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Psychodynamic insights from narratives of people with amyotrophic lateral sclerosis: A qualitative phenomenological study

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Abstract

This study explored the illness experience of people with amyotrophic lateral sclerosis (ALS) to widen narrative research on patients' perspectives, adopting object relations theory as interpretative framework. A qualitative phenomenological analysis was conducted on the illness stories of 12 adult Italian patients with ALS, collected through an Internet-based database for the sharing of illness experiences of people with rare and chronic degenerative diseases. Three thematic areas were identified: "the experience of ALS from symptom onset to diagnosis", "impact of illness", and "coping with illness". Overall, the central conflict experienced by people with ALS refers to the progressive loss of control on bodily experience, that is handled by means of denial and splitting defences to contrast such a process of somatic depersonalization. As well, the investment on interpersonal domain responds to a repairing strategy ensuring psychic vitality and sensorial integration to rebuild the relation between the self and the external world.

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1. Introduction

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative, chronic and terminal condition progressively affecting mobility, speech, and breathing and is currently the most common form of degeneration of motor neurons in adult life. About 2/3 of patients with ALS show the spinal/limb form of the disease, characterised by amyotrophy, fasciculations, paresis, and spasticity. Patients with bulbar form have speaking, swallowing and cognitive-behavioural impairments; whereas those with respiratory onset show breathing difficulties and a worse prognosis compared to other forms. Indeed, respiratory failure generally leads to death within 1-5 years after the first symptomatic manifestations (Bastos et al., 2011). The incidence of ALS across European countries is 2-3 per 100,000 of the general population per year, while the prevalence is 6-7 per 100,000, with evidence of family history only in 5% of cases (Logroscino et al., 2009).

ALS is currently included among rare diseases, overall featured by complex aetiology, poor public awareness, lack of timely diagnosis and absence of effective treatment, with a very negative impact on patients' lives in terms of anxiety and depression issues (Chen et al., 2015) and increasing hopelessness, particularly in those with faster functional decline (Paganoni et al., 2017). Therefore, there is a general consensus about the need for more effective symptom management and care planning (Galvin, Gaffney, Corr, Mays, & Hardiman, 2017) to improve patients' quality of life (Caputo, 2014) and reduce their invisibility, social isolation, distress, and family daily burden (Cohen & Biesecker, 2010). Along with evidence-based medicine, narrative medicine has been developed to recognize, interpret, and make decisions from patients' perspectives (Charon, 2006), focusing on patients' experiences and psychosocial aspects involved, from a qualitative analysis of their illness stories (Sakellariou, Boniface, & Brown, 2013). This is particularly relevant if considering that illness experience and perceived quality of life among people with ALS are not necessarily associated with measures of strength and physical function (Cipolletta, Gammino, & Palmieri, 2017).

Overall, some recurring themes have been found in illness stories, such as loneliness and social isolation (Madsen, Jeppesen, & Handberg, 2018), hopelessness related to illness chronicity (Caputo, 2014), uncertainty about future and death anxiety (Sakellariou et al., 2013). At the same time, such depressive feelings are accompanied with the search for a meaningful life (Cipolletta et al., 2017), the need for autonomy and control over one's condition (Caputo, 2014; Lemoignan & Ells, 2010) and efforts to restore a sense of normality or learn to live with altered circumstances (Sakellariou et al., 2013). ALS seems thus to be experienced as a biographical disruption and life challenge that seriously threats self-identity and may enable repairing strategies to make sense of one's own condition (Locock, Ziebland, & Dumelow, 2009).

Consistently with object relations theory (Schattner & Shahar, 2011) dealing with mental representations of the self and external environment that are important for both psychological functioning and social interaction, body image (as internal object) and symbolism attached to illness (as external object) may have a role in adjustment to diagnosis and treatment. Specifically, the presence of chronic disease may represent an object loss that needs to be recognized, accepted and worked through (D'Alberton, Nardi, & Zucchini, 2012), because individuals who have to face a so disabling and life-consuming disease may experience the loss of bodily intactness and profound narcissistic injuries (Goldstein, 2001), feeling that illness is invading the psychological territory of the self. This may lead to the personification of being ill as a "bad" internal object, because over time chronic illness tends to become a mental representation that may influence both emotional and physical wellbeing according to a psychosomatic paradigm (Schattner, Shahar, & Abu-shakra, 2008; Shahar & Lerman, 2013). The capacity to repair internal

objects and rely on psychic resources to reframe one's condition can thus be regarded as clinically significant, also in the light of the difficulty to make sense of illness in such patients (Mock & Boerner, 2010). Indeed, previous research has highlighted issues of anxiety and depression in people with ALS (Diaz et al., 2014), as well as the negative role of unresolved or denied depression in the course of the disease (Brown & Mueller, 1970). In this regard, psychotherapy and psychological interventions are suggested as strategies for reducing patient depression and anxiety, coping with the fear of death and improving wellbeing and quality of life (Harris et al., 2017; Pagnini, Rossi, Lunetta, Banfi, & Corbo, 2010). Specifically, therapeutic writing and expressive disclosure interventions facilitating the emotional processing of thoughts and feelings about the ALS experience have been regarded as particularly promising (Gould et al., 2015; Oberstadt, Esser, Classen, & Mehnert, 2018).

The present study aims at exploring the illness experience of patients with ALS through a qualitative phenomenological analysis of illness narratives, adopting object relations theory as interpretative framework consistent with previous studies (D'Alberton et al., 2012; Schattner at al., 2008; Schattner & Shahar, 2011). This is to detect possible unconscious meanings of illness and provide some insights about how people may cope with disruption through narrative, seeking "the repair and restoring of meanings when they are threatened" (Bury, 2001, p. 264), especially when the aetiological explanation of the disease remains unknown and decisive treatments are lacking. Indeed, narrative skills may allow "the doctor's and patient's understanding of the origin of the illness following the background of the problems, the reason of the illness and the whole body approach" (Taruscio et al., 2004, p. s596). Therefore, this study has clinical not just research or theoretical purposes in order to support final recommendation on the best practices. As well, it may show a broader range of practical usefulness among social and health professionals, patients with ALS and their families, and patient organizations.

2. Method

2.1 Study Participants

The illness stories written by 12 adult Italian patients with ALS (8 women and 4 men) were retrieved through the Internet-based database of the Italian National Centre for Rare Diseases, as part of a community-based participatory project promoted by the Medical Ethics Committee of the Italian National Health Service. Along with documentation, communication and training activities, the project focused on the sharing of illness experiences of people with rare and chronic degenerative diseases. The aim was to develop narrative medicine methods at the clinical

level with regard to rare and chronic degenerative diseases and to identify indicators useful to evaluate their implementation.

Textual data from the collected illness stories were overall composed of 23 pages and included 9,746 word occurrences, with a mean of 812 words per story. In detail, patients were asked to freely provide an account of their subjective illness experience, with regard to their perception of disease and its potential impact on their life. All participants gave their written informed consent to be included in the study before posting their stories.

2.2 Text analysis

A qualitative phenomenological analysis of illness stories was conducted according to Giorgi's method (Giorgi, 1975) already used in past research on chronic diseases (Schattner & Shahar, 2008). It consists in a descriptive and explorative method for thematic cross-case analysis of different types of qualitative data, such as interviews or written texts, requiring only a small number of participants and allowing the researcher to access individuals' lived experiences.

The procedure consists in a manual (i.e., paper and pencil) coding of text-based qualitative data according to the following steps: 1) reading the transcriptions several times in order to get a total impression and identify preliminary themes, i.e. the main issues/matters concerning the participants' ALS experience. Such themes are starting points for organizing data which require further elaboration with systematic reflection (from chaos to themes); 2) identifying and sorting meaning units, i.e. text fragments providing any knowledge potentially regarding the ALS experience. Related meaning units are then grouped under the same code headings, defined through an iterative process where code groups can be developed from the initial themes or newly identified from the emerging meaning units (from themes to codes); 3) collecting together meaning units through condensation, sorting the content of the previously detected code groups into subgroups and then abstracting the content of each subgroup into a condensate, i.e. an artificial quotation maintaining the original terminology applied by the participants (from code to meaning); 4) synthesizing the psychological structure of experience, transforming the condensates within each code subgroup into an analytical text accompanied by authentic illustrative quotes. For presenting the results, some final thematic areas are then defined as categories that organize and synthesize cross-case condensates, providing summaries/descriptions of the related findings (from condensation to descriptions and concepts).

In the present study, thematic areas are complemented by interpretations of the findings grounded on object relations theory as psychodynamic framework (Schattner & Shahar, 2011) paying attention to emotional functioning, unconscious meanings and conflicting motivational

states related to the psychological experience of illness. The aim is to grasp some symbolic and unconscious components, beyond the explicit meaning of reported statements, which may provide further insights about participants' conflicts, defences and repairing strategies in dealing with illness.

3. Results

The analysis resulted in three thematic areas respectively referring to: 1) the illness experience from symptom onset to diagnosis, 2) impact of illness, and 3) coping with illness. Each thematic area is described including direct quotations from participants' accounts in the presentation of findings (quotations are reported in Tables 1-3), then followed by interpretations grounded on object relations framework.

3.1 Illness experience from symptom onset to diagnosis

This thematic area refers to the initial experience of and reaction to being ill, from the time of symptom onset to communication of ALS diagnosis (Table 1). Overall, participants report the lack of consideration for early bodily signs and seem to underestimate their health-related problems, thus continuing to live a normal life. As the perceived severity of physical impairment progresses, participants start going through a prolonged stressful period of time before receiving an accurate diagnosis, until they figure out they are affected by an incurable disease.

Table 1. Examples of direct quotations regarding illness experience from symptom onset to diagnosis

"I realized that symptoms had already begun to appear since far-off time, even if I had not taken them into any consideration: since about one year before the problem with my hand, I had annoying fasciculations on the back, I woke up at night unable to swallow and was affected by painful cramps in the calves and toes [...] ALS is a travel companion that does not allow you to ignore it, calls you to order continuously and forces you to change your daily life, to draw all your weapons and put all your talents to good use in order to try to maintain your role." (story 1, female)
"Despite being aware of the severity of my illness, I never wanted to go through the trouble of investigating its origins and certainly I did not try to know its final consequences [...]I had to go through an ordeal of tribulations that lasted more than seven years during which I really did my best, without being able to stop the advance of the terrible disease that progressed rapidly [...] the evil mechanism that generates so terrible and unfortunately still irreparable failures." (story 2, male)

"I noticed that my hand did not obey my instructions well [...] In the following days I tried to lead an absolutely normal life, despite realizing that my voice was becoming more and more slurred and my legs weaker and weaker [...] After a week I talked to the doctor, who explained me the situation: masked by the cervical hernia, there was a neurological disease. I asked him whether the disease had a name, and he answered me: amyotrophic lateral sclerosis. It was an incurable and progressive disease leading to death in 3-5 years." (story 3, male)

The narrative trajectory regarding illness symbolization from symptom onset to diagnosis reveals a vivid picture of the disruption in self-representation caused by ALS. The patient's central conflict refers to the progressive loss of control on bodily experience, consistent with a process of somatic depersonalization in terms of increasing detachment from the self. Patients' initial reactions to symptom onset seem to rely on denial as a defence mechanism that prevents from evaluating the extent and the implications of one's illness and from feeling health-related anxiety. With the progress of the disease, the body does not react as expected and does not follow routine commands anymore, thus leading to the personification of ALS as persecutor working to bring about the death of the subject from within. From the time of diagnosis communication, the main defence enabled to challenge such a somatic disruption is splitting, which allows the handling of body/mind disconnection through the preservation of the good self from the incumbent evil.

3.2 Impact of illness

This thematic area refers to the impact of illness in terms of physical and psychological consequences and disease-related life changes (Table 2). Overall, participants report severe problems with mobility and speech, along with breathing and feeding, which do not allow them to lead a normal life anymore. The physical impairment is mostly associated with the perceived discontinuity between their past and present, emotionally characterised by loss of identity, sense of isolation and strong dependency on other people.

Table 2. Examples of direct quotations regarding impact of illness

"In this moment of great difficulty, not being able to communicate easily with others creates a strong discomfort to me. What is a person if s/he cannot communicate? Nothing .... because communicating is living!." (story 9, male)

"Ill people have to be disciplined and patient, infinitely dependent and passive as in the condition of those who live in a total institution. The ill person becomes a prisoner of one's own body and of the environment in which s/he lives. One remembers with difficulty the past emotions as a "normal" person." (story 10, female)

"So after a few years, my legs and arms do not move anymore, I feed through a tube, I breathe with the help of a fan and moreover I do not speak anymore. The disease has taken my words away but has filled me with thoughts and reflections." (story 12, female)

The main physical problems reported by participants refer to the impaired capacity to freely move and easily communicate with others. Mobility and speech can be intended as vital functions revealing the intentional agency in relating to reality. The ill person thus progressively becomes a prisoner of one's own body and of the environment in which s/he lives and relies on others to address one's most basic needs (e.g., feeding, washing, dressing). The feelings concerning loss of identity, sense of isolation and strong dependency on others seem to suggest a potential regression towards early stages of life, when regulation of emotional and physiological functions is almost defective. The impossibility of transforming psychic activity into communicable experiences and effective actions may thus evoke overwhelming feelings of anxiety and helplessness, featured by the prevalence of regulatory mechanisms that are externally oriented.

3.3 Coping with illness

This thematic area refers to the potential adjustment strategies enacted to cope with illness. Overall, participants report those factors or life situations that may best meet their needs and serve as psychological resources to face disease. The willingness to engage in social relationships seems to be most fruitful factor providing satisfaction and interest in life. Specifically, participants express the need to be recognized as subjects both in care and personal interactions, which are authentically based on love and mutuality, and respectful of the ill person's autonomy and decisions.

Table 3. Examples of direct quotations regarding coping with illness

"We have to enact all those behaviours that can strengthen our desire to live, therefore, create satisfaction, optimism, new positive incentives, a great willingness to participate and socialize and above all, a lot of strength to support one's own interest in life of any kind it is." (story 3, male)
"I would like to highlight that for the ill person it is important to develop the sensitivity and the ability to make friends, so to keep alive a relationship that is not based on assistance but on respect and tenderness. The exchange of thoughts, mutual help (even the ill person has something to give and to say, moreover because of the experience of suffering), allow us to have moments in which the disease seems to recede and the relationship can go back to being authentically human." (story 10, female)

"Those who take care of the ill person have to be professionally prepared to deal with the psychological aspects of the therapeutic relationship. This means to recognize the ill person as a subject and to stand by him/her respecting his/her activities and possibility to choose what, from a human point of view, is better for him/her. Nothing is more violent than being treated as an object." (story 11, female)

The relational domain appears as the most salient psychological resource for people with ALS. Beyond the relevance of social support and care relationships to cope with a chronic illness, the underlying motivations expressed by participants to engage in such relationships help clarifying repairing processes from a psychodynamic perspective. The emotional investment on the relational domain seems to ensure the recovery of a psychic vitality, which contrasts death-anxiety and allows the recognition of the ill person as an autonomous subject with one's own identity. Whereas disease progressively dehumanizes the ill person and treatment-based care contributes to confirm his/her being damaged, passive and dependent, social interactions may provide the opportunity to share and exchange with others and experience the holding of personal resources. Others may thus ensure a state of body integration through affective experiences that help rebuilding the relation between the self and the external world.

4. Discussion

Three different thematic areas have been detected from the illness stories of patients with ALS that respectively refer to the illness experience from symptom onset to diagnosis, impact of illness, and coping with illness, overall showing the biographical disruption caused by ALS as a life challenge threatening self-identity (Sakellariou et al., 2013).

The experience of illness depicts a progressive adjustment process from symptom onset to diagnosis, accordingly with an ongoing change featured by diagnostic delays and failures to recognize early symptoms, as reported in previous narrative-based studies (King, Duke, & O'Connor, 2009; O'Brien, Whitehead, Jack, & Mitchell, 2011). As well, with the worsening of physical impairment, psychic processes of personification and protagonisation are enacted to make sense of the chronic disease (Schattner et al., 2008). Illness is thus given the traits of a hidden enemy (contrasting the self that is experienced as victim) and is gradually assigned with the role of protagonist in the narrative as an internal persecutor (whereas the self is the hero facing it). Participants' initial reactions to symptom onset seem to rely on denial, reported in previous research on people with ALS (Ferro, Riefolo, Nesci, & Mazza, 1989) as a defence mechanism preventing from evaluating the extent and the implications of one's illness and from experiencing death anxiety. Whereas after diagnosis communication, as physical decay

progresses, the main defence enabled to challenge such a somatic disruption is splitting to preserve the good self from the incumbent evil, because of a body patients cannot trust (Sakellariou et al., 2013). As suggested by King et al. (2009), the numerous changes in response to progressive decline in functioning determine a strong feelings of uncertainty, not knowing what aspect of life would be lost next. Consequently, the individual may resort to splitting in order to cope with the perceived body/mind disconnection, because "the patient lives a progressive destructuration of his body image which has been integrated during the early stages of the development of the self" (Ferro et al., 1987, p. 315).

Illness is found to mainly affect mobility and speech as vital functions revealing the intentional agency in relating to reality, leading the patient to regress to a needy and dependent condition, with physical and practical needs (De Wit, 2017). Indeed, changes in levels of engagement in activities may result to the loss of valued social roles and of an adult status (Brott, Hocking, & Paddy, 2007), thus explaining most findings about the need for autonomy and search for identity expressed by patients with ALS (Bassola, Sansone, & Lusignani, 2018; Caputo, 2014; Lemoignan & Ells, 2010). Our study highlights that over time this condition of self-imprisonment (Ferro et al., 1987) may also impair the capacity to regulate internal states, thus making regulatory mechanisms as externally oriented due to the defective capacity to translate mental states into actions. Indeed, from a psychodynamic perspective, ALS can be deemed as a paradoxical disease that immobilizes the body while respecting the lucid functioning of the mind, thus triggering profound anxieties and primitive feelings of non-existence (Ferro et al., 1987). This process may explain for what reported in previous research about ambivalent feelings towards adaptive equipment or assistive technology that is experienced as both good and bad (Sakellariou et al., 2013). Indeed, being subjected to external regulation to accomplish daily activities might emotionally evoke states of non-existence, in turn contributing to reinforce splitting as a coping strategy fluctuating between idealization and devaluation towards the source of help, so to maintain control and independence.

Then, the relational domain emerges as the most relevant resource for people with ALS to cope with illness, thus confirming qualitative research findings about the relevance of social adjustment for their quality of life and meaning in life instead of perceived health status (Caputo, 2014, 2015; Fegg et al., 2010). Interpersonal relationships seem to serve as a way to recover a psychic vitality, which contrasts death-anxiety and allows the recognition of the ill person as an autonomous subject with one's own identity (Bassola et al., 2018). In this regard, the distance between caregivers' and patients' perspectives (Foley, Timonen, & Hardiman, 2016; Oh & Kim, 2017) as well as ill people's need for control over their own health care and decisions (Caputo, 2014; Lemoignan & Ells, 2010) seem to indicate the perceived risk of being treated as a mere

object of medical intervention. Healthcare's tendency to exclusively focus on physical conditions, taking care of the "evil other" as separated from the "own good" of the patient (Caputo, 2013; Carli, Paniccia, Policelli, & Caputo, 2017), may thus increase patients' anxiety, within a condition of self-imprisonment where the psychic component succumbs to body experience as internal persecutor and repairing processes are impeded.

With regard to the study limitations, given its qualitative nature, the present research study provides non-exhaustive results about the ALS experience (also because of the limited quantity of textual data) needing further investigation and can just be considered as preliminary according to a psychological clinical case study approach (Langher, Caputo, & Martino, 2017). As well, the low sample size - entirely composed by Italian participants - does not consent any generalization and does not ensure trans-cultural validity, despite their being limitations that generally affect past ALS-related narrative research. Besides, this study does not allow identifying causal relationships between ALS and narratives' themes, because of the lack of a baseline assessment and further information about participants' characteristics, medical conditions and context-related variables that may have a role in accounting their lived experiences.

This notwithstanding, this study may make a significant contribution to a psychodynamic informed research perspective when exploring subjectivity in illness experience of people with ALS. Overall, the patients' central conflict refers to the progressive loss of control on bodily experience, that is handled by means of denial and splitting defences to contrast such a process of somatic depersonalization. Indeed, defence mechanisms may play a significant role in the modulation of psychological adaptation to illness, as already demonstrated in several psychodynamic studies in further health-related fields - such as obesity (La Grutta et al., 2013), diabetes (Marchini et al., 2018) or drug addiction (Caputo, 2019a, 2019b) - highlighting the greater use of denial dynamics to protect the self, because avoidance coping may be beneficial to lessen anxiety and contrast feelings of despair and impotence (Tomai, Lauriola, & Caputo, 2018). This has also significant implications on the relationship with healthcare services, thus requiring greater understanding of patients' reactions to both diagnosis and gradual physical impairment in order to make sense of their apparently unclear attitudes or behaviours, such as shifting their focus away from decreasing health status (Fegg et al., 2010) or experiencing ambivalent feelings towards adaptive equipment (Sakellariou et al., 2013).

Besides, because the investment on interpersonal domain responds to a repairing strategy ensuring psychic vitality to rebuild the relation between the self and the external world, social and relational adjustment of people with ALS should be considered as a priority in healthcare

provision. This may contribute not only to strengthen patients' perceived social support and quality of life, but also to guarantee them biographical continuity and coherence to the self over the course of chronic illness (Harnett & Jönson, 2017). In conclusion, the research-to-practice focus represents the main strength of the present study for improving management and care planning of ALS patients. Our results may provide methodologically trustworthy informative resources about illness experience, so to develop reliable and up-to-date ALS clinical guidelines and set up consistent training activities and educational tools for healthcare professionals. Therefore, rehabilitation, narrative medicine and health psychology intervention could thus benefit from such fruitful psychodynamic insights in order to better recognize and interpret patients' perspectives, as well as to implement narrative skills in daily practice to enrich general clinical information focused on both the needs and the critical aspects of patients' lives.

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