

## Integrated narrative assessment exemplification: a leukaemia case history

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**Abstract.** *Background and aim:* In the Integrated Narrative Nursing Assessment (INNA), the Evidence-Based Nursing Model is integrated with the Narrative-Based Nursing Model. The INNA makes use of quantitative instruments, arising from the natural sciences as well as of qualitative ones, arising from the human achieving results of standardization and reproducibility, as well as of customization and uniqueness. Accordingly, the purpose of this work is to exemplify the thinking process of and the method adopted by a nurse adopting an integrated narrative assessment in the evaluation of a patient. *Method:* The patient suffered from acute myeloid leukaemia, treated with chemotherapy. Her nurse worked in a haematology ward in a North Italy Hospital. The nurse had previous experience in conducting the assessment according to INNA. Based on patient's characteristics, the nurse chose to use the narration (to explore needs from their subjective perception) and the scales (to measure them objectively) among the various assessment instruments provided by the INNA. *Results:* The resultant integrated outcomes helped the nurse to have a comprehensive overview of the person's health-care needs and their connections. These outcomes derive from the integration of narrative information with those obtained from the scales, which in this paper have shown consistent results. *Conclusion:* It is very difficult to reach this complexity by considering qualitative and quantitative assessment strategies as mutually foreclosing, given that both emerged as being very useful in identifying, understanding and measuring the needs of the assisted person. Then they both could be used to design a customized intervention, encouraging new connections between disease, illness, sickness and everyday life.

**Key words:** leukaemia, integrated narrative assessment, nursing, scales, narratives

### Introduction

As we have previously argued, the Integrated Nursing Assessment (1) is based on the Integrated Narrative Nursing Model (INNM), a groundbreaking approach that integrates the positivist paradigm, focused on disease, with the interpretive paradigm, focused on illness and sickness (2, 3).

Integrating the signs and the symptoms of a disease with the idiosyncratic perception of the illness (4) requires a mastery of epistemological approaches and

diversified instruments in assessing the dimension of the disease, the sickness and the illness (3). In the Integrated Narrative Nursing Assessment (INNA), the Evidence-Based Nursing Model is integrated with the Narrative-Based Nursing Model, two epistemological paradigms long considered as irreconcilable (1). Therefore the INNA makes use of quantitative instruments, arising from the natural sciences (e.g. scales, tests, questionnaires) as well as of qualitative ones, arising from the human sciences (e.g. interview, therapeutic emplotment, patient's agenda), achieving results of

standardization and reproducibility, as well as of customization and uniqueness.

According to Marcadelli and Artioli (5) the qualitative dimension of the story can enrich the 'traditional' method by detecting and confirming the same problem, or by increasing the information already found by the traditional method, providing more detail, or by finding issues that are difficult to trace through the traditional method. As Charon stated (6), this allows the professionals to recognize, absorb, metabolize, interpret and be moved by stories of illness: it helps doctors, nurses, social workers and therapists to improve the effectiveness of care by enhancing the level of attention, reflection, representation and affiliation in relation to patients and colleagues.

For these reasons, the INNA presupposes that the concept of the assessment is to be understood not as a simple collection of information and its transcription, but as a multidimensional process of thinking, not only because it considers the patient as a whole, consisting of an interconnected plurality of dimensions (e.g. biological, physiological, psychological, socio-cultural, spiritual), but also because it uses, when possible, a multidisciplinary and multiprofessional expertise (7).

Its objective is to reach a gestalt, which goes beyond the simple sum of the parts, trying to offer, in its completeness and immediacy, a thorough insight into the different needs of that specific patient. This advanced assessment requires a critical process of thinking, a mental and intentional activity with which to process the ideas and make the judgments, and which

inquires and classifies the phenomena, integrating previous experiences, exploring alternatives, evaluating the available opportunities, establishing relationships between thoughts and concepts and making inferences from the data (8). Critical thinking helps the nurse to establish the needs and health-care priorities, and to choose the most suitable method of assessment (in terms of strategies and instruments), based on the person and on the situation (9), at least in that moment in time. This advanced assessment is in fact understood as a dynamic process of thinking, always susceptible to modification over time, constantly evolving in relation to the changing needs and biopsychosocial conditions of the patient.

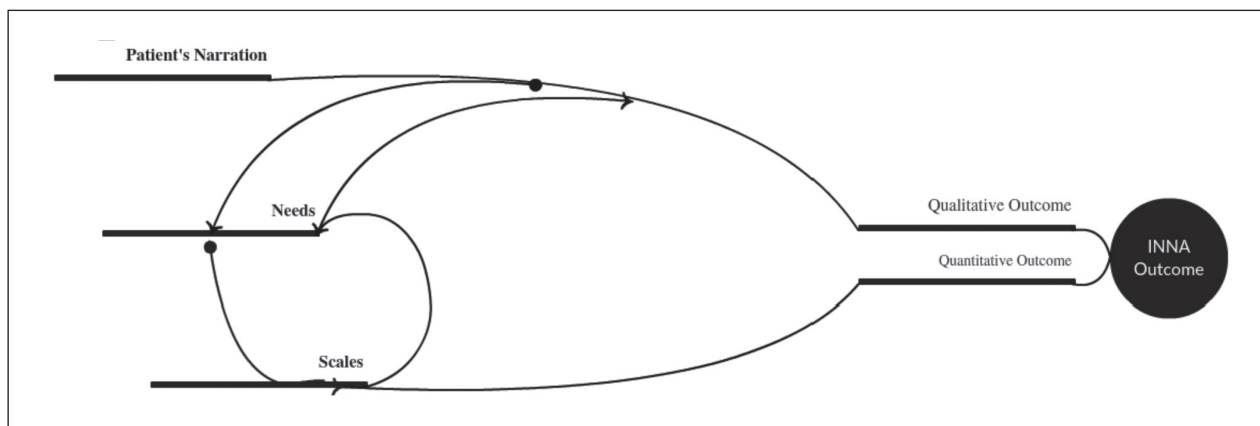
## Objective

On the basis of these premises, the purpose of this work is to exemplify the thinking process of and the method adopted by a nurse who uses the INNA in the evaluation of a patient, Giulia (see Figure 1).

## Method

### Subjects

The patient, Giulia, was 42 years old and suffered from acute myeloid leukaemia, treated with chemotherapy. After marrow transplantation, a manifestation



**Figure 1.** Process of thinking and methodological choices adopted by the nurse

of acute graft versus host disease (GvHD) appeared with pulmonary and hepatic involvement. At the time of the study, she had a chronic pulmonary graft.

The nurse is 34 years old and has 10 years of working experience, including 4 years in Haematology.

At the moment of the assessment, carried out in 2016, she was working in a haematology ward in a North Italy Hospital.

This nurse had previous experience in conducting the assessment according to INNA.

### *Instruments*

Choosing the right strategies and instruments is the central focus of the INNA approach. In this particular case of INNA, the nurse chose to integrate two different instruments, the patient's narration and the scales.

Narration is understood here as a communicative and relational exchange between the patient and the nurse collecting her illness story. Using the narration, the patient is able to move freely in the spatio-temporal continuum to reconstruct her story. This enables us to glimpse the importance of what is freely narrated, which traces a first 'map' necessary for the effective identification of unmet needs.

Giulia seemed to have the following suitable features to interact through a narration:

- Younger age
- No cognitive impairment
- Ability to interact with the staff
- Severe and multidimensional pathology, which justified the choice of a more demanding and thorough assessment instrument
- Expected long-term care and continuity of care

The interview (about 40 minutes long) was conducted in a properly prepared setting: a private room with no special intensity or potentially distracting noises, in the exclusive presence of the experienced nurse. The nurse asked just a few simple questions to develop the topics the patient chose to share. She started with a stimulus question ('can you tell me the story of your illness?'). To this main question, the nurse added some brief questions of specification, immediately stimulated by the story flow of the patient's narration. Therefore, listening to the unmet needs that emerged from

the narration, the nurse decided to measure them using three quantitative scales (see in the Results section).

### *Data analysis*

Although here we include some interview extracts, the nurse's narrative assessment was simultaneous to the interview with Giulia. This is the result of the nurse's previous narrative competence that allowed her to recognize and interpret the illness history by tracing *in vivo* the patient's needs from among the 23 identified by the INNM model (1, 2). The patient's narration enables the met and unmet needs to be defined in a complex, wide, thorough, dynamic and subjective way. Therefore, the needs are expressed in Giulia's words, while minimizing the professional's interpretations. Unmet needs in this study merit special attention because they can lead the nurse to various reflective and reprocessing processes subject to further evaluation and interventions, even though the met needs can also play a supporting role in identifying care interventions, since they are a resource to cope with detected problems.

Even though they will not be presented here, to specify the different dimensions of the detected needs, the nurse considered different items and/or sub-dimensions of each chosen assessment scale that specifically evaluates certain features. The evaluation of the answers given to the individual item therefore allows the nurse to evaluate the needs – including their facets – in depth, thus passing from a subjective description (narration) to a more objective one (item/dimension of the scale).

To measure the needs, the nurse calculated a final score, including the cut-off point if present. In this first phase the nurse collected an initial score on the need, which can be taken as a baseline and a starting point for the activation of the care process and for the further evaluations.

So the information coming from the scales can identify the dimensions and the quantification of the needs, formerly emerged from the free narration of the patient.

The resultant integrated outcomes helped the nurse to have a comprehensive overview of the person's health-care needs.

## Results

The nurse's assessment carried out using INNA methodology, as described in the methodological section, was as follows:

### 1. Qualitative outcomes: The narrative assessment

In this phase, the nurse uses active listening to identify the patient's care needs through the free story she reports. As an example, we include some extracts that refer only to three of the patient's needs among the many identified by the nurse (e.g. pain, movement, tissue integrity, nutrition, quality of life, stress adaptation, resilience and coping strategies, self-esteem and self-efficacy, self-care, therapeutic adherence, experience, hopes and expectations, socio-cultural dimension, value and spiritual dimension).

The three central needs identified are: respiratory function, body image and mood. These needs appear many times in the patient's free story, as not being satisfied, therefore are unmet. As lived and told by the patient, they seem particularly disabling, and are related to many other needs in the bio-physical, psycho-social, spiritual and value-related domains.

What follows below illustrates how the nurse, starting with some extracts of the patient's narration on the three needs, made the narrative assessment outcome for each of them.

#### 1.1 Functionality of the respiratory system

##### Patient narration

*From the beginning, I went into it [...] with great hope. [...] I did say that once the treatment was over it would be all right [...]. I must admit, however, that I suffered a lot [...] since I am very sporty, a lover of the outdoors, when I knew my friends were going around [...] the sense of seclusion was perhaps slightly worse than physical pain. [...] for me, moving is what makes me feel alive. [...] but I couldn't breathe [Extract n. 1]*

*I don't know why I didn't go to see the pulmonologist [...] maybe they hoped to succeed with the therapies and keep it under control. Then it degenerated. I went [...] to do the spirometry tests and the lungs had lost almost all their*

*capacity – so then I don't know why they didn't think about giving me oxygen before! In retrospect I'd say ... why did I go on suffering? I have always hoped that things would get better [Extract 15].*

*There we were, still in 2014. 'It's been such hard work'.but at the same time I went on a sailing weekend and for the first time I dived in the water and found that I couldn't swim ... then, because I couldn't breathe, they had to throw me a life jacket .. I've always swum like a fish and well ... well, I've tried to do all those things that ... I was trying to lead a normal life even if my body was no longer able to do it [Extract n. 16].*

*Then the last spirometry [...]. Boom! My lungs had just gone, there was no way to recover and so I had to adjust to the situation [...] so many things made me have to change my life... the perspectives on my life. I readjusted. For example, when I was still not well, my sister used to take me to the mountains by car because I loved the mountains, then I had to stop; we used to drive in the hills. And I said, 'Think about it, I did these climbs with my bike once!'... We used to go biking in a group; I also miss my friends so much, and I miss going running a lot. I used to do it with my dog [...]. I miss walking in the mountains so much [Extract n. 22]*

*We were inside the biennial warehouses that were closed. Then suddenly it got cold and started to rain ... when we came out it was dark and cold and I couldn't walk because I couldn't breathe. Venice is not easy for anyone who has breathing problems because there are bridges and you can only walk everywhere. You can't take a taxi and go ... or you can get a wheelchair chair and go, that's another part of my life I had to change, somehow reverse and readjust. [Extract 18].*

*But the moment I realized that there was nothing left that I could do was this year when the pulmonologist told me that 'the lungs are shrunken, hardened, so the respiratory capacity cannot be resumed' [...] then I adjusted, hanging around with my oxygen machine [Extract no. 24].*

##### Narrative outcomes

Giulia shows a significant change in the respiratory function need: 'I couldn't breathe'. Respiratory problems, since the onset of illness, prevent Giulia from moving, taking part in the normal activities of her daily life, and enjoying the company of friends – 'I was trying to lead a

normal life even if my body was no longer able to do it'. Later, the situation gradually deteriorated, until 'I couldn't walk because I couldn't breathe'. Giulia now knows that 'the lungs are shrunken, hardened so the respiratory capacity cannot be resumed', completely readjusting her life: 'then I adjusted, hanging around with my oxygen machine'.

## 1.2 Body image

### Patient narration

*Another problem was the stains on the skin; before there were plenty of them, on the skin, on my face, on my body. Now I don't have many any more. Even on the aesthetic level I took a beating: I was a beauty queen once and I had my long blond hair, a nice silhouette, in short a normal person, boobs ... well everything right. I used to feel more feminine [...] always trying to lose weight, trying to be a little less .. and to be careful .. well, as normal people do, then I started gaining weight because of the cortisone and started losing my hair [Extract 12]*

*The chronic GRAFT began to really debilitate me because it stole everything. My eyes, the mucous membranes of my mouth, lungs, organs, my intimate parts: they also burned because all the mucous membranes were dried. [Extract 10].*

*The fact is that even from the point of view of my femininity I am not the person I used to be before. I mean I haven't had further relationships since I broke up with my ex. I don't even know if I can have them [...]. Because of the physical problems and the strength I lack and the breath I lack I say it is .. I haven't even met interesting people also because I don't see myself as interesting ... [...]. I don't know if I can ever trust myself and have the strength to [... face falling in love [...] in a relationship with another person. [Extract 27].*

### Narrative outcomes

Giulia shows a great discomfort with her current body image, compared to the past when, on the contrary, that dimension of her life was the origin of pride and self-esteem. Today, she says, 'I don't see myself as interesting,' openly declaring that disease and GRAFT have altered her 'femininity', especially in terms of hair loss, skin stain and weight gain.

## 1.3 Mood

### Patient narration

*But, in addition, that summer my boyfriend broke up with me ... so having gone through all the treatments for the leukaemia but I found myself sick, with another illness that stole more from me than the cure for the leukaemia did. My family was around me, my friends were around me, but my friends' circle is quite small and it went away [...] That is, he was with me for the entire period of the disease, and then, when he saw that I could not recover he left me [Extract 13].*

*I also got smacked in the face on two fronts at the psychological level. The GRAFT just threw me down ... when I was incredibly down I started having therapy here with the psychologist in the early months of 2015 .. I was at my wit's end. [...]. Because I wanted to heal, but my body couldn't heal, it seemed to me to get even worse. So I began to do psychotherapy, and at the beginning it seemed completely unhelpful as I was so knocked down... so close to the point of putting an end to it... and I started thinking at this point, since I got worse: why did I let them start the cure? Perhaps it would have been better to end it with the illness rather than survive the illness and be an invalid for the rest of my life. Living my life as a half or one-third of what it used to be before, in each aspect, both physical and psychological [...] I also went to a psychiatrist who gave me the medicines that I think worked [...]. They've got me out of the suicide tunnel [Extract 17].*

*We were in Venice, my sister and my friend. [...]. I couldn't walk because I couldn't breathe. [...] There was a moment, there was that canal.. I was this close to throwing myself in it [Extract 18].*

*[...] To my mother, above all, [...] and also to my sister [...] I used to tell talk to them about ending it all. My mother said, 'Don't say that, what are you saying?' [...]. But I felt it and I have to say that I had chemotherapy for nothing, not for living. These suicidal thoughts, now that we are in November 2016, are far away ... but they are still present somehow [Extract 21].*

*From the physical point of view, I'm definitely recovering, but there's always this worm in my mind [...] that could make me fall into the abyss. [...] this craving for getting it over with and thus solving everything, both for me and for my family, since I know I've become a burden.*



*There is this worm of being no longer the person I used to be. And there is the fear of getting sick again [Extract 27].*

### **Narrative outcomes**

Giulia shows a mood that is often deflected, which led her several times, since the onset of the disease to now, to think that *'it would have been better to end it with the illness rather than survive the illness and be an invalid for the rest of my life'* referring to the aforementioned alteration in her respiratory function and motion.

Over time, Giulia managed to get *'out of the suicide tunnel'*, though *'it has not gone altogether'*.

### **2. Quantitative outcomes: Scale assessment**

As already explained, the needs found through the narration were respiratory function, body image and mood tone. The nurse decided to explore and measure them using the scales.

#### **2.1 Functionality of the respiratory system**

For the quantitative evaluation of this need, for a better more in-depth analysis of this need, we used the Chronic Fatigue Syndrome Scale (10). This choice was due to the chronic condition of the patient and the persistence of the dysfunctional breathing condition, and also to the patient's 'physical and mental fatigue' in dealing with normal daily activity. In fact, the scale offers the ability to define two distinct scores for physical fatigue and for mental fatigue, as well as defining a total score. For each single item the patient can respond with a three-position scale (0 = as usual; 1 = worse than usual; 2 = much worse than usual). This allows the evaluation, through retesting, of the variability of fatigue rate in the function of clinical changes.

Ease of administration (items, 14 in total are short and of immediate response) was a further criterion of choosing this scale.

The score obtained was 14/16 for physical fatigue, showing a considerable physical/muscular fatigue that could result in additional needs (e.g. movement, care - due to space limitation this is not covered in this article). Likewise, mental fatigue had a high score of 8/10, which also shows how this aspect is affecting other

needs/care dimensions, such as lowering the tone of the mood (see below).

#### **2.2 Body image**

As highlighted by the narrative, the change in body image has been repeatedly indicated by the patient as a central element in her clinical-therapeutic pathway. There are several scales in the literature that allow us to evaluate this problem. The choice in this case is the Body Image Rating Scale (11).

The scale consists of 23 items, the minimum expected score being 36, with a maximum of 105. The patient received a total score of 85, showing a high level of body image disorder. The analysis of the items shows in particular that Giulia tends to conceal her body from herself (the item 'does not look') and from others (item; conceal the negative changes of my body to others; known negative changes in relationships with others because of my physical appearance).

#### **2.3 Mood**

From the narration there emerges an anxious-depressive illness of the patient. In literature, there are several tools that allow us to quantitatively evaluate the mood. The scale used for this patient is called the Hospital Anxiety and Depression Scale (12). Like the previous one, it is a self-administered scale, consisting of 14 items, and allows the measurement of the components anxiety and depression. Scores range from 0 to 21 for each dimension. The patient reported quite high values of in both dimensions - 12 for anxiety and 18 for depression.

### **3. Integrated outcomes: An advanced assessment**

This section describes the integrated outcomes of the nurse, thanks to the advanced assessment. These outcomes derive from the integration of narrative information with those obtained from the scales, which have shown consistent results.

#### **3.1 Functionality of the respiratory system**

Giulia *'couldn't breathe'*. This is upstream of a state of physical fatigue (CSF; Ph = 14) that has a decisive impact on the sphere of movement: *'I couldn't walk be-*

cause I couldn't breathe'. This is progressively more compromised, reaching almost a total loss of autonomy: 'For me, moving is what makes me feel alive, but I couldn't breathe'. Respiratory alteration is also expressed in the presence of a state of mental fatigue (CSF; M = 8), which implies the emergence of problems also at the social and relational level, with the risk of isolation: 'When I knew my friends were going around, the sense of seclusion was perhaps slightly worse than physical pain'. While showing the ability to adapt to stress and high resilience 'I had to change, somehow reverse and readjust', this alteration in respiratory function shows significant repercussions on the quality of life: 'I was trying to lead a normal life even if my body was no longer able to do it', with a shrinking of hopes and expectations

– 'So many things made me have to change my life' the perspectives of my life'.

### 3.2 Body Image

Giulia 'even on the aesthetic level took a beating' (BIRS = 85) after the onset of the disease 'I was a beauty queen once'. She feels ashamed of her own image 'from the point of view of femininity, I am not the person I used to be before'. Particularly toward weight gain 'I started to gain weight because of the cortisone' which led her to hide her body from herself and from others. The altered body image is therefore related to a decrease in self-esteem and self-efficacy 'I don't know if I can even trust myself', to a narrowing of the socio-cultural

dimension of existence, especially in the affective and sentimental dimension – 'I haven't had further relationships since I broke up with my ex', as well as being related to psycho-physical pain, tissue integrity 'all the mucosal membranes were dried' and to the respiratory function 'because of the physical problems and the strength I lack and the breath I lack'. In relation to her own image, however, she maintains positive and functional areas, and continues to appreciate her face and breasts.

### 3.3 Mood

Giulia was 'so close to the point of putting an end to it, although at the moment she is more stable and has less dramatic feelings at the moment: 'they've got me out of the suicide tunnel'. Although far from suicidal intentions that have historically characterized her history 'there was that canal... I was this close to throwing myself in it', she has important anxiety and depressive symptoms (HADS A = 12; D = 18). The repercussions of the disease on her mood seem to have altered the quality of life, intimate and family relationships 'getting it over with and thus solving everything, both for me and for my family, since I know I have become a burden', with a shrinking of hopes and expectations of life 'living my life as a half or one-third of what it used to be before', with the fear of getting sick again, both physically and psychologically – 'and there is the fear of getting sick again'.

Figure 2 shows the conceptual map of the unmet needs of the patient.

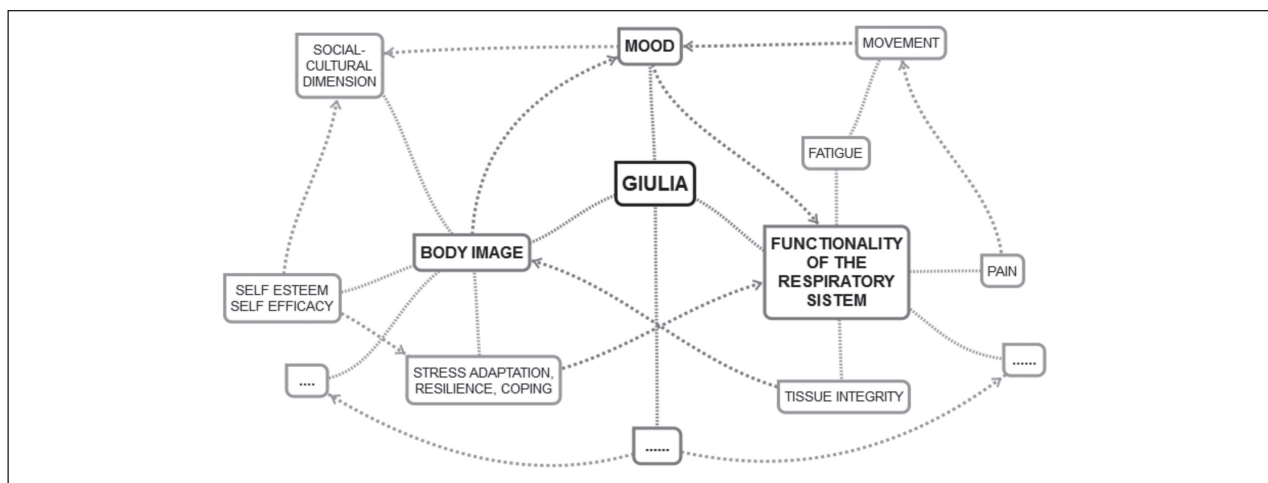


Figure 2. Conceptual map of Giulia's unmet needs

## Discussions and Conclusions

As we have previously argued, the ability to make inferences and formulate forecasting assumptions requires not only an adequate knowledge and a basic nursing skill, but also the ability to use a multidimensional and critical thinking (8, 9). The purpose of this work was to exemplify the thinking process and the method used by the nurse adopting an integrated narrative assessment (INNA).

Based on Giulia's characteristics, the nurse chose to use the narration (to explore needs from their subjective perception) and the scales (to measure them objectively) among the various assessment instruments provided by the INNA: quantitative (e.g. questionnaires, tests, surveys, scientific evidence) and qualitative (e.g. autobiographies, therapeutic emplotment and the patient's agenda)

This method was also chosen because the nurse had gained an integrated competence, which in particular included both a narrative competence and expertise in the proper use of scales (13).

Thanks to the acquired narrative competence, the nurse was able to understand Giulia and the meanings she attributes to her illness, to identify the priority of her needs, and their interconnections with other needs, actively listening to the patient herself and her point of view.

The acquired expertise on the correct use of the scales has enabled the nurse to know the available and validated nursing scales, and to be able to select the most suitable ones for Giulia. This competence also enabled her to correctly use and interpret the scores, and thus to obtain a useful baseline value for the evaluation over time. The care path can, in fact, be monitored by administering multiple sessions of the scale selected at the assessment time, so as to accurately verify whether the pathway is effective in supporting those needs emerging as unmet.

Then, collected data are characterized by recursiveness and by the synergistic use of the qualitative-quantitative instruments. The resulting integrated outcomes, while retaining a component of objectivity and measurability, are at the same time unique and subjective, as they arise from the patient herself and her language. In fact, the structure of the illness history

is not linear, but circular; it has not only rational but also emotional order, based on the recursiveness of the theme (14).

Also Giulia's narrative with her unique language and communicative styles, offers an intuitive and simple way to express her experience that could be immediately shared among the various professionals, even if they use their own specific professional language.

So, among the 23 needs of the assisted person recently indicated by Artioli and collaborators (1, 2), we chose to only some of them: that choice was made based on the importance that the patient herself assigned to the alteration of breath, body image, and mood. In this way, through her narrative, the patient emerged as the real expert in her illness, sickness, and in this case, disease (3). It is very difficult to reach this complexity by considering qualitative and quantitative assessment strategies as mutually foreclosing, given that both emerged as being very useful in identifying, understanding and measuring the needs of the assisted person. Only this integration allowed the nurse to enrich the 'cases', such as the set of data and information collected by the professional, with the 'stories', such as the narratives told by the person (5, 15). In a complementary, synergistic way, they both could be used to identify the patient's needs and to design a customized intervention, encouraging new connections between disease, illness, sickness and everyday life.

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