The interview with a patient on dialisi: feeling, emotions and fears

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Abstract

This study has been performed in the Nephrology and Dialysis Unit, in Desio Hospital, Italy. The aim of this study is to evaluate, starting from research questions, which information is given to patient in the pre-dialysis colloquia for his/her chosen dialysis methods. Moreover, the study evaluated feelings, emotions and fears since the announcement of the necessity of dialysis treatment. The objective of the study was reached through the interview with patients on dialysis. The fact-finding survey was based on the tools of social research, as the semi-structured interview. Instead of using the questionnaire, even though it make it easier to collect larger set of data, the Authors decided to interview patients in person, since the interview allows direct patient contact and to build a relationship of trust with the interviewer, in order to allow patient explain better his/her feeling.

Key words: dialysis, fear, feeling, health care needs, semi-structured interview

Introduction

In advanced stages of CKD (Chronic Kidney Disease), it is important that patient is adequately informed about the different dialysis methods when approaching entrance on dialysis, thus he can take a shared and informed decision about the choice of replacement therapy, thanks to a comparison with his family and physicians. Peritoneal dialysis (PD) is recognized as a viable alternative to the better known extracorporeal dialysis treatment (HD). The PD has the advantage of being carried out at home, in a known and friendly place for patients and can be managed independently by the dialysis person or assisted with the help of a family member, nurse or care-giver [1] (full text). Furthermore, the technical simplicity of PD allows patients to be able to perform therapy even outside home (place of work, holidays, etc). As regards quality of life, many studies demonstrate that patients in PD enjoy a quality of life comparable or even better respecting of HD patients [2] [3] [4] [5] (full text) [6].

We cannot avoid mentioning cost issues in this period of spending review and cost savings, in particular as regards direct and indirect costs (transport costs to hospital, dedicated per-
sonnel, working hours lost). Nevertheless, PD is still an underused method. In Italy, the latest data of the National Dialysis and Transplantation Registry 2009-2010 report a prevalence of 10% in PD with a slightly declining trend in recent years [7]. Even at the facility where the research took place, data are comparable to those National ones: 91% of patients in HD and 9% on PD. Every year in Italy, 8500 patients are initiated to dialysis treatment, with an incidence of 160 patients / million inhabitants [7]. It should not be forgotten that the analysis of the data also shows how in these years there has been an ageing of the population switched to dialysis treatment. If in 2000, 40% of the incident population was over 70 years old, in 2010, last census available in Italy, this percentage rose to 55%, and the average age of early replacement treatment was 71.4 years [8].

Therefore, ageing raises issues about knowledge of life quality, expectations and fears of this new type of population undergoing dialysis. In literature, the most widely used instruments for this analysis are questionnaires with multiple-choice answer which, on the one hand, have the advantage of being repeatable and comparable, on the other hand limit the possibility of bringing out the real patient's point of view, emotions, sensations but also expectations and fears. For these reasons, we decided to use semi-structured interviews.

Background
Department of Nephrology and Dialysis of Azienda Ospedaliera Vimercate and Desio cover an area of about 445,000 people.

The Department consists of three CAL (Limited Care Unit): Cesano Maderno 46 patients, Carate Brianza 46 patients and Seregno 52 patients and a main hospital centre in Desio with 76 patients, totally the department takes care of 220 patients. In each center, patients are treated in two shifts: the first in the morning (8:00 a.m. to 1:00 p.m) and the second in the afternoon (2:00 p.m. - 7:00 p.m.). The nurse-patient ratio is 1:3; there is 1 doctor for each CAL and 2 for hospital dialysis center. Patients on PD are in charge to 1 doctor and 2 nurses.

Purposes
Aim of our study was to investigate, through a semi-structured interview, how patients face their daily life after the start of therapy, whether and how the choice of therapies influenced perception of disease, that is HD or PD.

Methods
Interviews were performed in August and September 2015 in 70 volunteers patients, which corresponds approximately to 1/3 of the total population. Of these 70, the interview was done in 43 patients, equal to 61.4% of the sample. Waivers are to be found mainly in the lack of interest, transport difficulties, work engagements or coincidence with a period of vacation.

All interviews were conducted in a room in the dialysis ward, by the same interviewer. Talks had an average duration of 17 minutes.

After completing the interviews, audio files have been completely rewritten, reporting faithfully what the interviewee said. This allowed to carry out a more accurate analysis and comparison of the interviews.
Semi-structured interviews

The first phase of the work was dedicated to interviews of available patients. All 43 interviews were carried out in the hospital, considered as hostile place for research, but which enable us to reach as many patients as possible.

Interviews are all based on semi-structured method. About this instrument Corbetta writes: “semi-structured interview, [...] involves the administration of questions focused on a default theme, but not prepared in a specific form. This technique allows the researcher to talk with the interviewee and obtain the appropriate information, through a seemingly improvised and informal conversation, guided by wisdom towards collection of the desired knowledge.” [9].

First, themes to be discussed were defined and detailed between the researcher and the medical and nursing staff of Desio Hospital, in order to thoroughly examine issues to face. These latter were divided into 4 parts as: (a) dialysis method; (b) perception of disease; (c) Quality of Life (QoL); (d) future expectations. During interviews further aspects emerged, not considered at the beginning by the researcher and staff, such as fears and patient care.

Secondly, trace interview was created, characterized by a peculiar aspect: flexibility. This feature allowed to modify or increase the basic schedule, where an unclear or particularly interesting issue requires to be deepened, integrating interview with further questions, giving more space to interviewee to comment on the various topics. In addition to flexibility a further positive aspect, linked to the semi-structured interviews, is possible to choose how and in what order to ask questions. In this way, interviews are adapted to the circumstance and to interviewee’s approach which was, in some cases, particularly negative at the beginning, and subsequently "more flexible" during the interview.

The same questions were asked to all patients, according a different order or manner.

Of the 43 interviews conducted, 31 are related to patients who are currently in HD, while 12 in PD patients. Among 31 patients currently in HD, 18 have used one or more types of therapy (eg. switch from PD-HD, PD-transplant-HD, HD-transplant-HD).

Results

From a research point of view, some interesting data emerged as regards to:

Dialysis method

The percentage of patients treated in HD and PD reflects the national trend, 91% in HD and 9% in Pd (Figure 1).

Perception of disease

In 51% (22 out of 43) of patients interviewed, the need to undergo dialysis caused a trauma, both for the disease itself and as regards the need to initiate a therapy. Whereas in 49% (21 out of 43) of cases, disease was accepted. This percentage also includes 10 patients who, before starting dialysis, had other diseases and/or an outpatient pathways in pre-dialysis which allowed to start the treatment in a less negative attitude compared to those patients who did not have this important period of contact in the nephrology division.

Perception of disease does not present significant differences between females and males; in HD patients perception is stronger negative (18 out of 31 patients, 58%), while PD patients are able to accept their condition and consequently to deal with disease through a positive perception (8 out of 12 patients, 67%) (Figure 2, Figure 3).
**Perception of patient's daily life**

In 79% of cases (34 out of 43), patient reports a decrease in his/her daily activities, but he/she recognizes benefits of therapy even if it is itself a cause of limitation.

Only 7% of cases (3 out of 43), patient reports a treatment benefit based on a greater improvement compared to his/her previous standards before starting therapy.

Finally, 14% of patients (6 out of 43) claims to have had a clear worsening compared to the previous habits before starting therapy (Figure 4).

**Fears**

During the survey, it was found that some patients (especially in HD), refrained from holidays or travel in order to avoid to leave the place where they usually do dialysis.
Lots of fears have emerged in patient who is facing disease: 23 (19 in HD, 4 PD) patients reported at least one type of fear: away from the dialysis center, new staff on dialysis room, new doctors, different dialysis machine. In 20 (12 in HD, 8 PD) did not express any fear.

Expressed as a percentage, it is observed that 61% of patients in HD evidenced at least one fear, while in PD only 33% referred to at least one fear.

Even transplant causes many interviewees’ thoughts. There is especially a fear of not knowing how to react in the case of a call from the transplant center.

Here below is a short excerpt from a patient’s interview: "...let’s say that now my head is ready to say ” it is time to perform a kidney transplant "... three (3) years have passed but I'm afraid, however I'm still afraid, I do not know... " (Figure 5, Figure 6).
Future expectations
This research on future expectations aims to investigate on patients' demands.

The majority addressed thoughts to a possible care but also to a form of acceptance of the disease by the family. Transplant, albeit between fears and concerns, particularly among patients in HD, is the future expectation that holds greater importance. This expectation shows how the desire for a better life is among the most frequent patients' thoughts.

Reference is also made to medical field, with hope that new technologies and new inventions can improve/or reduce time who patients must spend attached to the dialysis machine.

There are also 9 patients, all male in HD, that have no expectations about future: “I’ve accepted the disease even though I know that this will take me on the other side, okay, I have accepted and what will be, will be!...” (Figure 7, Figure 8).

Assistance
From interviews it emerged that many patients refer to "need" of care: 65% of patients expressed this need, not only when they are told they will start the substitute therapy, but also and especially since the beginning of it (Figure 9).

32% of patients (14 out of 43, 12 HD and 2 in PD) refers to psychological assistance that will help them to deal with this disruption in their lives. Interviewees also referred to the relationship they establish with the dialysis machine, for many of them it is the only saves lives but still an instrument not always accepted, "... Then I continue to support that it depends on how mentally accept that... between me and the dialysis machine there is love and hate, and I tell you it is really a pain in the ass, but if this dialysis machine did not exist I was already in the ground... and then try to... although I must be honest, after 8 (eight) years I begin hating the blue door..." This short
interview excerpt shows patient’s thought and the relationship created, not only with the dialysis machine, but also with the place where the dialysis sessions were held.

28% of patients (12 out of 43, 11 in HD and 1 in PD) claim that is "appropriate" a creation or an increasing use of associations and volunteers in hospitals and limited care units. The presence of a person who could exchange a few words during therapy hours, is viewed by patients as an important help to spend faster morning or afternoon doing dialysis, “...But they come only in the morning and twice a week at fixed times, arrive and exchange a few jokes and then... it is also a moment of... especially in a hospital where there are most of elderly people, it is a pleasant moment... “.

5% (2 out of 43) of patients refers to nurse technical assistance. As regards technical aspects, patients would like to learn more about dialyzer and its operating principles and also require an increased presence of technicians in cases of malfunctioning of dialysis machines for PD patients. As for nursing care, it is referred to home-care for PD patients.

Finally, 35% of patients (15 out of 43, 7 in HD and 8 in PD) affirm no assistance is needed, in some cases they consider it harmful, saying to be able to accept disease without anybody’s assistance, but considering helpful an assistance for old people or some patients who have not yet metabolized the disease.

It should be noted the distribution of patients for dialysis therapies who make reference to a type of patient care. In fact, 56% of the total respondents (24 out of 43), or 77% of total patients in HD (24 out of 31) refer at least to one type of care, while only 9% of the total interviews (4 out of 43) in PD (Figure 10).

Of the 43 patients interviewed, 15 (35%) declare to have discussed the choice of dialysis method. Secondly, data were analyzed among patients who had the opportunity to choose

![Figure 9](image9.png)

Valori percentuali di assistenza

![Figure 10](image10.png)

Analisi numerica per metodica dialitica dei pazienti che fanno riferimento ad un tipo di assistenza
dialysis method and the remaining 28 patients (65%) did not reveal this information during interviews.

The only relevant data in the analysis may be those referred to "fears" and "support."

Patients who affirm not to have fear in case of an informal talk are 67% (10 out of 15), while only 35% (10 out of 28) if there was no informal talk; the overall data represent 46% (20 out of 43). From these results, it emerges a necessity to have an informal talk on choice of dialysis modalities and therefore an interaction between nurse/physician and patient in order to have a lower perception of fear.

About patient care, 71% of patients (20 out of 28) had no a previous informal talk, for this reason it requires at least one type of support (psychological + other + mix). This value is higher than the overall figure 65% (28 out of 43) and much higher than patients who had an informal talk on the choice 53% (8 out of 15).

**Discussion**

To our knowledge, this study is the first study in literature in which semi-structured interviews has been used in the nephrology field.

The choice of this instrument allowed us to bring out emotions, patients’ feelings and fears in the course of “face to face” talks, difficult to perceive in case of the qualified questionnaire SF-36 [10](full text). Interviews have also allowed us a greater interaction with the researcher and established a trust relationship which permitted patients to express themselves freely during interview.

With reference to emerged data from our study, more emphasis is given to "fears" and "support." These features come to light as needs that sometimes are taken for granted or not detected by staff towards patients.

Fear of getting away, may even emerged in the course of the study, points out, especially in patients in HD, how "to lose" ordinary relationship with physician/nurse staff constitutes a waiver. This is perhaps due to fear of unknown staff who is not be able to deal with patients’ different personalities, now accustomed to certain standard procedures made by well-known staff [11](full text) [12] [13] [14]. (e.g. start/end treatment performed by the same nurse etc.).

Transplant too, in some cases, is not experienced as a "return" to life before dialysis. Fear is attributable to a patients’ reaction in case of a call for transplant.

Reference to patient care emerged in 65% (28 out of 43) of the interviews. Patients have expressed their help needed, especially in the early stages of the disease and during the first period of therapy. This latter consideration is particularly addressed to dialysis machine acceptance by patients: 32% (14 out of 43) of interviewees refers to a type of psychological consult which also allows to overcome the initial trauma in dealing with the disruption of everyday life [15].

Psychological consult may be supported by volunteers and/or associations which meet dialysis patients during hours treatment, both in the hospital and dialysis care unit, focused on sharing moments of interaction and entertainment.

From interviews, it is revealed how patient in PD needs less assistance with the disease and subsequently the acceptable of it in order to lead a “regular” life. This may be due to a greater family closeness, but also because therapy is conducted at home, or by specific personality traits, such as the need for independence [16](full text) [17](full text).
As mentioned in the introduction, the employee patient chooses generally PD [1] (full text). With regard to the individual characteristics which were highlighted in patients who opt for peritoneal method, in literature we find that these patients have a better body awareness, good adaptability (coping strategies), a greater awareness about the possible obstacles to adherence to treatment and preference for active participation [12] [16] (full text).

Conclusions

A first step to improve the perception of disease in dialysis patients should be the creation of a basic patient-physician networks to improve patient’s knowledge about kidney disease and to provide, thanks to nephrologists, more information to patients on how behave and what he/she will face.

A further step will lead to create exploratory research questionnaires to be administered to patients before starting dialysis, in order to understand what might be the best method to choose.

From interviews merged the need of meetings with family members and patient, supported by a psychologist, a figure within the department dealing exclusively with these patients, in order to improve their reactions to dialysis, not only when they are told they will face this disease but also and above all in the following months.

Finally, interviews revealed that some patients refer to the cumulative effects generated when many patients are in the same room. For example, the alarms sound of the dialysis machines worry patients, increasing in these fear that there is something serious or dangerous for their health. It would therefore be very interesting to investigate, through new studies, this phenomenon.

References


