

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

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

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

1. Introduction

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

2. Aim

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

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

3. Method

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

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

QUALITATIVE ANALYSIS

Level I: Needs assessment

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

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

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

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

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

Level II: Narrative Diagnosis

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

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

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

QUANTITATIVE ANALYSIS

Level III: The use of measurement scales

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

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

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

INTEGRATED ANALYSIS

Level IV: an overview

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

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

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

4. Research context

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

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

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

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

5. Results

5.1. Case Description

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

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

5.2 Patient Description

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

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

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

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

5.3 Need Assessment: which are the primary unmet needs?

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

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

PAIN

Patient Narration Extracts

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

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

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

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

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

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

Narrative outcome

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

SELF-ESTEEM AND SELF-EFFICACY

Patient Narration Extracts

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

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

Narrative outcome

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

QUALITY OF LIFE

Patient Narration Extracts

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

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

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

Narrative outcome

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

SOCIOCULTURAL DIMENSION: PERSON, FAMILY, COMMUNITY

Patient Narration Extracts

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

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

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

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

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

Narrative outcome

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

The patient reported the following results:

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

Global health status (QL2) 16.7%

Physical functioning (PF2) 0%

Role functioning (RF) 0%

Emotional functioning (EF) 33%

Cognitive functioning (CF) 50%

Social functioning (SF) 0%

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

Fatigue (F) 88%

Nausea and vomiting (NV) 33%

Pain (P) 100%

Dyspnoea (D) 33%

Insomnia (I) 100%

Appetite loss (AL) 33%

Constipation (C) 66%

Diarrhoea (D) 0%

Financial difficulties (FD) 33%

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

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

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

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

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

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

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

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

5.6. Integrated outcomes

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

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

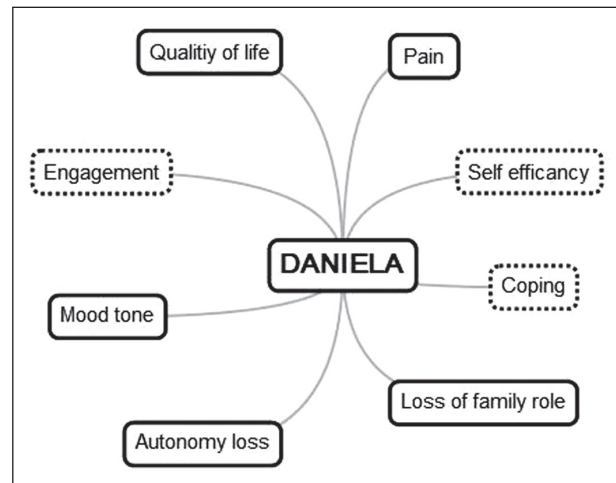


Figure 1.

6. Towards the co-construction of the educational intervention

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

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

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

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

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

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

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

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

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

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

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

7. Conclusions

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

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

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

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

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

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

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

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

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

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

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

Acknowledgement

The Authors want to acknowledge Mirta Rocchi for her priceless contribution to this work.

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