

Lived experiences of patients on hemodialytic treatment: A discursive perspective on fatigue and motivational issues

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Abstract

Fatigue is an incapacitating symptom for patients on chronic hemodialysis treatment. This study explored the relationship between hemodialysis patients' subjective experience and motivation. The investigation of patients' narratives and fatigue-related factors was performed by holding semi-structured interviews with 31 hemodialysis patients. Fatigue Severity Scale and Behavioral Inhibition/Activation System questionnaire were used to assess fatigue severity and motivational mechanisms. Results showed significant differences in the use of specific topics and words (such as "family," "to manage," "dialysis," "psychological issues") depending on high, medium, and low Behavioral Inhibition System, Behavioral Activation System, and Fatigue Severity Scale scores, indicating that hemodialysis patients' narratives contain keywords related to the motivational sphere.

Keywords

Behavioral Inhibition/Activation System, fatigue, hemodialysis treatment, motivation, semi-structured interviews

Introduction

Causes and mediators of fatigue symptoms in patients undergoing chronic hemodialysis treatment are still under debate and often undertreated. Therefore, healthcare providers should better understand the lived experiences of patients with chronic kidney disease in order to expand knowledge and to provide individualized and specific interventions.

Recent international research in the field of nephrology has increasingly investigated fatigue in hemodialysis (HD) patients by using mixed research methods that combine both quantitative and qualitative techniques and that consider comprehensively the viewpoint of patients and professionals involved in HD treatment process (Evangelidis et al., 2017; Ju et al., 2018; Tong et al., 2017; Urquhart-Secord et al., 2016). The added value of these studies is that they helped to uncover many unexpected psychosocial topics related to patients' well-being (such as the "washed out after dialysis" feeling) and to lifestyle (such as "ability to travel" and "dialysis-free time"), which were rated higher among patients and caregivers compared to medical staff. Also, clinicians remarked that they thought post-dialysis

fatigue would have been the most critical issue for patients because they frequently reported it in clinical settings, but recent investigations highlighted that life participation, tiredness, and level of energy in general (not limited to the period immediately after dialysis) are instead rated by patients as more important (Ju et al., 2018). Still, it is relevant to notice that fatigue appeared consistently across all measures for all groups and may thus be considered one of the major priorities (together with vascular access problems, death/mortality, cardiovascular disease, and dialysis adequacy) for all the stakeholders involved in the healthcare process related to HD (Evangelidis et al., 2017).

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With the purpose of deepening the understanding of HD patients' lived experiences, fatigue symptoms, illness representation, and coping strategies, another line of research identified many interesting topics that have been widely unexplored (Lee et al., 2007; Lin et al., 2013; Wu et al., 2015). These qualitative studies used interviews and discourse analysis as methods to elicit patients' in-depth experiences, to identify relevant recursive themes, and to analyze the content and presentation of patients' subjective experience (Bayhakki and Hatthakit, 2012; Cox et al., 2017; Lee et al., 2004, 2007; Lin et al., 2013; Wu et al., 2015). One assumption of critical discourse analysis is that language constructs how individuals think about relationships, identity, knowledge, and power (Fairclough, 2001), which are all central concepts in subjective experience of illness. That assumption grounds on social constructivist models, which claim that the social world is socially constructed and that people do not find or discover knowledge but rather construct or make it (Fairclough, 2003; Schwandt, 2000). Critical discourse analysis has already been used in qualitative studies aimed at investigating patient participation in the context of HD treatment by examining their narratives and those of their relatives and nurses (Aasen, 2015; Aasen et al., 2012a, 2012b, 2012c).

Even if it was previously suggested to move toward a multi-disciplinary approach to improve fatigue in HD patients and to promote the development of improved survey modalities including interviews (Jhamb et al., 2008), overall few qualitative studies focused on individual experiences of patients on chronic HD and even less on their fatigue symptom (Bayhakki and Hatthakit, 2012; Cox et al., 2017; Jhamb et al., 2008; Lee et al., 2004, 2007; Weisbord et al., 2005). Within that frame, fatigue is conceptualized as a "multi-dimensional experience," whose manifestation can be influenced by sociodemographic, physiological, physical, dialysis-related, and psychological/behavioral factors (Choi and Lee, 2005; Jhamb et al., 2008; Unruh et al., 2004; Weisbord et al., 2005).

On the other side, some evidence of connections between chronic inflammation and fatigue onset were provided (Bossola et al., 2015; Dantzer et al., 2015) and it has been hypothesized that inflammation could be the cause of a reduced motivation and altered reward processes in chronic populations (Dobryakova et al., 2017; Tanaka et al., 2004). Indeed, there are also two motivational dimensions related to the construct of fatigue—a physical and a mental one (Chaudhuri and Behan, 2000; Hardy and Studenski, 2010; Johansen et al., 2005)—and their failure has been noticed in other populations with chronic illnesses (Dobryakova et al., 2017). Regarding the mental dimension, the reward system, which is responsible for regulating motivational disposition mechanisms that predispose to the activation (Behavioral Activation System, BAS) or inhibition of behavior (Behavioral Inhibition System, BIS; Gray, 1981), has been demonstrated to have a role in chronic fatigue (Dantzer et al., 2015).

Specifically, Dantzer et al. (2015) proposed that an inflammation-induced impairment in frontostriatal circuits, which mediate response–outcome associations and reward-based decision-making, negatively influences the creation of habits and makes even daily routine hard to manage for fatigued patients. Such impairment was suggested to account for the cognitive fatigability of fatigued patients. Moreover, the frontal cortex also plays a critical role with regard to the BIS/BAS systems and, whereas the left prefrontal area was shown to be involved in approach-related motivations and emotions, the right prefrontal area was found to be associated to withdrawal-related motivations and emotions (Balconi and Mazza, 2009, 2010; Davidson, 2004; Harmon-Jones, 2004).

For this reason, BIS/BAS components could be considered as a useful tool for testing behavioral motivational responses that are relevant to approach and withdrawal behavior in this context. Indeed, BAS was conceptualized as a motivational system that is sensitive to signals of reward, engaging approach behavior, and positive emotional attitudes. BIS reflects the sensitivity to punishment that promotes negative reinforcement of avoidance (withdrawal behavior; Carver and White, 1994; Gray, 1981).

This study aimed at investigating potential differences in patients' discourses reflecting their subjective experience of dialysis in relation to fatigue and to motivational components (BIS/BAS), which we have hypothesized to play a role for this clinical population facing a chronic condition. In particular, it was expected that patients with different levels of BIS would have preferably used words semantically related to aversive aspects of their HD treatment experience; while we supposed that BAS patients would have more likely referred to strategies to face dialysis with an active approach tendency. Again, we have hypothesized that distinct degrees of fatigue severity would have influenced HD patients' discourses in terms of how they would have described their daily routine and coping strategies that they adopt to manage the degree and the subjective sense of tiredness.

Semi-structured interviews were conducted to explore patients' discourses concerning HD and fatigue-related factors. The identification of relevant topics and, within each topic, of significant and repeated words was considered as an evidence of the relevance of specific themes for the patients. Patients' discourses were supposed not only to describe widely their daily life experiences and efforts related to the HD treatment but also to highlight some coping strategies (such as socio-relational aspects) that could help them to face their life challenges.

Method

Participants

A total of 31 Italian patients (18 males; mean age = 61.23 years, standard deviation (SD) = 15.44; dialytic

mean age in months=97.17, SD=45.34) were enrolled in the study. They were recruited at the Hemodialysis Unit of the University Hospital that they attended three times a week. Exclusion criteria were as follows: clinical instability requiring hospital admissions such as infective disease, rheumatic disease, inflammatory bowel disease, autoimmune disease, acute hepatitis, liver failure, and active cancer; a previous diagnosis of dementia or psychotic disorders based on *Diagnostic and Statistical Manual of Mental Disorders* 4th ed. (DSM-IV) criteria; previous history of alcohol or substance abuse.

Each participant has been assessed with a focus on symptoms of depression and anxiety through the Beck Depression Inventory-II and the State-Trait Anxiety Inventory, Form Y1 and Y2 (Beck et al., 1996; Sica and Ghisi, 2007; Spielberger et al., 2012). Weight, height, and body mass index (BMI) were also collected. Demographic, clinical, and laboratory data (age, gender, underlying renal disease, HD regimen, and duration on dialysis) were recorded and controlled for each patient at the moment of the inclusion in the study.

Furthermore, the Italian version of the Fatigue Severity Scale (FSS; Krupp et al., 1989) was used to assess fatigue severity and the Italian version of BIS/BAS questionnaire was used to assess propensity for approach versus avoidance goals (tendency toward activation or inhibition of actions), sensitivity to aversive or to rewarding stimuli, and anxiety/impulsivity dimension of personality (Carver and White, 1994; Leone et al., 2002).

The ethics committee of the institution where the research was conducted approved this study and written informed consent was obtained by patients according to the ethical standards of the World Medical Association Declaration of Helsinki (Rickam, 1964).

BIS/BAS assessment

The Italian version of the “Behavioral Inhibition/Activation System” questionnaire is a self-report measure intended to assess individual differences that reflect the sensitivity of two physiological self-regulatory systems, one of which bears on appetitive motivation and the other one on aversive motivation (Carver and White, 1994; Leone et al., 2002). It includes 24 items (20 score items and 4 fillers, each measured on a 5-point Likert-type scale), and two total scores for BIS (range=7–28; 7 items, such as “I feel worried when I think I have done something inadequately”) and BAS (range=13–52; 13 items, e.g. “When I get something I want, I feel excited and energized”).

Fatigue severity assessment

Patients’ fatigue severity levels were evaluated using the Italian version of the Fatigue Severity Scale (FSS; Krupp et al., 1989), a 9-item self-administered scale investigating

the severity of fatigue in different situations during the last week (e.g. “The sense of fatigue interferes with my work, my family, and my social life”). Grading of each item ranges from 1 to 7, where 1 indicates “strong disagreement” and 7 “strong agreement” with the statement. The final score is the sum of ratings at the 9 items.

Semi-structured interview

Data were collected using a semi-structured interview with open-ended questions which took place in the HD department. The interview was divided into three main sections on the basis of the following areas: (1) sociodemographic details (2) experience related to HD treatment, and (3) socio-relational aspects (see Appendix 1). In order to guarantee greater emotional involvement during the interview, patients were advised to take all the time they would have required to answer the questions. The interview lasted about 40–60 minutes and each verbatim was properly transcribed by the interviewers.

Data analysis

As the first step, a well-established approach that consists in a qualitative content analysis (Hsieh and Shannon, 2005) was used to analyze the semi-structured interviews. All interviewers checked and coded all the transcripts according to the approach described by Lincoln and Guba (1985). Verbatim transcripts were tested by other researchers of the team to ensure that transcriptions provided a true description of the interaction between patients and interviewer and verbal answers accuracy. Researchers examined the verbatim several times, comparing their analysis with three other judges (method of agreement between judges) until the transcripts had represented the interview in a realistic and descriptive way. The agreement reliability for raters was Cohen’s kappa=.89. The aim of this analysis is to identify common themes within the verbatim of patients in the department.

Following repeated reading of interview transcripts, a thematic analysis of their content was performed, consisting of a first coding through the identification of the recurring elements discussed in each interview. This manifest content analysis (Potter and Levine-Donnerstein, 1999) suggested that the verbatim content could be closely outlined within five topics across all patients: (1) pervasiveness of the disease, (2) experience in the HD unit, (3) psychologist in the HD department, (4) coping with the HD treatment, and (5) heterogeneity of patient daily activities.

As a second step, critical discourse analysis (Fairclough, 1992, 2001, 2003) was used to analyze, in particular, the use of language and the reproduction of dominant belief systems within the discourse. For this purpose, systematic and repeated readings of patients’ verbatim were performed in order to examine what pieces of evidence were used

from the text to identify the topics and its usefulness in patient's description of himself. The focus of discourse analysis was to highlight the exact words from the text that appeared to capture the key thoughts or concepts in our sample of patients on HD.

Thus, transcripts were reanalyzed by researchers setting themselves the following questions: which words have the patients used to describe the situation and the interactions between primary actors? Have the patients used words related to appraisal? Which were the most used words to describe their situation? Which were their contents (Aasen et al., 2012c)?

Data analysis continued with qualitative computer-assisted searches for occurrences of the semantically meaningful words, based on the semantic content of transcripts that were subdivided into the five topics. During this inductive process, the words were further selected in order to deepen the transcribed material, to identify significant dimensions or issues, and to determine which of them had the most semantic relevance (Polit and Beck, 2004). In this way, for each topic, only the words with the highest frequency of use were considered, comparing them with the total words contained in the same topic (see Table 1).

Results

Statistical analysis was performed by using the Statistical Package for Social Science (SPSS), release 15.0. Continuous variables were expressed as mean \pm SD. As for BIS, BAS, and FSS variables' categorization, we followed the canonical approach to convert their values in Z scores, thus stratifying them into three groups (low, medium, and high levels of each measure corresponding to Z score < -1 , ranging from -1 to 1 and > 1 , respectively). A repeated measure analysis of variance (ANOVA) with independent factors BIS, BAS, and FSS was applied to each dependent measure (word count indexes for each topic). For all the ANOVA tests, the degrees of freedom have been corrected using Greenhouse-Geisser epsilon where appropriate. Post hoc comparisons (contrast analyses) were applied to the data. Simple effects for significant interactions were further checked via pair-wise comparisons, and Bonferroni correction ($\alpha = .001$) was used to reduce multiple comparisons potential biases. Furthermore, the normality of the data distribution was preliminarily assessed by checking kurtosis and asymmetry indices.

As shown by ANOVA, significant effects were found for BAS with regard to the words: "useful" $F[2, 30] = 6.78$, $p \leq .001$, $\eta^2 = .29$ (with increased percentage for medium and high than low BAS, all comparisons $p \leq .001$); "family" $F[2, 30] = 7.02$, $p \leq .001$, $\eta^2 = .31$ (with increased percentage for low and medium than high BAS, all comparisons $p \leq .001$); and "to manage" $F[2, 30] = 6.98$, $p \leq .001$, $\eta^2 = .30$ (with increased percentage for medium and high than low BAS, all comparisons $p \leq .001$; Figure 1).

About the BIS factor, ANOVA showed significant differences for the words: "dialysis" $F[2, 30] = 7.12$, $p \leq .001$, $\eta^2 = .32$, (with increased percentage for medium and high than low BIS and high more than medium BIS, all comparisons $p \leq .001$); "psychological issues" $F[2, 30] = 7.02$, $p \leq .001$, $\eta^2 = .32$ (with increased percentage for medium and high more than low BIS, all comparisons $p \leq .001$); "useful" $F[2, 30] = 6.09$, $p \leq .001$, $\eta^2 = .28$ (with increased percentage for medium and high more than low BIS, all comparisons $p \leq .001$); and "to manage" $F[2, 30] = 7.32$, $p \leq .001$, $\eta^2 = .33$ (with increased percentage for medium and high than low BIS, all comparisons $p \leq .001$, Figure 2).

Finally, as for FSS, ANOVA showed significant differences for the words: "diet" $F[2, 30] = 7.45$, $p \leq .001$, $\eta^2 = .34$ (with increased percentage for low than medium and high FSS, and medium more than high FSS, all comparisons $p \leq .001$); and "familiar staff" (with increased percentage for low than medium and high FSS, all comparisons $p \leq .001$, Figure 3).

Discussion

This study aimed at exploring the relationship between narratives of patients on HD treatment describing their subjective experience, fatigue severity, and motivational dispositions related to reward mechanisms.

First, the analysis of semi-structured interviews disclosed the presence of five major recurring topics (pervasiveness of the disease, experience in the HD unit, psychologist in the HD department, coping with the HD treatment, and heterogeneity of patient daily activities) and significant keywords that we considered as an evidence of the relevance of specific themes for the patients.

Before, other studies referred to the existence of core themes to HD patients (Aasen, 2015; Lee et al., 2007; Wu et al., 2015). In this case, patients' discourses described widely their struggle in daily life experiences and efforts related to the HD treatment, citing in particular socio-relational aspects as major strength points to cope with their exhausting weekly routine. Within these themes, it was demonstrated that patients with different levels of fatigue, BIS and BAS tendencies used to a greater extent different significant words. Regarding these variables three main effects related to BIS, BAS, and FSS components were found.

A significant effect of inhibition tendency was found showing that patients with high and medium levels of BIS said more times the following words: "dialysis," "psychological issues," "useful," and "to manage," compared to patients with low levels of BIS. The first two words were considered in a negative sense and belong to the topic of the pervasiveness of the disease reflecting the impact of the illness on daily life, during work, or leisure time. Moreover, patients with high and medium BIS cited more the word "to

Table 1. Description of the five recurring topics within patients' sample and list of the relevant words within each corresponding topic.

Topics	Description	Relevant words	Examples of verbatim
1. Pervasiveness of the disease	Impact of the treatment on daily life, during work, or leisure time	Dialysis	"Dialysis treatment completely transforms your life." "I didn't expect dialysis. It has cheated me of many things: trips, holidays ... In this way I don't have a good life." "With the diet it is very difficult, especially now that summer is coming and it's hot." "About my diet I could write an encyclopedia. Now that I'm diabetic I'm trying to lose weight in order to facilitate transplantation." "I didn't succeed to play sports. It's very disabling for me." "I used to cook when I was fine. Now I cannot get up, I abandoned any kind of activity, because I didn't succeed to do it." "Lack of motivation, so much weariness. Fatigue also depends on the activities I have to do at home." "I'm visually more tired, then I'm much more anxious, because I had some problems right at the beginning of dialysis, so I got scared. Now I'm learning to handle my concerns." "The staff loves me very much. They are as a family. I feel at home." "They are a family for me, they are all kind and the doctor is very dedicated (to us)." "There should be a psychological service before starting the therapy and entering the unit. It would be very useful. For example, I would have need it while waiting for the transplant." "It would be very useful because, for example, I think I am a very anxious person and dialysis creates stress." "Faith helps me to understand and justify what is happening to me." "I am Catholic, and faith helps me to be strong." "Thanks to my friends, I get distracted. They always call me and this gives me pleasure and strength to go on." "Having many friends helps me a lot. The important thing is not to think about dialysis. They help me to not be feeling down and react." "My child and my family give me strength. Basically, I have started the dialysis for them." "I do a lot of effort. But my wife, my family, help me a lot." "The disease is at the center of my life, but I manage the rest, I go and come with my car, I do not get tired." "I cannot do some things, because they are very heavy, but in general I manage them and I can do everything." "I mainly have medical commitments to which my daughter accompanies me. In the days when I have hemodialysis treatment I do not do anything, because I'm really tired." "Hemodialytic treatment is annoying, because I no longer have freedom. Point! Nothing more than this."
2. Experience in the HD unit	Global assessment of the relationship with the staff of the department and the perceived quality of the medical services	Familiar (referred to the staff)	
3. Psychologist in the HD department	Exploration of the usefulness of the psychological figure within the HD department	Useful	
4. Coping with the HD treatment	Seeking religious support, cultivating significant relationships, focus on job, cognitive activities, humor	Faith Friends	
5. Heterogeneity of patient daily activities	Amount of different activities carried out by the patient during the day	Family To manage Hemodialytic treatment	

HD: hemodialysis.

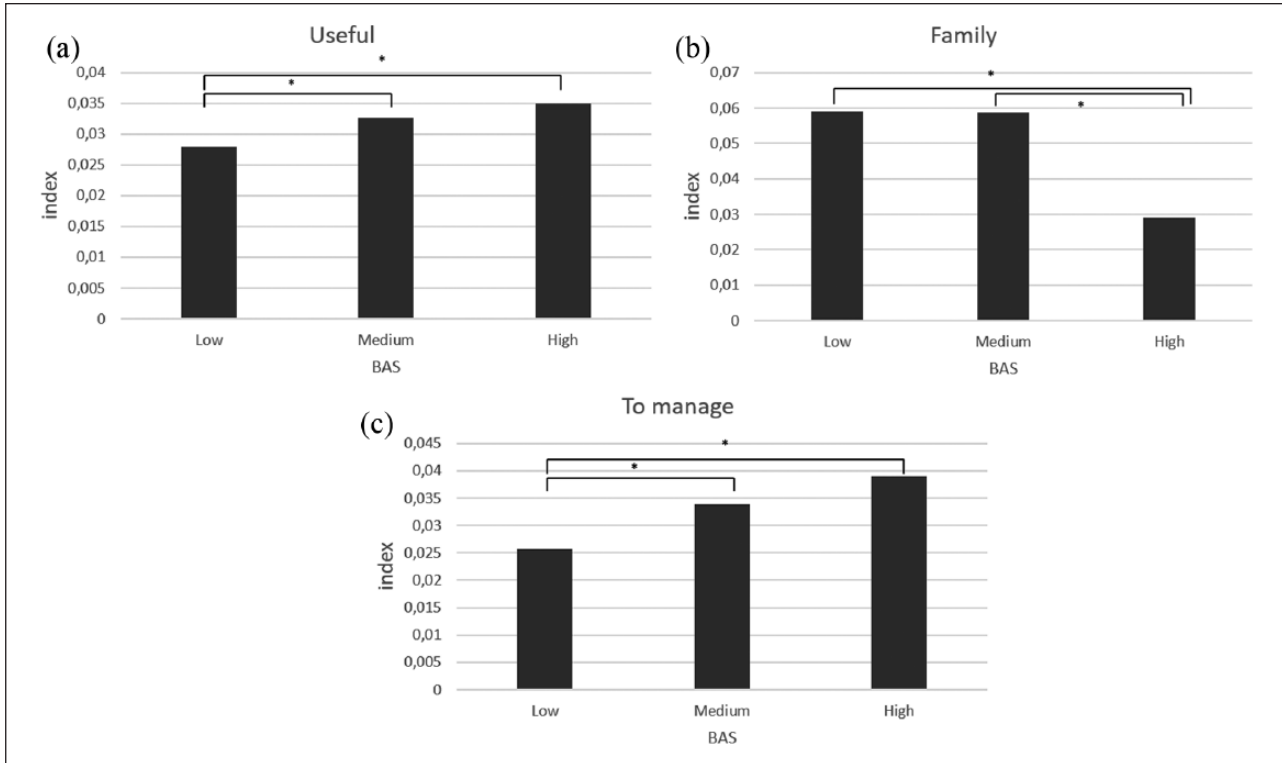


Figure 1. Mean profile of significant words referred for different levels of BAS (low, medium, and high): (a) useful, (b) family, and (c) to manage.

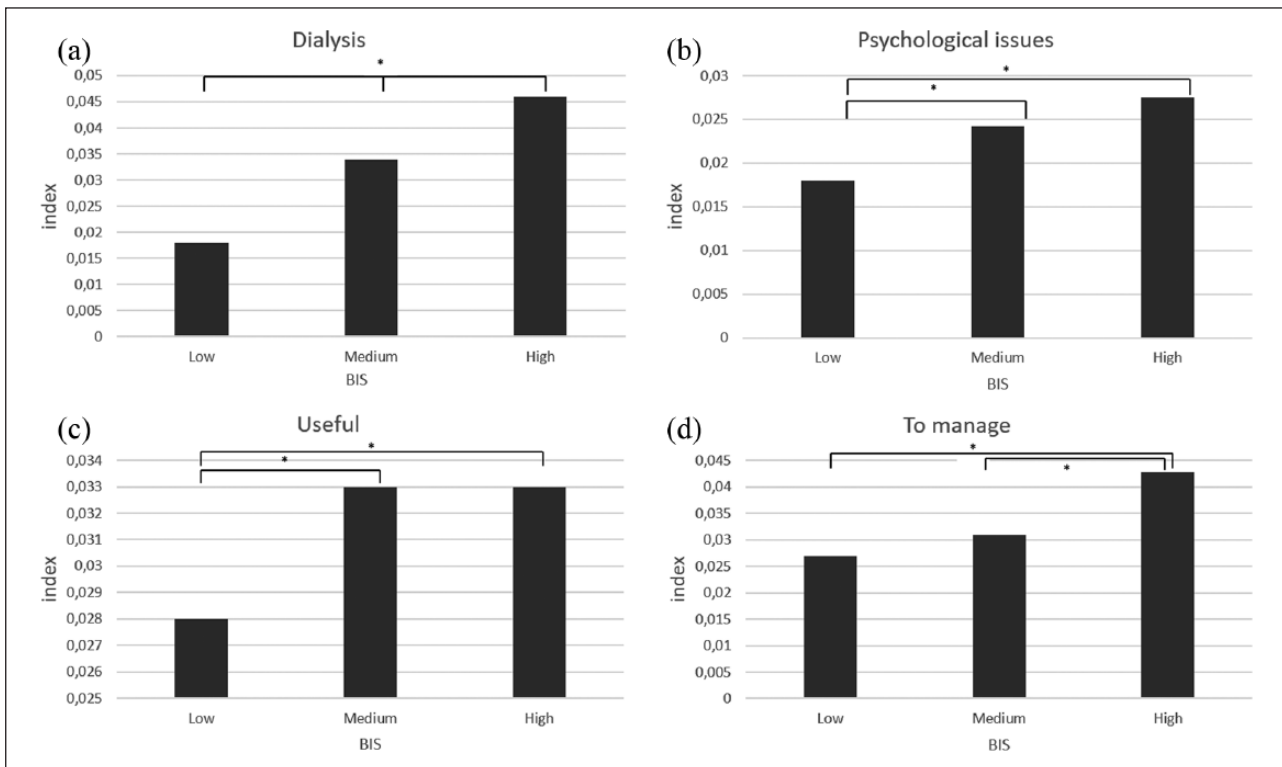


Figure 2. Mean profile of significant words reported as a function of BIS (low, medium, and high): (a) dialysis, (b) psychological issues, (c) useful, and (d) to manage.

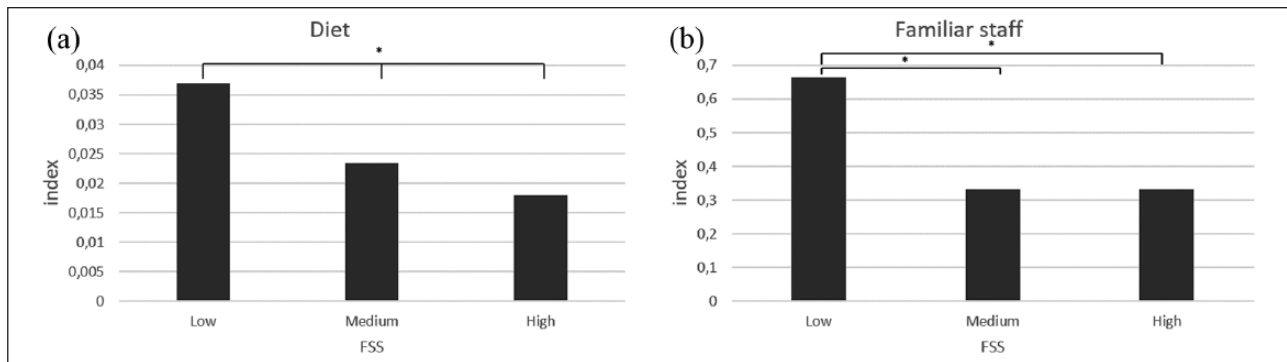


Figure 3. Mean profile of significant words reported as a function of FSS (low, medium, and high): (a) diet and (b) familiar, attributed to the staff.

manage” as referred to the need of organizing their daily activities, including the HD treatment. Thus, our group of patients with higher negative emotional attitudes and social withdrawal tended to stress more negative aspects of their daily routine. Nevertheless, they also recognized to a greater extent the usefulness of the figure of the psychologist in the HD unit, perhaps to manage their anxiety dimension of personality (BIS; Carver and White, 1994; Gray, 1981).

Then, a significant effect was found in relation to BAS levels. Even in this case, patients with high and medium levels of BAS used the word “useful” more for describing the figure of the psychologist in the HD department and used more often the verb “to manage” when discussing the amount different activities carried out during the day, thus highlighting the other side of the coin, that is their role in seeking strategies to activate new resources when facing their condition. Indeed, as opposed to BIS, people with higher levels of BAS has the tendency to engage themselves in approach behavior and positive emotional attitudes (Carver and White, 1994; Gray, 1981). In addition, patients with low and medium levels of approach conduct talked more about “family”—a word that belongs to the topic related to how to cope with HD treatment—perhaps reflecting their need to external social support.

Reward system was previously hypothesized as involved in the functioning of clinical populations with chronic disease (Dantzer et al., 2015; Dobryakova et al., 2017; Tanaka et al., 2004). However, to our best knowledge, here for the first time BIS/BAS components as conceptualized by Gray (1981) were combined to thematic discourse analysis in HD patients.

Interestingly, both groups of patients with high and medium levels of BIS and BAS, compared to those with low-level scores, shared the highest use of the words “to manage” and “useful.” The first word referred to the heterogeneity of patient daily activities, while the second one to the presence of the psychologist in the HD department. Perhaps a possible explanation could be that these two words reflect two needs that are relevant for both these categories by different perspectives. For example, patients

with higher level of BIS might recognize the usefulness of the psychologist based on the degree to which they internalized the experience of being under dialysis treatment and their withdrawal toward the reality of the department, thus explaining why patients with lower levels of BIS do not report verbally the need of a psychologist figure. Whereas, focusing on patients with higher levels of BAS, references to the usefulness of the psychologist might be interpreted as a call for an active strategy to increase the search for support, which might be felt as less urgent by patients with lower levels of BAS. Also, we have previously discussed the potential difference between the use of the word “to manage” by patients showing high and medium levels of BIS and BAS, suggesting that patients presenting higher levels of BIS might preferably use an avoidance behavioral tendency when facing daily routine, while higher-BAS individuals might tend to use an approach behavioral propensity.

Regarding patients with low levels of BIS and of BAS, it might be possible that the limited degree to which they report the words “useful” and “to manage” is related to a less perceived and compelling need for psychological support and organization in their daily routine, otherwise further explanations are needed.

However, even if our findings have been framed within the context of behavioral motivation systems, further qualitative studies are needed to deeply explore how discrepancies between patients scoring differently at the BIS and/or BAS scale could be associated to the experience of living with a chronic disease—namely, on maintenance HD treatment—and to all aspects related to this condition.

Regarding FSS, patients with low levels of fatigue severity used to cite more frequently two words related to the HD treatment: “diet” and “familiar,” attributed to the staff. The word “diet” was identified within the topic related to the pervasiveness of the disease as a possible issue; while “familiar (staff)” was positively referred to patients’ experience in the HD unit.

Given the importance of relational aspects when facing fatigue (Jhamb et al., 2008), caregivers and professionals

should be aware of their relevant role (and of the correlates of fatigue), take it seriously, and assist patients in developing coping strategies to prevent and respond to such clinical signs. By establishing a therapeutic relationship, clinical staff can help to validate patients' illness experiences and can provide information more efficiently, by taking into account patients' and family actual understanding of fatigue correlates and factors related to HD regimen, such as diet. In doing that, the staff can also support patients' families in establishing and maintaining connections with other medical figures (such as dieticians). Thus, as already highlighted in previous studies in which patients referred to trust the healthcare team (Aasen, 2015), the clinical staff could play a greater role in coordinating all the activities of those involved in the care of HD patients.

With regard to the relationship between diet and fatigue in HD population, literature so far focused mainly on pathological conditions related to nutrition. Therefore, it could be of interest to study the degree in which diet influences fatigue severity (Bossola et al., 2006, 2009; Burrowes et al., 2005; Carrero et al., 2007; Jhamb et al., 2008; Kalantar-Zadeh et al., 2004).

Finally, we acknowledge that data collection was limited to one Italian hospital, thus findings might not reflect the experiences of all HD patients and how fatigue is experienced and managed in other cultures. Furthermore, this study considered fatigue as multi-dimensional and as composed of affective, cognitive, and physical aspects but quantified it considering its severity only. Future studies should focus on fatigue pervasiveness at all levels of complexity, even involving family members and professionals.

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References

- Aasen EM (2015) A comparison of the discursive practices of perception of patient participation in haemodialysis units. *Nursing Ethics* 22(3): 341–351.
- Aasen EM, Kvangarsnes M and Heggen K (2012a) Nurses' perceptions of patient participation in hemodialysis treatment. *Nursing Ethics* 19(3): 419–430.
- Aasen EM, Kvangarsnes M and Heggen K (2012b) Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. *Scandinavian Journal of Caring Sciences* 26(1): 61–69.
- Aasen EM, Kvangarsnes M, Wold B, et al. (2012c) The next of kin of older people undergoing haemodialysis: A discursive perspective on perceptions of participation. *Journal of Advanced Nursing* 68(8): 1716–1725.
- Balconi M and Mazza G (2009) Brain oscillations and BIS/BAS (behavioral inhibition/activation system) effects on processing masked emotional cues. ERS/ERD and coherence measures of alpha band. *International Journal of Psychophysiology* 74(2): 158–165.
- Balconi M and Mazza G (2010) Lateralisation effect in comprehension of emotional facial expression: A comparison between EEG alpha band power and behavioral inhibition (BIS) and activation (BAS) systems. *Laterality* 15(3): 361–384.
- Bayhakki B and Hatthakit U (2012) Lived experiences of patients on hemodialysis: a meta-synthesis. *Nephrology Nursing Journal*: 39(4): 295–304.
- Beck A, Ster R and Brown G (1996) *Manual for the Beck Depression Inventory-II*. San Antonio, TX: Psychological Corporation.
- Bossola M, Di Stasio E, Antocicco M, et al. (2015) Fatigue is associated with increased risk of mortality in patients on chronic hemodialysis. *Nephron* 130(2): 113–118.
- Bossola M, Luciani G and Tazza L (2009) Fatigue and its correlates in chronic hemodialysis patients. *Blood Purification* 28(3): 245–252.
- Bossola M, Tazza L, Giungi S, et al. (2006) Anorexia in hemodialysis patients: An update. *Kidney International* 70(3): 417–422.
- Burrowes JD, Larive B, Chertow GM, et al. (2005) Self-reported appetite, hospitalization and death in haemodialysis patients: Findings from the Hemodialysis (HEMO) Study. *Nephrology Dialysis Transplantation* 20: 2765–2774.
- Carrero JJ, Qureshi AR, Axelsson J, et al. (2007) Comparison of nutritional and inflammatory markers in dialysis patients with reduced appetite. *The American Journal of Clinical Nutrition* 85(3): 695–701.
- Carver CS and White TL (1994) Behavioral inhibition, behavioral activation, and affective responses to impending reward and punishment: The BIS/BAS Scales. *Journal of Personality and Social Psychology* 67(2): 319–333.
- Chaudhuri A and Behan PO (2000) Fatigue and basal ganglia. *Journal of the Neurological Sciences* 179(1): 34–42.
- Choi E and Lee H (2005) The relationship of fatigue, self-efficacy, family support and sleep factor in hemodialysis patients. *Journal of Korean Academy of Nursing* 17(3): 435–443.
- Cox KJ, Parshall MB, Hernandez SHA, et al. (2017) Symptoms among patients receiving in-center hemodialysis: A qualitative study. *Hemodialysis International* 21(4): 524–533.
- Dantzer R, Heijnen C, Kavelaars A, et al. (2015) The neuroimmune basis of fatigue. *Trends in Neuroscience* 37(1): 39–46.
- Davidson RJ (2004) What does the prefrontal cortex “do” in affect: Perspectives on frontal EEG asymmetry research. *Biological Psychology* 67(1–2): 219–233.
- Dobryakova E, Hulst HE, Spiro A, et al. (2017) Fronto-striatal network activation leads to less fatigue in multiple sclerosis. *Multiple Sclerosis Journal* 24: 1174–1182.

- Evangelidis N, Tong A, Manns B, et al. (2017) Developing a set of core outcomes for trials in hemodialysis: An international delphi survey. *American Journal of Kidney Diseases* 70(4): 464–475.
- Fairclough N (1992) *Discourse and Social Change*. Cambridge: Polity Press.
- Fairclough N (2001) *Language and Power* (2nd edn). Edinburgh: Longman Group.
- Fairclough N (2003) *Analysis Discourse: Textual Analysis for Social Research*. New York: Routledge.
- Gray J (1981) A critique of Eysenck's theory of personality. In: Eysenck H (ed.) *A Model for Personality*. Berlin: Springer, pp. 246–276.
- Hardy SE and Studenski SA (2010) Qualities of fatigue and associated chronic conditions among older adults. *Journal of Pain and Symptom Management* 39(6): 1033–1042.
- Harmon-Jones E (2004) Contributions from research on anger and cognitive dissonance to understanding the motivational functions of asymmetrical frontal brain activity. *Biological Psychology* 67(1–2): 51–76.
- Hsieh H and Shannon SE (2005) Three approaches to qualitative content analysis. *Qualitative Health Research* 15(9): 1277–1288.
- Jhamb M, Weishbord SD, Steel JL, et al. (2008) Fatigue in patients receiving maintenance dialysis: A review of definitions, measures, and contributing factors. *American Journal of Kidney Disease* 52(2): 353–365.
- Johansen KL, Doyle J, Sakkas GK, et al. (2005) Neural and metabolic mechanisms of excessive muscle fatigue in maintenance hemodialysis patients. *American Journal of Physiology-Regulatory, Integrative and Comparative Physiology* 289(3): R805–R813.
- Ju A, Unruh M, Davison S, et al. (2018) Establishing core outcome domains in hemodialysis: Report of the Standardized Outcomes in Nephrology–Hemodialysis (SONG-HD) Consensus Workshop. *American Journal of Kidney Diseases* 69(1): 97–107.
- Kalantar-Zadeh K, Block G, McAllister CJ, et al. (2004) Appetite and inflammation, nutrition, anemia, and clinical outcome in hemodialysis patients. *American Journal of Clinical Nutrition* 80(2): 299–307.
- Krupp LB, LaRocca NG, Muir-Nash J, et al. (1989) The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. *Archives of Neurology* 46(10): 1121–1123.
- Lee B, Lin C and Chaboyer W (2007) The fatigue experience of haemodialysis patients in Taiwan. *Journal of Clinical Nursing* 16: 407–413.
- Lee S-K, Lee H-S, Lee T-B, et al. (2004) The effects of antidepressant treatment on serum cytokines and nutritional status in hemodialysis patients. *Journal of Korean Medical Science* 19(3): 384–389.
- Leone L, Pierro A and Mannetti L (2002) Validità della versione Italiana delle Scale BIS/BAS di Carver e White (1994): Generalizzabilità della struttura e relazioni con costrutti affini. *Giornale Italiano di Psicologia* 29(2): 413–436.
- Lin C-C, Chen M-C, Hsieh H-F, et al. (2013) Illness representations and coping processes of Taiwanese patients with early-stage chronic kidney disease. *Journal of Nursing Research* 21(2): 120–128.
- Lincoln YS and Guba EG (1985) *Naturalistic Inquiry*. Thousand Oaks, CA: SAGE.
- Polit D and Beck C (2004) *Nursing Research: Principles and Methods* (7th edn). Philadelphia, PA: Lippincott Williams & Wilkins.
- Potter WJ and Levine-Donnerstein D (1999) Rethinking validity and reliability in content analysis. *Journal of Applied Communication Research* 27(3): 258–284.
- Rickam PP (1964) Human experimentation. Code of ethics of the world medical association. Declaration of Helsinki. *British Medical Journal* 2(5402): 177.
- Schwandt TA (2000) Three epistemological stances for qualitative inquiry: Interpretivism, hermeneutics, and social constructionism. *Handbook of Qualitative Research* 2: 189–213.
- Sica C and Ghisi M (2007) The Italian versions of the Beck Anxiety Inventory and the Beck Depression Inventory-II: Psychometric properties and discriminant power. In: Lange MAE (ed.) *Leading-Edge Psychological Tests and Testing Research*. Hauppauge, NY: Nova Science Publishers, pp. 27–50.
- Spielberger C, Pedrabissi L and Santinello M (2012) *STAI State-Trait Anxiety Inventory Form Y: Manuale*. Florence: Giunti O.S. Organizzazioni Speciali.
- Tanaka SC, Doya K, Okada G, et al. (2004) Prediction of immediate and future rewards differentially recruits cortico-basal ganglia loops. *Nature Neuroscience* 7(8): 887–893.
- Tong A, Manns B, Hemmelgarn B, et al. (2017) Establishing core outcome domains in hemodialysis: Report of the Standardized Outcomes in Nephrology–Hemodialysis (SONG-HD) Consensus Workshop. *American Journal of Kidney Diseases* 69(1): 97–107.
- Unruh M, Miskulin D, Yan G, et al. (2004) Racial differences in health-related quality of life among hemodialysis patients. *Kidney International* 65(4): 1482–1491.
- Urquhart-Secord R, Craig JC, Hemmelgarn B, et al. (2016) Patient and caregiver priorities for outcomes in hemodialysis: An international nominal group technique study. *American Journal of Kidney Diseases* 68(3): 444–454.
- Weisbord SD, Fried LF, Arnold RM, et al. (2005) Prevalence, severity, and importance of physical and emotional symptoms in chronic hemodialysis patients. *Journal of the American Society of Nephrology* 16: 2487–2494.
- Wu CC, Lin CC, Hsieh HF, et al. (2015) Lived experiences and illness representation of Taiwanese patients with late-stage chronic kidney disease. *Journal of Health Psychology* 21(12): 2788–2798.

Appendix I

The brief interview schedule concerning the participants' living situation related to HD treatment and dialysis-related fatigue is given below.

Semi-structured interview guideline

Sociodemographic characteristics

What is your age?

What is your marital status? Who do you live with?

Which degree of study you have achieved?

What is/was your job (specify the socio-professional category)?

Lived experience with HD treatment

How much time has elapsed since starting the HD treatment?

What do you usually do in your daily life?

Tell me about your daily or weekly routine: do you have pets? Do you practice any sport activities? Do you have any hobby?

Is there somebody or something that helps you particularly in facing the effort of HD treatment? If yes, who/what?

Socio-relational sphere

Have concerns about HD treatment ever interfered in your daily activities? If yes, how often? And, how it interferes?

Do you keep your family and friends informed about HD treatment? If not, why?

In general, on a scale of 1–5 (where 1 stands for “not at all” and 5 for “very much”) how important is your family members'/friends' understanding of your situation (related to HD treatment)?

Do you have any person (friend/confidant) with whom you prefer to talk about yourself? If, yes indicate the type of relationship?

As for your ability to perform activities (your skills and your effectiveness), do you feel that something has changed/have remained the same? If yes, what and how (compared to the past, before starting HD treatment)?

Notes, comments, or other relevant information

HD: hemodialysis.