
A Narrative Medicine Pilot Study Using the McGill Illness Narrative Interview (MINI) with Patients Suffering from Nephropathy and on Dialysis

Venusia Covelli^{1,*}, Linda Figini¹, Antonio Santangelo¹, Francesca Memini², Giuseppe Bonforte³

¹Faculty of Psychology, E-Campus University, Como, Italy

²Italian Society of Narrative Medicine (SIMEN), Catania, Italy

³Nephrology and Hemodialysis, Beata Vergine Regional Hospital, Mendrisio, Switzerland

Email address

venusia.covelli@unicampus.it (V. Covelli)

*Corresponding author

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Abstract: The present study, that belongs to a wider project intended to the introduction of Narrative Medicine with patients suffering from nephropathy and on dialysis (NeD), aims to explore the experience of patients suffering from NeD and to address physicians in the use of the McGill Illness Narrative Interview (MINI) when they collect patients' illness narratives in their Narrative Medicine clinical practice. We conducted a narrative research study in October 2015 with the cooperation of an Hospital in Como (Italy). Ten patients suffering from nephropathy and on dialysis were interviewed and their illness narratives were collected using the Italian version of MINI. Then, a thematic analysis was realized referring to the *disease, illness* and *sickness* dimensions in relation to main sections of MINI interview. Different perspectives through which these patients feel the experience of living with a chronic pathology along with illness, disease and sickness dimensions emerged and were discussed. The study has pointed out the MINI narrative interview as a useful instrument to investigate the patients' experiences suffering from a chronic illness and it provides a number of issues clinicians and medical professionals might integrate into the clinical practice when they use this narrative interview.

Keywords: Narrative Medicine, Narrative Research, Chronic Nephropathy and Dialysis

1. Introduction

The thirty year literature on advantages of Narrative Medicine (NM) on clinical practice and the increasing available studies demonstrating the usefulness of narrative research on health care system [1-2], pointed out our attention on their application with patients suffering from nephropathy and on dialysis (NeD). Although many studies investigated the impact of dialysis on patients' daily life experience and the use of the narrative approach with nephrologic patients [3-5], also in Italian context [6-7], to the best of our knowledge no studies have used the MINI interview to collect illness narratives of patient suffering from NeD, in order to introduce Narrative Medicine into clinical practice by the use of parallel chart [8].

NM could be defined as "a framework for clinical practice

based on developing and utilizing this skill set. It is a way of approaching the clinical encounter that focuses on appreciating and reflecting on the patient's experience and the patient-physician relationship in order to improve both by building trust, developing empathy, and fostering a sense of shared responsibility in a patient's health" [9]. Through the specific narrative competences identified by Charon (close reading, attentive listening, creative writing, bearing witness to suffering), health professionals might embrace the patients' narratives in their clinical practice by using a parallel chart [8], a tool for self-reflection and hermeneutical practice, in order to co-construct with patient a shared responsibility and shared care pathways. Considering all available NM instruments to collect the patients' narratives [10-11], preparatory to the use of the parallel chart, we choose the McGill Illness Narrative Interview (MINI) [12] because, as emerged in previous studies [13-14], its open-ended questions elicit narrative and offer the

opportunity to explore some aspects typically left uncharted in clinical setting. Among many, Groleau [12] has analyzed the stories told by 51 Canadian patients (both men and women) after a myocardial infarction. All interviews have been gathered at the patient's home by a clinician between one and three months after the struck by using the MINI interview. In accordance with Kleinman's assumption [15], these studies underline how culture may influence the different impact of illness on body and self and introduce the MINI as a useful instrument for the illness stories collection.

The present study that belongs to wider project intended to the introduction of Narrative Medicine in the broad domain of nephrology, aims to investigate the usefulness of MINI narrative interview with patients suffering from NeD. Our research was guided by the Narrative Medicine principles that utilizes people's illness narratives in clinical practice and was designed to the twofold purposes of to explore the experience of patients suffering from NeD and to address physicians in the use of MINI interview when they collecting patients' illness narratives in their clinical practice (parallel chart).

2. Method

By adopting a qualitative approach, we conducted a narrative research study [16] with the aim of to explore the experience of patients suffering from NeD and to investigate

the usefulness of MINI narrative interview with these patients.

Illness narratives were collected using the Italian version of MINI [17] and a thematic analysis was realized to examine the data collected [18]. The thematic analysis was based on the Kleinman difference in *disease, illness* and *sickness* [15] in relation to main sections of MINI: Initial illness Narrative, Prototype narrative, Explanatory model narrative, Services and response to treatment, Impact on life. No previous qualitative studies about patients suffering from NeD have analyzed the narratives using this tri-partite classification (*disease, illness* and *sickness*).

The study was carried out between October 2015 and March 2016 with the cooperation of an Hospital in Como (Italy). The main inclusion criteria was: adult patients, over 18 years old, and suffering from chronic kidney disease. The recruitment was consecutively and on voluntary basis. Before proceeding with the audio taped interviews, participants have been asked to sign an informed consent for the use of personal data with research aims.

3. Results and Discussion

A total of ten patients (average age 58 years old, 6 males and 4 females) were enrolled in the narrative study. Socio demographic data of the participants are reported in Table 1.

Table 1. Socio demographical data of the participants.

Participant	Age	Male/female	Education	Education years	Status	Job	Years after prognosis
1	50	Male	High school.	13	Married	Unemployed	> 10
2	58	Male	Secondary school	8	Married	Retiree	> 10
3	55	Male	Secondary school	8	Married	Artisan	> 5
4	61	Female	Secondary school	10	Nubile	Retiree	> 5
5	48	Female	High school.	14	Nubile	Health assistant	> 5
6	72	Male	Primary school	5	Widowed	Retiree	> 5
7	51	Female	High school	11	Married	Unemployed	0.5
8	50	Male	High school	13	Bachelor	Mechanic	> 10
9	57	Male	High school	13	Cohabitant	Driver	> 10
10	80	Female	Secondary school	8	Widowed	Unemployed	< 5

From patients' illness narratives, it was possible to analyze the different perspectives through which they describe the experience of living with a chronic disease. According to Kleinman difference in *disease, illness* and *sickness* [15], the following main themes emerged: 1) as for *illness* domain, the main recurrent theme is referred to "resignation"; 2) as for *disease* domain, detailed description of examinations and treatments were identified; 3) with regard to *sickness* domain, loneliness and social retirement were described. We report some examples of the patients' experience concerning these three main domains. As regard to illness dimension, a patient stated: "I tried to do my best to adapt myself. There is not that much left to say. Nineteen years have passed. It is a long time. Now it is a part of my life". About disease dimension another patient stated: "I did not feel good and I made some examinations... I neglected myself and some years have passed. I went to the doctor and he told he could not do anything with it and that I had to visit a physician: some more examinations and the result was...I did not even remember the

name...a nephritis, a renal failure or it sounded like... And then again another glomerulo nephritis...He told me there was nothing more to do. The end of this story is the dialysis". With regard to sickness dimension, a patient stated: "Well, my friends were there, but...let's say...I did not have so many real friends. The reason is that you think more about yourself and you call friends the people suffering from the same problem you have".

Thematic analysis support previous results of studies that have pointed out the importance of the listening and the open mind attitude towards these patients suffering from a chronic disease. A research [19] involving patients with chronic renal disease has analyzed the patients' narratives focusing on five aspects of the narrations related to their own illness: living with death, difficult to language embodied experience, unthinkable, unknowable mystery and untold/unheard. A recent contribution [20] has investigated the importance of listening to the patients' fears and meanings with a chronic renal disease and focused the study on the emotional point of

view of these patients when they have been told they have to undergo a dialysis treatment, and then on the close relationship with the patient, an issue that clinicians are supposed to develop as well. Previously, Molzahn, Bruce & Shields [21] collected and analyzed 100 narratives, 62 from men and 38 from women with chronic kidney disease. Thematic analysis identified common themes related to dependence, restrictions, normality, and isolation. However, authors remarked that these patients have fully different experiences, and remind to nurses the important of recognize the distinctiveness of each person.

Considering the second aim of the present communication, results support the usefulness of MINI for gathering illness narratives from patients suffering from NeD and it provides a large numbers of issues clinicians and medical professionals might integrate into the clinical practice. Only some considerations to take into account during the interview of patients with this health condition. Some questions listed in the MINI revealed themselves to be redundant for this kind of illness, as patients get to the dialysis after they have received a diagnosis and biomedical explanations of the disease and the treatment. Therefore, we suggest to update to the current patient situation some questions – i.e. n°21. “Have you considered that you might have...?” or n° 24. “What is the best treatment for people who have...” - in the section related to the explanatory models. Besides that, the section concerning the social domain was not that much incisive during the interview, maybe because patients on dialysis are more focused on themselves rather than on the involvement of other people. Finally, we suggest to add a question about how patients think about the progression of their health status, that is the future. According to the narrative theories [22], the purpose of the narrative is to clarify the meaning of the illness experience, ordering the events in a timeline and in a structured plot that makes a sense, a direction to follow for future actions. Illness experience is a “biographical disruption” [23] between a “first” and a “after”, occurring in a lived time, not in the past. By telling their stories, patients can imagine a connection between the past, the present and the future, they can fix the disruption in order to become actor in the story of their life [24]. As stated by the sociologist Arthur Frank “Stories have to *repair* the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations” [25]. For the clinician is important to understand patient’s perspective on his future, his expectation and desire, because these aspects impact on patient engagement and, therefore, on adherence and therapeutic outcomes.

4. Conclusion

While this is a pilot study, by the use of MINI interview we aimed to provide a preliminary description, expressed by the illness, disease and sickness dimensions, about the experience of patients suffering from NeD. In addition to previous research findings, our results present novel information about the use of MINI instrument with patients suffering from NeD.

Although the MINI appears as structured instrument, it has been used as an open source to investigate the patients’ experiences in widespread pathologies, but we must even consider some specific issues concerning the future dimension and the patients’ expectations about their lives and about their narrative. It is the best way clinicians have in order to gather the narrative, to understand the meaning from the patient’s point of view and to integrate this point of view into the clinical practice. This allows a complete understanding of the patient’s perspective as for past, present and future.

Conflict of Interest Statement

All the authors do not have any possible conflicts of interest.

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