

The Patient's Narrative Agenda as an assessment tool: the story of Robert, suffering from osteosarcoma

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Abstract. *Background and aim of the work.* To activate the participation of the person in his/her care path, the literature highlights the impact of the professional's ability to show a genuine interest in the problems brought by the patient and to recognize him/her as 'competent'. In this sense the narrative patient's agenda could be a useful relational tool, because is focused on the perception of patient experiences of his/her illness. Thus this study aims to analyze the usefulness of patient's narrative agenda during the assessment phase. *Method.* A semi-structured interview has been adopted to explore the agenda of Robert, 21 years old, suffering from osteosarcoma. A first level analysis identified the four functional areas of the agenda: ideas and beliefs; expectations and desires and context in which he lives and interacts. A second level analysis assessed the main Robert's problems. *Results.* The narrative agenda has highlighted many central problems of Robert (e.g. therapeutic adherence, quality of life, mood, body image, existential problems related to experiences, hopes and expectations). Of course these results could be integrated with other tools: qualitative, to Understand difficulties and to formulate hypotheses, and quantitative, to measure the level of severity of problems reported. *Discussion and conclusion.* The narrative agenda has not only proved to be a valid instrument of assessment, allowing an adequate insight on the patient's problems, as we exemplified, but it can be also used for monitoring the dynamic situation of the person's history, lending itself to the re-exploration of its functional areas over time.

Key words: Patient's Narrative Agenda, interview, qualitative method, assessment, osteosarcoma, cancer

Introduction

Several Authors recognize that when healthcare professionals pay attention to the patient's concerns and needs, during a targeted interview, they promote the construction of the patient-healthcare professional therapeutic relationship. Conversely, a poor listening to the patient is associated to unresolved problems and can be assisted by superficial communications between the patient and the healthcare professional (1, 2).

Some studies, especially qualitative, aim to highlight the relevance of the assessment of the patient's concern through more or less structured communications interventions, which privileges the interview instead of the questionnaire for the data collection (2, 3).

The conclusive considerations of some of these studies underscore the intrinsic complexity of these consultations. It also emerges that the impact of a chronic pathology is very significant for the patients, while professionals do not recognize it as such in their assessments (3).

Two different approaches to clinical consultation are still evident today: a first approach, in which the professional fixes his/her agenda and focuses on the chronic condition of the disease; a second approach, in which there is more harmony between the clinician's agenda (disease oriented) and the patient's one (disease but also illness and sickness oriented). The Authors go so far as to say that clinical consultations represented an 'alibi' for patients to reveal some of

their worrying concerns (4, 5), especially concerning chronic, disabling (3) and oncological pathologies (4, 6). Listening to the person, in terms of what he/she wants to report about his/her experience of illness, reduces the risk of generating discomfort or frustration due to the absence of attention to what he/she considers important (7).

Recent literature wonders about how clinician and health professionals may stimulate and require to arouse patient's concerns and expectations, examining how the interview opens and how it closes, including the event using of pre-interview strategies or tools such as easing questions. Studies show the extent to which a patient verbalizes his/her agenda depends on the quality of the clinical interaction (8). An appropriate communication ability, capable of exploring patient's expectations, problems and emotions, is the necessary condition for activating the participation of the person in his/her care path. Concerning ways to improve participation, many studies highlight how the areas of greatest impact are thus related to the professional's ability to show a genuine interest in the problems brought by the person, to give information already adapted to his/her need and to use the patient's knowledge, so as to recognize him/her as 'competent' (9). These communication skills also require the possibility of using well-defined strategies that foster the healthcare relationship between the professional and the patient, the knowledge of his/her needs and the strengthening of the self-care attitude (10) including, for example, showing respect, creating engagement, focusing on listening to the other, generating trust and encouragement.

It therefore clearly emerges that, for the healthcare professional, it is necessary to explore in depth the patient's agenda, considered not only as a series of specific questions asked by clinics that answer short (11), but as a tool used in a narrative way, to offer the possibility for the person to express feelings, emotions, expectations, ideas and experience of illness and to reconstruct the story of illness through the empathic communication.

Also in response to this need, in the late 1980s, Levenstein and his collaborators introduced the concept of the patient's narrative agenda as the key to understand assisted people (12). The patient's narrative

agenda is indeed a relationship tool of great utility in the care context, as it focuses on the subjective perception of the problem, the symptoms reported and the ways in which the patient experiences the illness, also allowing to accommodate the needs of a psycho-social matrix (e.g. being understood, accepted and supported) which the patient carries at the time of the meeting with the professional. More specifically, the patient's narrative agenda makes use of a semi-structured qualitative interview, with open questions designed to explore the following functional areas:

a) *feelings* (e.g. fear, anxiety, guilt), which concern previous events and the subjective expression of how the person suffers; b) *ideas and beliefs*: which concern the personal interpretations of the disease, articulated to generate a more complex construction of beliefs or frames; c) *expectations and desires*, related to the requests for help, more or less explicit, and the ways in which to implement it; d) *context*, which affects the working, social, family and cultural contexts, in which the patient lives and interacts, as well as concomitant events, stressors and the presence of a supportive network (14). With this structure, the patient's narrative agenda allows professionals to create an empathic but sufficiently structured setting to encourage the patient to express his/her experience through an effective relationship.

The literature recognizes from many sides the need to have more relational attention with the patient in order to provide him/her with greater spaces of verbal expression; there are also several studies in which the clinical agenda is used to stimulate the person to also express his/her point of view about signs and symptoms.

On the other hand, the literature that declines the use of the patient's narrative agenda, highlighting its advantages and limitation in the assessment phase, is scarce.

Aim

In accordance with the literature, this study aims to analyze the patient's narrative agenda during the assessment phase. Through its application in a case study, the elements making up the agenda of a single patient with its main problems, advantages and limitations that this tool can offer to the clinic have been pointed out.

Method

A qualitative analysis of the patient's illness narrative has been adopted.

Instrument

We used patient's narrative agenda by Moja e Vegni (13), integrated and adapted in a version that includes:

a) Introduction

The professional, in this phase: greets the patient, introduces him/herself and qualifies his/her professional role; makes the patient feel comfortable; collects some socio-demographic data (e.g. *How old are you? What job do you do? Who do you live with? Where do you live?*); asks the "why now" of the consultation, especially if outpatient (e.g. *What brought you here today? What is the reason for your visit?*).

b) Central phase

The professional explores the areas of the agenda that is the personal meaning of the illness and of the symptoms, and the context of the person. Here are some sample questions for each area, suggesting the professional to select the most relevant questions for that specific situation:

- the patient's feelings (e.g. *Do you want to tell us how you live this illness situation? Do you feel like telling us how you feel? What are the feelings that you recognize in yourself?*);
- the patient's ideas and beliefs (e.g. *How do you think you got sick? What did you think the first time you were sick? Do you want to tell us what idea you have concerning your illness? What do you fear most about your current illness? Do you want to tell us if there are any of your beliefs about this illness?*);
- the patient's expectations and desires (e.g. *Can you tell us what has changed since you have had these health problems? What expectations have you about your illness and its possible evolution? What could help you? What do you expect to happen? What wishes would you like to fulfil? What would you like what happened?*);
- the patient's context (e.g. *What else happened in the period in which you started to feel bad? What other problems did you face in that period? Who helps you in this situation (in terms of illness, therapy, emotional dis-*

stress or other, if it emerged)? Who can you talk to about your problems? What do your family members think or say about your health problem? How did they react to your health problem?).

c) Conclusions

Finally, the professional makes a summary of the various points and asks if the patient wants to add something and shares with him/her how to continue the process started.

Data collection and analysis

The professional initially identified the patient to administer the semi-structured interview for the extrapolation of the narrative agenda, as previously defined. Then, he asked the patient for the informed consent. In order to facilitate the application of the agenda in clinical practice, it was decided not to register and therefore deregister the interview. The professional, through paper notes, wrote down significative elements derived from the interview itself and completed these notes with richer notes described immediately at the end of the interview. The qualitative analysis adopted the framework method described by Gale and Coll. (15). In particular, two steps were taken to carry out: a first thematic analysis of the data collected to define the four areas of Robert's agenda (first level analysis); a subsequent qualitative analysis of comparison between the data to identify the main patient's problems (second level analysis), among those the needs highlighted by Artioli and coll. (16).

Context and participant

The context in which the assessment interview took place was the patient's home; Robert, 21, asked his mother to leave the room and not be interrupted or disturbed. Considering the young age of the patient, the conversation was set with an informal tone and a colloquial language. Below is a brief description of Robert's clinical case.

Robert was diagnosed with bone cancer in 2018 and, in particular, a grade 4 osteoblastic osteosarcoma of the left proximal tibia. The therapeutic indication was to start the adjuvant chemotherapy treatment. In relation to the risk of possible consequent infertility, he is also advised to preventively deposit the sperm

at a specialist institution. Robert then begins cyclical chemotherapy treatments, with short hospitalizations at the specialist clinical institution.

After the first treatment, he develops a toxic liver disease, which forces him to postpone the next treatment. This was followed by urgent access to the First Aid Station for a massive bilateral epistaxis, caused by the important thrombocytopenia induced by the chemotherapy. Robert, after a few hours of observation, signs for discharge and refuses hospitalization. In early march 2019, more than a month later than the established therapeutic program, surgical resection of the left proximal tibia and the application of antibiotic-loaded cement have been performed

Results

The results are presented according to the two levels previously described: the first refers to the identification of the four functional areas of Robert's agenda; the second level analyses the data in order to assess Robert's main problems.

First level analysis: Robert's narrative agenda.

The thematic analysis leads to define the following Robert's narrative agenda:

a) Robert's feelings area

When he learned of the disease, he felt *"dazed and a little incredulous"*. After the interview with his general practitioner, who explained to him the path to take and the repercussions of the therapy, initially he did not fully understand what would have happened. From Robert's point of view, the recovery of the physical form and his physical aspect before the disease appeared primary: *"You know what muscles I had! And now I have nothing left. I look white with eye bags."* Before the surgery, the limb was deformed by tumefaction in the tibial region and painful enough to compromise normal activities such as walking, driving, simple supporting the load of the body weight in an upright position. After the surgery, an important scar remained and the limb became hypotonic. Walking and support the load of the body weight are still compromised. The change in muscle mass had thrown him into despair, so much so that he started using crutches in the hope of

strengthening and redefining the muscle of his arms: *"A few months ago I saw myself as an old man!"*. These limitations led him to experience feelings of anger and frustration: *"The changes in the image I have of me actually modify my mood both positively and negatively; it depends on how I am...on the chemo...and then, in reality, also the physical aspect is modified by the mood, they are two things that change a little...[...] if I am in a good mood also the physical aspect profits, if I'm in a deflected mood, the physical aspect also gets worse"*.

From a phase of anger and rebellion, then he moved on to a sense of loneliness and isolation and of a lack of understanding from the people around him. He is currently going through a more conscious acceptance phase of his disease: *"I adapted myself to this situation"*. *"Then, in the end, I realized that women like... RoboCop...because with all these wires and scars I look a bit like RoboCop"*.

When asked if there is something that scares him, he avoided answering, but at the same time said: *"I'm not ashamed, but now I've given up going out"*.

b) Robert's ideas and beliefs area

The diagnosis came at a time when life events seemed positive (house purchase, removal from his mother's partner, permanent employment). The illness was interpreted as the biggest misfortune of his life: *"Why all bad to me? What idea should I do? What idea would you make yourself? In the end, when things were starting to go well, a bigger bad luck than all came. Bad luck, fate, karma...no, not karma...bad luck above all!"*.

Robert offers very personal interpretations regarding the effectiveness of medicines, underlining that he knew what was good for himself: *"Eventually, more or less everyone will develop their way of doing things; there are those who do everything that doctors say and those who act a bit in their own way"*. He therefore imposed his opposition to certain drugs: *"Concerning medicines I try to take as few as possible, only in case of need or in serious cases...like growth factors, they serve no purpose and by the way I feel good; I take them when I feel sick."*; *"I don't take growth factors because they increase negative values, that is, therefore is useless to take them since they make things not needed grow. I tried this thing myself and also other guys I talked to in the Hospital and therefore I prefer not to take them, instead I take other medicines, if necessary"*.

Chemotherapy is experienced as the main problem: *“Actually I had already recovered a couple of months ago, but after I did chemotherapy cycles again, which I don't want to do anymore, I got worse again because my hair fell again and I started again being very tired of not recovering faster [...]...I take a step forward the cycle pushes me two steps back, so I don't recover anymore, that's all”*.

Attitudes of defiance, rebellion and the refusal to take certain therapies or to be taken a blood sample (*“I don't want holes! I look like a shitty junkie!”*) seem to indicate an attempt to regain the control of his condition.

c) Robert's expectations and desires area.

It wasn't initially clear to Robert what would happen to him. As reported by him, not being very patient in nature, he expected the path to be faster. His desire was that everything would end as quickly as possible and, in the meantime, he tried to maintain a semblance of normalcy, as long as the effects of chemotherapy became too debilitating: *“At the beginning, when I started loosing my hair, I put on hats, which I never did; then when I realized I was feeling bad I stopped putting them on, I gave up”*. At that point, the only desire was to isolate himself and reject personal contacts with friends. Currently, the most pressing desire is to end treatments quickly and undergo the definitive intervention, aiming to speedily recover life as before: *“I wait for treatments to finish quickly because they are really disturbing me. I want to undergo the final surgery and that's enough. I take other two-three months to recuperate 100% and then I don't want to know anymore”*; *“All of these changes have had an impact on my daily life, but then when I finish I'll recover speedily”*; *“I just have to recover, nothing else can happen to my body...Let's say I took a break...Like this summer that I was ok, when I felt good I didn't think about it at all, then, when I did the cycles that I was a little worse, I took a break, I recovered and I made some mess”*, referring to the use of alcohol and drug used as palliatives. After some time, he evaluates that is useless to search for meanings and causes of the illness, because he considers them incomprehensible. It seems he's looking to the future with a certain denial of the problem: *“But, since you can't do anything about it and so going back is useless because you can't understand the reason, so let's just go on, a little unconsciously so you think less about it”*.

d) Robert's context area.

Robert is of Romanian nationality and currently he lives with his mother in Italy. He is unemployed because of the disease, but he has always worked since he was 16 as an electrician and bricklayer. In the last period, before the disease, he had been permanently employed by a medium-sized company as a workman. Owing a car and independent from an economic point of view, he was helping his mother to pay the bank loan to purchase the small house where they currently live.

At present, only his mother works, even up to 15 hours a day. Robert lived in Romania until the age of 10, raised by his grandmother. Robert's mother (single parent) went in Italy to work and find a stable accommodation (income and placing) that would allow her to re-join with her son.

In Italy, she found an Italian partner, older than her, from whom they both suffered domestic abuse for the following eleven years. Only recently she decided to separate from him and move to another town with her son.

Robert has also an aunt and an uncle living in Rome, with whom he maintains regular phone contacts and whom he sometimes meets for short visits. He also has an uncle who resides in his own town but they have no relationship. He maintains frequent phone contact also with the rest of the family and friends network living in Romania. He has a conflicting relationship with his mother, due to the ease with which Robert puts himself in problematic situations (complaints, fines, fights, road accidents). He has few friends, to whom he tried to hide the disease for as far as he could. Since onset of the disease, he has maintained mostly virtual relationship on social networks.

Concerning the current context, it is clear that many things have changed in Robert's social life, starting from his staying at home, to not being able to walk as before, to the sense of constant fatigue, to the change in sleep-wake rhythm and his physical appearance: *“Indeed my physical condition influenced my social life heavily, because I don't want to go out now”*;

“I am always at home. Let's say, I'm much more there, that is, forced to stay at home. Many things have changed [...]...I can no longer go out as before, I can no longer walk as before, I immediately get tired, I sleep a lot and noth-

ing...I lose my hair. I'm sick after chemo. I don't want to go to Hospital to do chemo cycles, because afterwards I'm getting worse and worse";

"Chemotherapy brought me mouth sores, plaques in the throat, yellow face (I look Chinese!), hair loss, leg pain, absurd tiredness...of my body I'd like to change the leg, the leg that is not good! For the rest, it's ok.";

"I look in the mirror even if, let's face it...what I see...I preferred before".

The disease also had repercussions on affective and sexual life: *"The changes in relationship with friends, girls and family happened when the effects of chemo were very serious, when instead the effects were under control, the problems were not there, on the contrary I was the same as before...I've always went my own way as before".*

The impact has also an economic nature. Being on sick leave from work, he receives a minimum income: *"I still have a bit of economic independence...but it annoys me that I have no way to spend the money [...], I miss the opportunity to go out and spend it because I'm closed here".*

Second level analysis: assessment of Robert's main problems

The second level analysis allowed to identify some assistance problems, which mainly refer to the psycho-socio-relational dimension. Exploring Robert's agenda, according to the needs of the assisted person (16), different care problems emerge across the various functional areas.

A central aspect, which must arise the professional's attention, is the **poor therapeutic adherence**, understood as the measure with which Robert does not take the drugs prescribed by the healthcare providers, as agreed in the treatment plan. The scarce adherence is, in Robert's case, intentional, that is characterized by a conscious decision not to assume the growth factors, in the subjective belief that drugs are potentially toxic. In addition to Robert's personal beliefs on the use of medicines, the side effects of chemotherapy, such as hair loss and a sense of fatigue, enhance this problem.

From the different areas of the agenda it emerges that the difficulty in accepting the treatments is mainly due to the alteration of the **body image** that seems distorted by the disease and the treatments themselves. The alteration seems to be due not only to the leg surgery, but also to other factors such as pallor, alopecia,

weakening of the muscles, drowsiness and the presence of signs and scars. It is evident that the current image has altered a positive self-ideal previous to the disease (as he was in terms of standards, aspirations and personal goals), self-esteem and attractiveness (in terms of opinion about one's own value), role performances (understood as socially accepted models associated with Robert's social role) and therefore, in general, his social, work and sexual identity, which led him to experience a sense of shame and a progressive social withdrawal.

Relational isolation also highlights issues related to the **mood**; Robert himself, in fact, connects changes in his body image to feeling psychologically well: mood tone influences body image and vice versa. In this case, it seems that thymic deflections are thus linked to chemotherapy and its related side effects.

We can therefore underline across the area of the agenda a poor **quality of life** connected to socio-economic and social marginality of the family (absence of the father, socio-cultural eradication, poverty) and to the health, thus properly what is meant by health-related quality of life.

The quality of life is altered both from an objective point of view, emerged above all from the context dimension (housing, health, economic, working conditions, related to social roles), and also subjective, more transversely across the areas of the agenda (in connection to the self-esteem, the satisfaction of one's aspirations and to the degree of satisfaction for one's social, emotional and working life). The quality of life, that is, seems compromised both from the physical-the subjective wellbeing (self-esteem, possibility of personal fulfilment, autonomy) point of view, and from the point of view which concerns social interactions (related to the integration into the community), both in economic, professional and social terms.

Other problems are related to these main problems, that is the alteration of **rest-sleep** (in terms of hypersomnia), of **movement** (in terms of fatigue and reduction of activities), of the **socio-cultural dimension**, concerning family and community, of the **value and spiritual dimension**, culture and ethnicity and, above all, the **dimension of experiences, hopes and expectations**.

It is in fact evident that the transition from a health to an illness condition is configured for Robert

as a true traumatic shock, with consequent experiences of uncertainty and threat to his physical and psychosocial integrity. From the shock phase he went to a reaction phase, in which he became aware of the reality and began to experience strong emotional response.

On one side, he seems still anchored to this phase in which he uses different defence strategies, such as denial of shame and regression (through social withdrawal), on the other he seems to be moving toward a phase of elaboration, in which Robert begins to look to the future instead of the past, foreshadowing himself to be better soon. He seems still far from the phase of reorientation, because the meaning of the disease is still linked to an adverse fate and bad luck, and he seems still distant from living with his own disease, with the associated limitation and to accept help if necessary.

Discussion and conclusion

From the results obtained, it emerged that the patient's narrative agenda has the advantage of exploring in depth especially the psycho-social, value and spiritual problems of the person, which a qualitative assessment would not allow to grasp in a personalized way. Furthermore, from the person's experience of illness it is possible to collect the ideas and the interpretations that he, based on his history and culture, attributes to the repercussion of the disease and the treatments on his life.

The narrative agenda thus becomes an in-depth tool for analysing the central needs for the assisted person (17). In the case reported, the professional was able to analyse and better understand Robert's needs by exploring his feelings, beliefs, opinions and concerns, expectations and desires concerning the health disorder, and therefore the meaning attributed to it. The narrative agenda also made it possible to know the interferences of Robert's illness on his quality of life, his work, his family, his social relationships and on his other more personal dimensions.

Compared to the tool of the narration (18, 19), the narrative agenda is easier to use, as the questions – structured in quadrants of interest – allow the professional to benefit from a topic guide to follow in the

assessment. However, it has to be kept in mind that the professional can move with some freedom in the use of questions (19). In addition, the analysis procedure needs less time compared to the interview, avoiding the registration and the deregistration of the discursive material. It therefore has a simultaneously “reassuring” structure for the professional and, which is at the same time, non-invasive for the patient, who feels guided and supported by a professional who accompanies him/her in the exploration of his/her interiority.

However, this process requires an active relationship from the professional, who must be trained in active listening and empathy (9, 10), instantly selecting the most salient contents to be pinned as a patient's answer to the stimulus questions provided. In fact, as happens during a narrative interview, the patient's narrative agenda is also based and promotes itself an emotionally genuine interaction between patient and professional, as well as the professional's acquisition of advanced listening and communication skills, reducing the use of a “professional face” (20). The tool therefore requires advanced skills and a specific training, especially in the chronic-degenerative and oncological fields (21, 22), both to use the tool itself and to analyse the data.

Another possible limitation of the patient's narrative agenda is that it mainly takes into consideration the psychosocial and socio-value aspects and does not specifically include a bio-clinical assessment.

This implies that it can be integrated with the professional's agenda (23), which examines the disease and its biophysical dimension, as well as it can be included in an integrated assessment model such as, for example, the Integrated Narrative Nursing Assessment (INNA; 24, 25). This method of assessment addresses the individual as a unit made up of a plurality of dimensions (bio-physiological, psychological, socio-cultural and spiritual). For this reason, the INNA uses different qualitative methodologies, typical of the human sciences (e.g. narrative interview, patient's narrative agenda), integrating them with quantitative methods deriving from the natural sciences (e.g. scales, tests and questionnaires).

For example, in the case of Robert, the narrative agenda highlighted several problems (e.g. therapeutic adherence, quality of life, mood, body image, existen-

tial problems related to experiences, hopes and expectations) that could be analysed with other tools, both qualitative, to deepen the understanding of some difficulties that seem central to the person and to formulate hypotheses that can occur with a further narrative interview, and quantitative, such as scales, to measure the level of severity of a disorder/problem reported.

Despite the possible limitation mentioned, the narrative agenda has not only proved to be a valid instrument of assessment, allowing an adequate insight on the patient's psychosocial problems, as we exemplified in the case reported, but it can also be a useful tool for monitoring the dynamic situation of the person's history, lending itself to the re-exploration of its functional areas over time.

To conclude, the patient's narrative agenda, in the social-health field, seems to have an important clinical and assistance value, allowing the professional to trace the assisted patient's psycho-social and value-spiritual problems, thanks to its transversal, simplicity and immediacy of use.

Soliciting the patient's agenda takes a little time and can improve interview and yield increased data (26). It therefore helps to direct the practice of health-care professionals towards a real holistic and deeply person-centred approach (5).

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