



## **Stories of Food, Walking Groups and Health: Narrative Approach as a Treatment Strategy in People Suffering from Chronic Renal Failure. Training Experience in ASLTO3 (IT)**

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### **Abstract**

*Therapeutic patient education is an effective intervention that has been shown to help people living with chronic conditions to better manage their illness and thereby achieve improved health outcomes, use of resources and quality of life. It has great potential for improving the lives of patients, while simultaneously easing the strain on health systems [1, 2]. Self-management is what patients living with chronic conditions do in order to manage their disease and prevent complications, balancing their lives with the illness and its daily challenges so as to achieve their best outcomes, and shift the perspective from illness to wellness. Narrative interventions can be provided by health professionals and/or patients. Patients can also have a key role in shaping services through processes such as co-design [1, 2].*

*The aim of the experience is to describe the training module carried out at the Nephrology and Dialysis Department of ASLTO3 based on narrative methods. The objective of the narrative practice in real time was to bring out the self-knowledge and self-reflection of chronic patients and healthcare professionals regarding adherence, dietary and physical activity recommendations.*

*Conclusions: The shared decision making requires awareness on self-care and self-management regarding the expected diagnostic-therapeutic and healthcare pathway. Knowing what will happen and what will have to be done, therefore, will become fundamental concepts for achieving high levels of adherence to therapy and recommendations. Giving priority to teaching methods based on the engagement of patients and caregivers is increasingly becoming a strong recommendation to influence changes in daily lifestyles.*

**Keywords:** *Self-care, self-monitoring, narrative methods, patient engagement*

### **Background**

Dietetic-nutritional therapy (TDN) is an important component regarding the conservative management of patients suffered from chronic renal failure in pharmacological therapies.

The TDN aims for the maintenance of an optimal nutritional status, the prevention and/or correction of signs, symptoms and complications of chronic renal failure and the delay in starting dialysis over time or even intervene, allowing a reduction in the dialysis dose weekly [3].

Several studies highlight the need for strict control of phosphates in people suffered by chronic renal failure to reduce the effects of secondary hyperparathyroidism: the risk of soft tissue calcifications, vascular calcifications and the cardiovascular complications linked to them and, above all, the mortality of patients with CKD [4] [5] [6] [7].

Correcting adherent to a balanced diet to limit the intake of phosphates, in fact, leads to the possibility of improving the health of the patient on dialysis, significantly reducing healthcare costs, since the use of chelators varies between 60 and 5,000 euros/ year for each patient, depending on the drug used, without the greater effectiveness of one chelator compared to another having yet been unequivocally demonstrated in terms of outcome [8].



Hyperkalemia also represents an important problem: in fact it is associated with an increase in general mortality, cardiovascular mortality and potentially lethal arrhythmias. A low potassium (K<sup>+</sup>) concentration in the blood of a patient on dialysis could, if excessive, lead to an increased risk of sudden death, therefore optimal adherence to dietary recommendations and any therapies with chelating resins are essential to limit harmful and potentially lethal effects of hyperkalemia on a cardiovascular level [9]. Currently it has also been reported that correct lifestyles, which include DASH (Dietary Approaches to Stop Hypertension) or our "Mediterranean diet", are able to reduce the incidence of chronic kidney disease and cardiovascular risk [3].

In this context, we believe that education based on narrative approaches to dialysis patient care is very effective in engaging and involving patients. In fact, therapeutic patient education is an effective intervention that has been shown to help people living with chronic conditions to better manage their illness and thereby achieve improved health outcomes, use of resources and quality of life. It has great potential for improving the lives of patients, while simultaneously easing the strain on health systems [1] [2]. Self-management is what patients living with chronic conditions do in order to manage their disease and prevent complications, balancing their lives with the illness and its daily challenges so as to achieve the best outcome, and a shift of perspective from illness to wellness. Interventions can be provided by health professionals and/or patients. Patients can also have a key role in shaping services through processes such as co-design [2].

Narrative techniques to support people's and professionals' awareness of adhering to recommendations in daily lifestyles, including eating habits and physical activity, are particularly important. The theme of narration generally becomes part of care contexts in order to intensify the link between science and existence, the reasons for caring with the demands of caring [10] [11] [12] [13]. The term "narrative medicine" refers to a form of expression through which health concerns are structured and conveyed by patients, relatives and friends, as well as by medical staff, in conversations, presentations and reports of specific cases [14] [15]. The act of telling gives the patient the ability to create meaning, to review past experiences, to build coherence and above all to orient himself towards the future [16].

The aim of our contribution is to describe the experiential path carried out in the Nephrology and Dialysis department of ASLTO3 based on narrative methods. The objective of the narrative laboratory was to bring out the self-knowledge and self-reflection of chronic patients and healthcare professionals regarding adherence to dietary and physical activity recommendations.

## **Materials and Methods**

*Innovative approach: the narrative experience lab in training pathway of ASLTO3*

The narrative experience lab consists of different work sessions: training modules in which the patients, caregivers and healthcare personal are involved in shared walking groups started in 2023. The training modules have been realised with the commitment of National Association "Emodializzati Dialisi e Trapianto" – APS.

The contents explored during the training course were: autobiographical narration as a moment of care; meanings and implications of food intake; reflection on one's own experiences related to nutrition; ability to cope; importance of building interpersonal relationships aimed to improve the adherence to recommendations. The methodologies used favored the interaction and participation of people: presentation of problems/cases, reflection on experiences, experiential training methods.

The contents of the experiential walking path were: how to walk (first step, rolling, pushing), posture, breathing, post-walk relaxation, physical adaptation rules, recognition of the first signs of tiredness, correct clothing and equipment.

The duration of this practice is 30 hours in total. The attendance is compulsory in order to guarantee the best work climate in terms of expected quality, wellness, satisfaction etc. The trainers are psychologist experts on narrative methods recruited by ASLTO3. The walking groups are included in the Health Promotion Hospital Plan of ASLTO3 according to the Regional Plan of chronic diseases.

### *Recruitment of the participants*

10 nurses and medical doctors who work in the Nephrology and the Dialysis Department of ASLTO3 and 15/20 patients and caregivers have been selected.

Patients were selected according to the criteria:



- on a voluntary basis starting from the objectives and characteristics of the paths carried out during the self-help group
- included in various pathways as well as pre-dialysis, hemodialysis, post transplant
- relating to the various locations of the ASLTO3 Nephrology and Dialysis Department.

*Impact evaluation*

Before and after the course, a questionnaire containing quantitative and qualitative questions was administered to the participants.

**Results**

The sample of patients appears to be composed mainly of males residing in the city and with a family unit of less than 3 units.

| <b>Item</b>        | <b>Data</b>   |   |
|--------------------|---------------|---|
| Gender             | Male          | 6 |
|                    | Female        | 4 |
| Age                | < 50 years    | 1 |
|                    | 50 – 65 years | 4 |
|                    | >70 years     | 5 |
| Region             | Piemonte      | 6 |
|                    | Liguria       | 2 |
|                    | Puglia        | 1 |
|                    | Calabria      | 1 |
| Residence          | City          | 8 |
|                    | Rural Area    | 2 |
| Family Unit Number | 3 units:      | 4 |
|                    | 4 units:      | 2 |
|                    | 5 units:      | 2 |
|                    | 6 units:      | 2 |

**Table 1.** Demographic characteristics of patients

Several patients believe they have not changed their diet and have no problems. However, several patients did not want to answer the question regarding feeding problems. However, the failure to adapt to the new eating style due to the onset of the disease needs to be explored further with further investigations. To change their lifestyle and maintain it over time, patients said that following a routine, doing physical activity, using specific products and being committed are important aspects of self-care.

Avoiding purchasing certain foods to avoid temptation is considered a good strategy. Several patients say they evaluate their diet throughout the day. Typical family foods are those chosen by most patients.

The typical family foods are those chosen by the majority of patients as well as the experimentation of new cooking recipes.

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|---|
| <i>I enjoyed sharing my experiences with other people because you understand your thoughts better and reduce problems by comparing yourself with others. A lot of internal work has been done. I was pleasantly surprised that the focus was not exclusively on kidney disease.</i> |
| <i>I was looking forward to the meeting because I wanted to exchange ideas. I really appreciated the climate that was created between us, above all it was pleasant to have had the opportunity to participate in mixed groups without any difference in roles.</i>                 |
| <i>The relationships with the other patients were already excellent and have remained so. With healthcare workers it was a way to share more intimately, putting us on an equal footing.</i>  |

**Table 2.** Quality comments from patients and caregivers



The sample of operators was mainly composed of women over the age of 39, living mainly in cities and in small families.

| Item               | Data                   |
|--------------------|------------------------|
| Gender             | Femmine 11             |
| Age                | < 40 years 1           |
|                    | Tra i 40 e 50 years: 4 |
|                    | >50 years 6            |
| Region             | Piemonte 8             |
|                    | Sardegna 1             |
|                    | Esterio 2              |
| Residence          | City 5                 |
|                    | Rural Area 3           |
|                    | Mountain 2             |
| Family Unit Number | 3/4 units: 9           |
|                    | 5 units: 2             |

**Table 3.** Professional demographic characteristics

The healthcare workers' responses confirm the interest in food, its link with emotional states, the general tendency to buy fresh foods and to cook carefully even if ready-made foods can be used.

The attention to nutrition is underlined with regards to quality and method control. The possibility of a loss of control and the need for strategies to avoid inappropriate foods are highlighted. The general trend is to dedicate time and space to food, eat with gusto, favor traditional foods while still being open to new things.

|  |
|--|
| <i>I understood how each of us's history can influence our relationship with food and the impact on disease management.</i>  |
| <i>This was an occasion where patients revealed their weaknesses, frustrations, but not only that, caregivers were also involved in this situation and did not always manage to overcome the problems. One couple admitted they had misunderstandings while shopping and preparing food. Another person avoids eating.</i> |
| <i>Looking back, I didn't think it would be so stimulating, and at the same time pleasant. It created a nostalgic state but also disappointment at not being able to remember so many moments, sensations, things... We hope to be able to remember them sooner or later, perhaps through a perfume, a flavour...</i>      |

**Table 4.** Quality comments from health professionals

## Conclusions

The training course allowed to highlight some aspects that are particularly relevant for professionals, patients and caregivers. In the treatment of chronic kidney disease it is important to consider the person in a holistic view, inserted into their social and family context, and their expectations. In fact, sharing decisions requires awareness on the part of people and clarity regarding the expected diagnostic-therapeutic and healthcare path.

Knowing what will happen and what will have to be done are therefore fundamental ingredients for achieving high levels of adherence to therapy and recommendations. Giving priority to teaching methods based on the involvement of patients and caregivers increasingly becomes a strong recommendation to influence changes in daily lifestyles.

The narrative methods used in this path have allowed patients, relatives and professionals to improve the level of awareness of their illness and their agency through shared, integrated and common moments of reflection. Telling your story and your experiences also allows you to enjoy that extra time to internalize the concepts which, in the absence of this, wouldn't be transmitted.



The authors underline the important value of narrative in care and hope for further studies to confirm the effectiveness of the selected approaches.

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