothing the patient's suffering, through the remodulation of helpful ongoing interventions (2), by new objectives of cure and care (3). The introduction of the 38/2010 law also clearly defines the basic elements that establish palliative care in Italian background, and also settle this care to people who are affected by chronic and degenerative disease (4, 5). Chronic conditions require long-term management and the presence of a morbid state without the possibility of a resolution (6). Although some chronic illness conditions cause only minor problems, others may cause serious symptoms and limitations of activities. The management of such conditions can be difficult for the patients, since it must include the learning of abilities that allow the coexistence with symptoms and disabilities, and facing up to identity problems that may result from the very own chronic condition (4). In various types of chronic diseases, the symptomatology is similar to that of oncological diseases; the only aspect that diversifies them is the prognosis. The chronic patient can coexist for years with his or her illness which passes through different phases and is characterized by episodes of flare. The trajectory is not always predictable, but it often ends in a gradual or fast decline, which leads to death (7).

Epidemiological data are also alarming. By 2050, a demographic and epidemiologic transition is expected that will bring an 8-fold increase in the number of people older than 80 years old, and a 20% increase in the incidence of chronic conditions (4). It follows that, according to WHO, the necessity of palliative care services will continue to grow because of the increase of chronic diseases and the world's ageing population (8). An analysis of the epidemiological data also highlights how dementia can be considered one of the most interesting diseases, both because of the many people with disabilities who are affected by it, and because of its significant social health impact (9).

Thus, among the different chronic diseases that represent an important public health problem – threatening both the patient's and their family's quality of life – dementia is not only increasing worldwide, but it has been described by the WHO as a global public health priority related to the alarming data associated with it. As with the majority of chronic and debilitating diseases, the patient with dementia requires specific, constant and complex care, which involves not only the medical and social health community, but also and above all the family (10). When a person is affected by a chronic and debilitating disease, one of the main consequences is the loss of ability to conduct everyday activities. As the disease gradually progresses, the patient becomes increasingly less autonomous and begins to depend on the caregiver's help in every activity. The caregiver is a helpful figure whose numbers are growing in Western countries. The caregiver is becoming more common mainly due to the increase in the elderly population, the lengthening of life expectancy, and because of the decrease in mortality due to the improvement in the preventive diagnostics and to the quality of care provided (11). Besides their helpful role, the caregiver must face the gradual deterioration of their relationship and communication with the patient with dementia. There are two main factors standing in the way: the decay of the cognitive function and the relentless progression of the disease (12). The therapeutic team should therefore "support the supporters" throughout the progression of the disease.

2. Aim of the work

The aim of the work is to investigate the point of view of cargivers of dementia patients receiving palliative care, in order to assess whether a common path shared with health personnel – from the early stages of the treatment process – may be a predisposing factor to the introduction of new therapeutic approaches.

3. Method

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 (13, 14). 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 dis-cover the subjective and personal meanings that participants give to their experienced (15, 16).

3.1. Participants

The participants are recluited according to the following criteria: to be a caregiver caregiver of patients with senile dementia and assisted in hospital; a willingess and approval to participate in the research. They have been selected by samples of convenience; 29 caregivers of patients with dementia joined the study (of which 26 were women). They were are staying in two facilities: Nursing Home Villa Paola of Castelnovo Ne Monti, a province of Reggio Emilia (15 participants, all women), and Hospice Vaglietti – Corsini Onlus of Cologno Al Serio (a province of Bergamo). Participants are aged between 51 and 70 years old.

3.2. Instrument

The data are collected through a semi-structured interview built ad hoc. The interview is characterized by flexible questions in which the interviewee and the interviewer have freedom of movement, while maintaining the rigour that allows the latter to address all the necessary topics to the research objectives (17, 18). Some guiding questions are expressed aimed at exploring three macro-areas: a. The caregiver and their history (interview question example: *What changes have occurred in your life since you've been taking care of him/her?*'); b. The application of palliative care (interview question example: '*How do you evaluate the possibility of applying palliative care to your relative?*); c. The collaboration with the health-care professionals (interview question example: '*How much do you feel included in the decision-making by the medical staff?*'). The interviews are conducted between October and December 2017, in a private room. They laste from 30 to 50 minutes.

3.3. Data analysis

The texts of the interviews have all been entirely transcribed, conferring to every partecipant a name[1]. The transcripts are exposed to the analysis of the thematic subject, according to some well-defined transitions (19): 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 caregivers' 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.

4. 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 subareas that highlight the prevalent contents (meanings) specified by the participants (Table 1).

4.1. The caregivers and their history

4.1.1. Because I am the caregiver

Thirty-nine participants describing the reason that leads them to be the main reference of care, speak of the **deep bond** that unites them to their relative: they describe being in the 'front line' in terms of affection, need for closeness and sense of responsibility towards those you love.

C2D: *my father is very close to me and consequently if he does not see me every day he goes into total panic.*

C4D: *It's me and my brother who has always been in charge of the care [...] I've always lived with her.*

Similarly, an equal number of participants argue that the reason that leads them to be the reference person is logistical / organizational (**family organization**): for example, because they live nearby, because

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[1] The operators are identified with the initial C corresponding to 'Carergiver' followed by a progressive number and gender (D=woman; U=man).

Table 1.

Macro area	Subarea	Meanings
1. The caregivers and their history	a. Because I am the caregiver	- Deep Bond - Family Organization - Gratitude - Gender
	b. Time dedicated to the relative	- Long Time - Average Time - Short Time
	c. Patient problems	- Cognitive Problems - Physical Problems - Emotional Problems
	d. Caregivers' problems	- Activities of daily living - Acceptance - Hard Work - Lack of Assistance - Inexperience
2. Application of palliative care	e. Expectations of the disease	- Cognitive and physical decline - Caregivers cannot imagine - Inevitable death
	f. Therapeutic Obstinacy	- No therapeutic obstinacy - Therapeutic obstinacy
	g. Knowledge of palliative care	- No information - Partial Idea - Good Information
	h. Receivers of palliative care	- End of life/Oncology - Everyone - No able to define
	i. Application of palliative care in the care project	- Favour - Chosen by the medical team - Not Agree
	j. Resistance to change	- No Resistance - Moral Doubt
3. Collaboration with health-care professionals	k. Relationship with the health-care professionals	- Good relationship - Fluctuating Relationship - Difficult Relationship
	l. Inclusion in the decisional trial	- Fully Included - Enough Included - Little Included
	m. Sanitary team as accompaniment to palliative care	- Delegation of Decision - Specific Explanations - Psychological Support

they are the only child, or because they were the only one to offer availability.

C19D: *Because I am the one who lives at home with her.*

C13D: *My brothers work, but I have stopped working and I have the possibility of staying at home.*

Sixteen caregivers describe the need to give back to their parents what they have received before, with a view to mutual exchange and **gratitude** towards parents, retracing the generational life cycle.

C17U: *Parents are definitely older, so we decided to help them and assist them in order to give them a bet-*

ter quality of life. After all they did for us it seemed more natural.

C3D: *She was alone; she kept my son when she was younger. Now I have a big house and I made an extra room for her with her bathroom and I took her into my house*.

Four caregivers claim that they are in charge of the elderly because they are women (**gender**). This evokes a gender bias, which sees the idea that women have a greater predisposition and responsibility toward care activities.

C16D: *It's because he had a female daughter in my opinion.*

C29D: *The other, my brother, as a man has other things to do.*

4.1.2. Time dedicated to the relative

Twelve participants despite having their relatives in a health facility tend to spend most of their time in caring (**long time**).

C19D: *Look at me, apart from my work, I dedicate all the time to her.*

C18U: *All the time I can steal from my work.*

Nine caregivers tend to give constant but not continuous assistance, trying to stay with their relative several times during the week, even if not every day (**average time**).

C10D: *I come one day yes and one day no, [...] Let's say three days a week I come to visit my mother.*

C21D: *I come four times a week, usually I stop two hours –two and a half hours.*

Six caregivers report not providing continuous and present assistance, mainly due to time and distance problems from the place of hospitalization (**short time**).

C17U: *I'm away all week and so weekends have always been available to my parents. One day is dedicated to me visiting them*

C23D: *Eh, not so much, I come once a week.*

4.1.3. Patient problems

In the eyes of 22 of the caregivers, describing the pathology of their relatives, **cognitive problems** appear primarily.

C17U: *He could not drive as much; he began to always repeat the same things, to show us at home the same things, which were his clothes, his paintings.*

C6D: *There were moments when my mother did not recognize my father. She called me and told me there is a man here at home and I do not know him, come, send him away, not only during the day, even at night.*

Three caregivers see the pathology of their relative as a **physical problem,** suggesting the progressive decay of the organism as peculiar to the pathological condition of the patient.

C8U: *Something that is incurable, that goes down the person who has it.*

C12D: *He started to walk less and less, to have more and more difficulties, he wanted to go on and on but he did not understand where and making him understand that he could not get up on his own again was very difficult.*

Finally, four caregivers define the problems related to the **psychological / emotional sphere** as characteristics of the pathology of their relatives, drawing attention to aspects such as depression, aggression and emotional crises.

C23D: *She suffered a lot and was in crisis; it is not that she has a strong character*

C8D: *…was very angry, there were scenes after scenes, until the bomb exploded and it went crazy and she even hit me that day.*

4.1.4 Caregivers' problems

Fifteen caregivers say that the main difficulties in the home concern the daily management (**activities of daily living**), activities of daily life such as dressing, eating, washing

C7D: *It took four women, but she did not want to know. Whoever washed it, who put it in place, put it at home, who put it in the tub.*

C17U: *Dad went from morning at nine up to six o'clock during the days of the week to a day centre and in the evening the caregiver came to prepare him for bed and everything.*

Ten caregivers report that the main difficulty in the home management of their relative concerns the emotional plan of **acceptance** of the situation and of the suffering observed.

C15D: *I see the unhappiness of my father, who never understood the situation.*

C21D: *I always thought about my mother even though there was this lady at home. More than once I asked the work to be able to get away from work so I lived badly and I saw that my mother always regressed.*

Eight caregivers say instead that the role they play has a heavy impact (**hard work**), changing lifestyle and habits.

C25U: *So many things change [...] now that I have to devote myself to him for half a day [...] I always lose three hours, three hours and a half. So I've had to give up so many things.*

C11D: *A lot, the hours that take you away are many and also it engages you morally in the sense that if you decide to go on vacation for even 2 days you have to know that there has to be someone to replace you. The last 2 years was much too hard, not being able to have even a free weekend.*

Six caregivers state that the main difficulty of home-based management was the presence of a higher welfare burden than the resources possessed (**lack of assistance**).

C23D: *I had put a woman close, but when I came home from work she always called me constantly for some trivial things and I was always under pressure.*

C5D: *They could not do too much; there were so many tips, I learned many things, but the service on Saturday and Sunday of the medical team was not there.*

Four participants state that they deal with a reality of which they knew nothing, with which they had never dealt with, making it necessary in a short time to understand everything. The problem referred to is therefore **inexperience**, finding themselves managing an unknown pathology with new tools.

C17U: *It was very difficult because I was not prepared.*

C16D: *I saw a reality different from the one I knew .... I have never looked after a person.*

4.2. Application of palliative care

4.2.1 Expectations of the disease

Caregivers view the course of their relative's illness according to three different aspects.

The **cognitive and physical decline** is considered the main reason for twelve caregivers for the relative's deterioration : the lack of memory, the inability to recognize relatives and friends, loss of appetite and difficulty in walking are the main symptoms described.

C1D: *He cannot move anymore, he does not understand, he does not know who he is, he does not know anyone. The only thing that can happen to him on a physical level will be when he will not eat again. I can hardly see a single person anymore. Honestly, I am of the idea that if he does not eat, he will meet his fate.*

C4D: *As they have told me it will only get worse. I don't know how it will end, it scares me. Looking at these five years, the more we go on, the more we will decline. She has no great expectations and the disease goes on, until the brain will no longer function and those stimuli like opening the mouth and swallowing – even those will disappear.*

Nine **caregivers cannot imagine** the course of the disease, some because they are not aware of what kind of worsening can lead to dementia, others do not want to think about it because the thought of losing their relative causes too much suffering

C23D: *here we have never discussed in deph my mother's illnes, we were in denial, we see that sometimes she will have those moments where she does not remember your name, does not know who you are but we have not gone beyond that.*

C17U: *Little, to tell you the truth, a little. I do not know. Dad is very old. Those are things that are hard work, but I was a bit scared. And I do not know, I do not know how it might be, I've never imagined it.*

Other partecipants speak of **inevitable death**, but with the hope that this will happen without suffering for their relatives

C3D:*I only hope that you fall asleep and do not wake up anymore, I don't want her to suffer. None of us can know when it's time, I accept what it is, the important thing is that she does not suffer.*

C21D: *I hope that if something happens, because more than that I do not think it gets worse. The only variation can be death; I hope it happens in your sleep.*

4.2.2 Therapeutic obstinacy

Twenty-six participants consider that the ideal would be an accompaniment to the end of life **without therapeutic obstinacy**, paying attention to the quality of life itself to the detriment of its duration.

C5D: *No, quality of life. I do not conceive the obstinacy, I think when it comes to the situation that there is nothing more to do, in my opinion is a torture, I see it that way. If one day I was in the same situation and if I had the reason to understand these things, I would pray that those around me did not make me undergo remedies.*

C28D: *I think that the obstinacy is violent. The obstinacy is for the family to get away from guilt and to stand the non-processing, I think the obstinacy is really an insult to the dignity and stories of people.*

Only two respondents say they were in favour (**therapeutic obstinacy**), exposing their difficulty in accepting the disease and death itself.

C16D: *If she lived 100 years I am happy because she is a cheerful, sunny person. I see her smiling a lot; she cries a little now, in fact I would miss her if she were not there anymore.*

C18U: *I would say for myself to stretch as much as possible because I want to die before my wife. I told my children that if she dies I die.*

4.2.3 Knowledge of palliative care

Eleven caregivers have declared that they have no knowledge of palliative care or have only heard of it, but are not informed or have not understood what they are actually dealing with (**no information**).

C20D: *Palliative care –I have heard about it, but I have not understood what it is.*

C10D: *Yes, I've heard about it, but I do not have a specific idea of what it is. I know what they say, but not that much. I have never studied the subject.*

Eleven caregivers show a **partial idea** on the topic, giving correct, but unclear and incomplete definitions. Most of them think that palliative care deals only with removing physical pain, while others define it as an accompaniment to death without knowing how this happens.

C15D: *Yes, I know very little about it. I know it is used in the case of strong pain. For me one should suffer as little as possible during the course of a disease.*

C8D: *Honestly, I've heard about it, but I'm not very informed. I do not know if I'm wrong, I do not know if it's those treatments that make you feel better but do not cure the disease.*

Seven instead show to have **good information** on palliative care, using clearer and more precise explanations, with terms such as 'quality of life' and statements on the psycho-physical aspect

C4D: *Yes, I've heard about it, these new treatments are welcome. If they are a help to those who suffer, that you take away a bit of suffering, well good. It always improves giving a little dignity to these people, removing the suffering and not only the physical suffering.*

4.2.4 Receivers of palliative care

Relating to the patients receiving palliative care, twelve caregivers answered that it is dedicated to the **end of life** and **to oncologic** patients, confirming the classic vision of their application

C25U: *Palliative care to terminal patients, to patients who fight against suffering everyday and patients who have no hope; according to me it's a slow walking towards death in a dignified condition. Without making people suffer.*

C9D: *I believe in people who are cancer patients, I've quickly read a couple of things on the Internet.*

On the contrary, twelve other caregivers think they are meant for all the patients **(everyone)** because they are treatments necessary for pain control: whoever has physical pain should be eligible for palliative care. Every suffering patient should have it, especially where traditional treatments have no more effectiveness, regardless of age and illness.

C28D: *So palliative care was, till some time ago, the care for the end of life. Recently, thanks to God, the field has grown and it has become, they waved like to become, they should become the cure of chronicity.*

C8D: *I think it is applied in the case of suffering. When a person hurts, no matter how old he or she is or which illness they have, it's fair not to make them suffer, it's a nonsense.*

Only four caregivers are **not able to define** the type of patients eligible for palliative care, because of the limited knowledge about them.

C10D: *No, sincerely I don't about this; I'm not able to answer you.*

4.2.5 Application of palliative care in the care project

The majority of the interviewees (fifteen) are in **favour** of introducing a palliative care approach to the assistance in order to reduce both physical suffering and emotional one.

C4D: *If I were sure that my mother had no pain I would be the happiest person of the world. In fact, I only ask that she isn't suffering, that she is brought to the end peacefully.*

C28D: *I hope my mother will have only palliative cures. I don't want any other treatments, I don't want her to go to hospital, and I want her end to be simple and natural.*

Five caregivers claim they agree with the application of palliative care but only if it's **chosen by the medical team**, with the assumption of responsibility, and if they don't feel at ease with the importance of this choice and its outcomes.

C27D: So, it's hard for me to answer, but I would ask the experts in palliative care. I trust them; that is, if it is a person who is specialized in this field, I may expect that they provide me information about what I can do; I think people who have studied are able to help me to manage this situation.

C8D: I don't know when … I wouldn't know when the moment comes. I think health-care professionals should decide when and how. They can see and understand better than me what she needs, when they think it's necessary.

A great part of the caregivers, ten, declare that they do **not agree** with the application of palliative care for their relative, matching to this choice the hope that the patient could live as long as possible as possible

C16D: *I don't know them but I want her to live as long as possible because she is a smiling happy person. If she lived 100 years,Ii wauld be happy.*

C18U: *But I don't believe in palliative care, I've never believed in it.*

4.2.6 Resistance to change

Twelve among the interviewees declare not to have any particular resistance to possible palliative approach; as a matter of fact, they wished this could be an active part of the supporting project (**no resistance**).

C4D: *For my mother I would also like to see it offered at this time. I don't want my mother's life to be extended.*

C21D: *Maybe, when you think about morphine. We thought about morphine as something hard, dangerous, and even in my ignorance, that it reduced life. Actually it only helps and so anything which can ward off pain is welcome.*

Two caregivers show, on the contrary, some decision-making uncertainties (**moral doubts**) because they don't know their dears will; but they also show a positive opinion towards palliative care; they underline the fact that, as they don't know the patient's thoughts, they have a moral duty.

C22D: *I could make a mistake, would I make a good decision in using palliative care? Is it good for a patient or not? I do a right thing for him or he wants to live despite everything. It's a moral matter.*

C15D: *The only thing which could stop me is not knowing what my mother wanted for herself. As far as I know she was against euthanasia. But if you told me my mother is suffering then I wouldn't think twice about it, beyond her will. When you arrive at the end of your life, as my mother who is 85 years, it's a nonsense to suffer. By now the bow of life is accomplished, it's not an option to make her live one more year with pain.*

4.3. Collaboration with health-care professionals

4.3.1 Relationship with the health-care professionals

Twenty-four caregivers declare that they have a

good relationship with the medical staff; particularly in respect to their presence, their availability and the possibility to have an open dialogue with them.

C21D: *Very good, always available. I am also perhaps, sometimes, I am always afraid of the sense of guilt and I always resort to you to be reassured and to know that what you are doing for my mother is the correct thing and also necessary.*

C13D: *I rate it as excellent, yes excellent. If I need to ask anything or they need to ask me something, I ask and I get an immediate answer to everything, both from the physicians and the nurses, from the volunteers and everyone .*

Four interviewees have talked of the relationship with the health professionals as a **fluctuating relationship**, which depends on the present operator in the context, and how much each builds a different collaboration.

C8D: *It's very subjective from person to person, in the sense that you don't succeed in having a collaboration with everyone. I find if I ask, however if I am not me to do before and to hardly ask they come me to say as the person you/he/she is going or if there are some problems.*

A **difficult relationship** has finally been rendered explicit by one single caregiver, because of the scarce availability of the health professionals to talk about his/her relative.

C19D: *No, I have not had of it, unless has not asked anything.*

4.3.2 Inclusion in the decisional trial

Fifteen relatives have expressed that they had been informed and involved in every change of treatment (**fully included**).

C2D: *In the health structures you/they have always asked me what I thought of things. When they have had to stop some of the therapies that were normally given, they have always asked me for my opinion and they have always told me the reasons for doing what they are doing.*

C28D:I was able to express my opinion and I was heard. I did not want any therapeutic fury and no fury was done.

Seven respond that they have not always been involved in the decisional trials or that they have not had the occasion (or for the past small time in structure or for lack of necessity) (**enough included**) of it

C5D: *At times him, at times no. any decision is picked me up I have the right to know it as daughter*

C13D: *I think that if they decide for a different care they inform me as principal referent, I think really that is their owe to inform me if they change the care. I think of him, to be included in these decisions.*

Finally, in equal measure, six participants say they have little collaboration with the team, specifying a lack of information with respect to changes of therapy and physicians of reference (**little included**).

C1D: … *little, because you only find out things when they have already happened.*

C8D: … *I don't feel very included because of this lack of collaboration and I know it is also probably a fault on my behalf as well. I miss out on these things and I would sincerely prefer to have a more in-depth relationship, to be more involved .*

4.3.3 Sanitary team as accompaniment to palliative care

Six caregivers have commented on the remarkable importance of the health professionals, attributing them with a fundamental role at the decisional (**delegation of the decision**) level in comparison to the application of the caregivers. The caregivers entrust themselves completely in the competences of the physicians and their evaluations.

C8D: *if theirs propose me this thing I trust me of the physician and of the nurses that are here there and if they made me this proposal it wants to say that they have appraised her and I would approve because surely it has been serious.*

C11D: *I am not competent in the matter, I could document myself, but I trust them, and I hope they are always working for the quality of life.*

In an equivalent way, six of those interviewed attribute an essential importance to the level of **specific explanations** given by the team. The caregivers expose the necessity to be well informed before taking a decision.

C4D: *The physician will be important to stuffed to understand the worsening situation of my mother, but then the decision will be up to me and my brother.*

C15D: *Personally I am not able to understand how much my mother can now cope with her suffering, and I would like the team to help me to understand it.*

One caregiver believes that the relationship with the health professionals can guarantee a suitable **psychological support**, in such a delicate moment from a mental and emotional point of view.

C5D: *I already have clear ideas, I know that I won't fight with obstinacy and therefore the health team will serve asa support for me with a moral support, so that I will know I have made the correct choice.*

5. Conclusion

The results show how caregivers, in most cases, belong to the patient's family and play this role on the basis of the emotional bond and the sense of responsibility towards those who require their care. The data also show a strong prejudice for type: the care of relatives seems to belong – again – mainly to the female gender. This is made explicit in the narratives and is also witnessed by the type of participants: men make up 10% of the participants.

In every case, independently from the type, the caregivers appear people with some characteristics of 'fragility', in how much they are forced to change in major ways their style of life (in terms of leisure time, habits, in demand competences) in order to be able to assist their relatives. Difficulties also emerge from the emotional-psychological point of view: social isolation, depression and problems with the actual family nucleus. From the point of view of the health professional it is therefore useful tener foresees the lived of these people, who are called to undertake a very complex task, with an emphatic attitude that takes into account both the needs and skills of each. A particularly interesting fact is that the greatest part of the caregivers do not know about palliative care, or they have only heard about it. In addition, those who are more informed, possess in every case confused and superficial knowledge: some exclusively associate palliative care with terminal illness or to the care of physical pain, while others have a broader vision, but based more on an abstract and theoretical level than on a real practical knowledge.

It is, however, worth noting that almost all of those interviewed possesses a positive vision of palliative care, considering it useful and necessary in chronically ill patients, leading to less suffering both on an emotional and physical level. And it emerged that although people knew little about palliative care, when better informed they show an open attitude and they are favourable to the its use with their relatives. The emerged data noticed a fundamental role of the provider at a decisional level: caregivers rely completely on the expertise of the medical staff and their assessments. The caregivers also declare that they have a good relationship with the health professionals, to have moments of comparison and feel they have been included in the therapeutic plan.

The practitioners are also identified by the caregiver as ideal to inform on palliative care and also to point out the correct moment for its introduction, with respect to the person. It is therefore fundamental that the providers from the medical point of view, but above all free from their own prejudices and resistances in such circumstances (9), sustaining the self-determination of the person.

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