

Psycho-educational Groups for People With Amyotrophic Lateral Sclerosis and Their Caregiver: a Qualitative Study

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Abstract

Background: Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease that strongly impacts both patients' and caregivers' lives. Only few previous studies investigated the psychosocial impact of group's interventions on ALS patients and their caregivers as well as needs they can answer.

The aim was to identify the needs of both ALS patients and caregivers who attended a psycho-educational group program, the prominent aspects of their experience, perceptions, and satisfaction.

Methods: Five patients and thirteen caregivers attended eight psycho-educational group meetings at the Respiratory Rehabilitation Unit of Fondazione Don Carlo Gnocchi, Milan (Italy) and underwent semi-structured interviews once the group meetings ended. Data obtained by group sessions' transcripts have been analysed using the Grounded Theory Paradigm (GT), while those obtained by interviews have been analysed using the Interpretative Phenomenological Analysis (IPA).

Results: The analysis of the meetings, allowed to identify seven themes and 21 sub-themes: practical advices, explanation of the pathology, recognition of emotions, adaptation, family and relationships, being caregiver of oneself and sharing. The analysis of the interviews allowed to deduce the main reasons to participate (i.e. to have information and to be able to share experiences), the positive and negative aspects of the experiences.

Conclusions: These results suggested the usefulness of psycho-educational groups into the regular clinical practice to allow patients and caregivers comparison with others in the same situation.

Background

Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease with unknown aetiology characterized by the progressive loss of lower and upper motor neurons (Chiò, Benzi, Dossena, Mutani, & Mora, 2005; Zarei et al., 2015). There are currently no effective disease-modifying therapies, management is symptomatic; death often occurs in 3 to 5 years from the onset (Brown & AlChalabi, 2017; Chiò et al., 2009; Mitchell & Borasio, 2007; Zarei et al., 2015). Care delivered by multidisciplinary team has been showed to better address the complex needs of patients (Hogden, Foley, Henderson, & James, 2017). Informal caregivers play a fundamental role in the ALS management, taking most of the responsibility (Aoun, Connors, Priddis, Breen, & Colyer, 2015; Cipolletta & Amicucci, 2015; De Wit et al., 2020).

Although there is limited information on the efficacy of group interventions, previous studies suggest the potentially positive impact of group interventions in people who is facing chronic diseases (Jensen et al., 2013; Kirk & Milnes, 2016; Macdonald & Greggans, 2010; Meade, Buchanan, & Coulson, 2017; Parkyn & Coveney, 2011). Previous studies had analysed psychological group intervention, providing some information regarding coping strategies used by people facing ALS and their caregivers (Cipolletta, Gammino, Francescon, & Palmieri, 2018; Locock & Brown, 2010; Madsen, Jeppesen, & Handberg, 2018). In particular, Madsen et al. (2018), analysed a group rehabilitation therapy for ALS people, detecting an

increased understanding of the disease and a sense of community, useful to *fight together against ALS* (Madsen et al., 2018). In their research, Locock and Brown (2010) found that, attending a support group, individuals gained both practical and social support, as well as opportunities for social comparison (Locock & Brown, 2010). Finally, the first study that analysed support group participation in Italy has been conducted by Cipolletta et al. (2018), showing that caregivers' experience is different for partners or children and that they had the opportunity to express feeling and experiences without being judged from others (Cipolletta et al., 2018).

As showed by De Wit et al. (2020), a support intervention which contains psychoeducation, mindfulness exercises and practical information could be helpful for family caregivers of people with ALS (De Wit et al., 2020)

Despite the contributions illustrated above, there is a lack of studies that examined the impact of psychoeducational groups for people with ALS and their caregivers as well as the needs they can answer during this experience. Such theory-based studies may help facilitate standardized psychoeducational intervention efforts tailored to the development of enhanced both psychological and quality of life outcomes.

The aim of the current study was to describe the development and initial implementation of a structured psychoeducational intervention in ALS, identifying the needs of both patients and their caregivers. We report preliminary results on patients and caregiver perceptions of the psychoeducational intervention's relevance to their lives and satisfaction about their attendance.

Methods

Study design

A qualitative descriptive design was used (Glaser & Strauss, 1967; Pietkiewicz, Smith, Pietkiewicz, & Smith, 2014). The study was approved by the Ethics Committee of IRCCS Fondazione Don Carlo Gnocchi of Comitato Etico Regione Lombardia, Milan (Italy) on 21th June 2018.

Participants

ALS patients and their informal caregivers attending the Respiratory Rehabilitation Unit of IRCCS Santa Maria Nascente of Fondazione Don Carlo Gnocchi, Milan (Italy), and the related outpatient clinic accesses, were recruited between June and November 2018.

They were approached by a research assistant (VAB) and provided with information about the research study. The psychoeducational program was advertised within the Unit and during the clinical appointments through verbal invitations, email and printed flyers. The opportunity to connect remotely via internet was given to patients and caregivers, but nobody accepted it. A psychological interview has been proposed to all the future participants in order to assess their suitability for participation; psychologists evaluated if there were the emotional and cognitive conditions to take part in the study as well as if

inclusion criteria were met (see Inclusion criteria). Participants choose which daily meeting take part to at their convenience (Monday or Friday meetings) and two groups have been created. Participants who expressed an interest in participating were given an information sheet, and contacted by phone to answer any queries, confirm agreement to participate and to arrange the interview. Informed written consent was obtained from all participants at the time of interview.

Inclusion criteria

Inclusion criteria for patients

- a. Definite diagnosis of ALS according to El Escorial's criteria (Brooks, Miller, Swash, & Munsat, 2000);
- b. Having received the diagnosis for at least three months;
- c. Being able to understand and to communicate what happens;
- d. ECAS (Edinburgh Cognitive and Behavioural Amyotrophic Lateral Sclerosis Screening) > 105 (Siciliano, Trojano, Trojsi, Greco, & Santangelo, 2017);
- e. Absence of Frontotemporal Dementia (FTD).

Inclusion criteria for caregivers

- a. Caregiver of a person with ALS;
- b. Between 18 and 85 years old;
- c. MMSE > 24 (Measso et al., 1993).

Procedure

Time and Setting

Between December 2018 and July 2019 two psycho-educational groups for people with ALS and their caregivers were conducted at the Respiratory Rehabilitation Unit of the IRCCS Santa Maria Nascente of Fondazione Don Carlo Gnocchi, in Milan (Italy). Each group met for a total of nine monthly sessions, of one hour and half/ two hours each.

Psychoeducation program

A psychoeducation program was developed and delivered by two psychologists at the Unit mentioned above, characterized by specialty trained staff, therapeutic programming, and specific family involvement. The program was facilitated monthly on-site by a psychologist (EV) and a professional of the multidisciplinary team. A program logic model which illustrates the linear flow, the involved professionals, priorities and topics is shown in Table 1.

Table 1
Group meetings

<i>Session</i>	<i>Date</i>	<i>Professional</i>	<i>Topic</i>	<i>Structured content</i>	<i>Key component</i>
1	December 2018	Psychologist	Presentation of the project.	<p>Presentation of the aim of the psycho-educational group project</p> <p>- What a group is useful for</p> <p>-Key point of a psychoeducational group.</p>	Opening
2	January 2019	Psychologist	First knowledge of participants and challenges.	<p>Participants' presentation to the others.</p> <p>Feedback and problem-solving:</p> <p>-Dealing with triggers</p> <p>-Planning for a challenging behaviour</p> <p>-Making action plan.</p>	Action planning
3	February 2019	Case manager	Problems about caring of a person with ALS: who to contact?	<p>-The case manager: who is and what he does in the hospital ward.</p> <p>- Explanation of the activities carried on at the Respiratory Unit to assess patients' and caregivers' needs.</p>	Psychoeducation

<i>Session</i>	<i>Date</i>	<i>Professional</i>	<i>Topic</i>	<i>Structured content</i>	<i>Key component</i>
4	March 2019	Psychologist	Sharing emotions	<p>Problem solving:</p> <ul style="list-style-type: none"> -Care partner's challenging behaviour: making decisions -Getting help -Stopping unhelpful thinking -Making an action plan 	Behavioural intervention
5	April 2019	Pulmonologist	Respiratory and motor problems common in ALS	Education and advices regarding patients' difficulties linked to the respiratory function.	Psychoeducation
6	May 2019	Respiratory physiotherapist	Use of physiotherapy tools	Explanation of the main physiotherapy respiratory tools: non-invasive ventilation (NIV) and cough machine.	Psychoeducation
7	May 2019	Nurse	Home care	<p>Orientation to the home care situation:</p> <ul style="list-style-type: none"> -Helpful thinking; -Medication usage; - Finding and hiring help; -Future planning and legal issues. 	Psychoeducation
8	June 2019	Psychologist	Meeting stress	Orientation to the full stress reaction and physical, emotional and cognitive sequelae; education regarding enduring and chronic stress models.	Modelling

<i>Session</i>	<i>Date</i>	<i>Professional</i>	<i>Topic</i>	<i>Structured content</i>	<i>Key component</i>
9	July 2019	Psychologist	The end of the journey: what will we bring at home?	Reviewing difficult care partner emotions; working with systems/providers; communication skills; looking back and planning for the future; closing.	Conclusion

Program aims were improving emotional well-being; increasing peer support and awareness; increasing knowledge and information about the illness and its challenges.

Data collection

Demographic data were collected to describe the sample. Each group session was audio-recorded and transcribed verbatim, then these transcripts have been used to investigate participants' needs. Observations and points of relevant information during and after the sessions filled in field notes. Moreover, a semi-structured and iterative interview guide was used at the end of the program to explore perceptions and satisfaction of joint attendance (Table 2). Field notes completed and prompted questions for future developments. Interviews lasted approximately 15 minutes, were conducted by a research assistant (VAB) thanks to a phone call, audiotaped and transcribed verbatim.

Table 2
Guide interview

<i>Questions</i>
1) Why did you choose to participate to psycho-educational groups' meetings? Why did you choose to interrupt groups' participation?
2) Which elements of groups' participation did you find positive? And which elements did you find negative?
3) Which advices would you suggest improving the psycho-educational groups' experience?
4) Are you satisfied with groups' participation?

Data analysis

Descriptive statistical analyses were performed using SPSS Version 24.0 to summarise the demographic and clinical data, characteristics of the caregivers and patients.

Qualitative data were analysed using NVivo software (Version 12, QSR International→).

Analysis of transcripts data considered both the group meetings and the semi-structured interviews: the two transcripts have been separately analysed in order to achieve the two different aims.

Data from sessions were analysed using dimensional analysis and constant comparative method, which are designed to be used with text in Grounded Theory (Corbin & Strauss, 2014; Glaser & Strauss, 1967). These strategies allow the two researchers (EV; VAB) to independently identify both implicit and explicit dimensions of relevant needs and concepts. Data were coded using open, axial and theoretical coding strategies (Charmaz, 2006). The comparative method allowed to detect similarities and differences in the levels of analysis (Glaser & Strauss, 1967).

Analysis of the semi-structured interviews followed Interpretative Phenomenological Analysis (IPA) in order to better understand patients' and caregivers' experiences and perceptions of the program (Pietkiewicz et al., 2014). Each interview was read several times to gain an overall impression of it. Researchers made notes in margins about the content and the language used by the interviewed. Phrases, key words and idiosyncratic feature of speech were highlighted. On re-reading the interviews notes have been transformed in themes and sub-themes. Finally, the themes obtained were ordered in a table.

Content analysis of audio recordings, process notes and exit interviews were conducted for triangulation. Discrepancies in theme categorization and coding were addressed by a third researcher (FP) in both the GT and IPA analysis.

Results

Characteristics of sample

Thirty patients and caregivers were approached and assessed to take part to the study: 9 refused to participate, 3 have been excluded due to cognitive impairment (ECAS < 105) and 18 joined group's attendance. The sample included 5 ALS patients (Table 3) (one had a bulbar onset, one a respiratory one and three a lumbar onset) and 13 caregivers (Table 4) (7 were partners and 6 children of the patients with ALS).

Table 3
Patients' characteristics

<i>Demographics characteristics</i>	<i>Patient (n = 5)</i>
<i>Age</i>	67.2 (11.16)
Mean (SD)	
<i>Gender</i>	
Male	3
Female	2
<i>Months since diagnosis</i>	20.4 (21.6)
Mean (SD)	
Tracheostomy	1
PEG	1
<i>ALSFRS-R</i>	42.47 (3.71)
Mean (SD)	

Table 4
Caregivers' characteristics

<i>Demographics characteristics</i>	<i>Caregivers (n = 13)</i>
<i>Age</i>	
Mean (SD)	61.38 (14.35)
<i>Gender</i>	
Male	5
Female	8

Themes and Sub-themes emerged from transcripts

The main findings emerged from the psychoeducational program sessions were organized into 7 key themes and 21 sub-themes (Table 5). The key themes represent the need expressed by participants, among which the need for practical advices and the need for an explanation of the pathology were the most frequent. Table 5 also shows the most frequently used words and the percentage of covered text for each theme.

Table 5
Themes and Sub-themes emerged from groups 'analysis

Themes	Most frequent word	Percentage of covered text	Sub-themes	Description	Citation
Practical advices	Person (n = 29)	18% of the second; 19% of the sixth	How to move to the rehabilitation ward	Advices about how to get requests to professional (nurse, case manager or physician) as quickly as possible, especially during the emergencies.	<i><< Now I must build the practical situation with my mother, so I need practical advices>></i> (I.D.1, Caregiver)
			Patient care management at home	Caregivers were concerned about patient care management at home: difficulties with feeding and use of NIV. They frequently discussed about the possible solutions to find out support of home assistants and associations.	
			Interpersonal relationship	Problems in interpersonal relationships concerned how to behave with home assistants, with who it was important to balance between an exclusively work relationship and a family or friendship relationship.	
Explanation of pathology	Patient (n = 49)	35% of the fourth; 27% of the second one	Amyotrophic Lateral Sclerosis	Even if the diagnostic label <i>ALS</i> is the same for all patients, symptoms and progression pathways showed are very different between subjects. Participants reported their diagnostic experiences, and their problems with diagnostic communications.	<i><< Maybe is better if you first explain it to us first and then we ask you questions>></i> (I.D. 7, Patient)

Themes	Most frequent word	Percentage of covered text	Sub-themes	Description	Citation
			Taking care of the patient	Each of the professionals who took part to group meetings explained which his role within the multidisciplinary team was. Participants appreciated the issues about humanization of care, feeling considered as people and respected in their dignity.	
			Equipment and economics help	Economic measures and the helps made available from the Italian State or Regions to help patients with ALS and their caregivers.	
			Emotions linked to ALS	Education about the emotional components linked to ALS: participants have been invited to make a distinction between emotions and thoughts.	

Themes	Most frequent word	Percentage of covered text	Sub-themes	Description	Citation
Recognition of emotions	Fear (n = 9)	6% of the third; 7% of the seventh	Most frequent emotions	Fear was referred by patients who often linked it to the inability to control the disease progression, and caregivers' burden (they were scared about the idea that they could compromise caregivers' physical or psychological health). Anger was often linked to the ALS and his progression by both patients and caregivers. Some caregivers (n = 3) referred that they were often angry with the patient they care for; other caregivers (n = 4) referred that they are not. In the first case, caregivers often linked angry to guilt because they recognized that patients have no blame in their own condition. Sadness was very common for patients who saw their body deteriorating. Caregivers felt patients' sadness and they often tried to console him, even if this was very difficult. Shame was often linked to the worsening of patient's health condition.	<<Emotionally it is exhausting>> (I.D. 3, Caregiver)
			Legitimize emotions	A difficulty to accept emotions was common between participants. This made it easier to legitimize this difficulty and negative emotions as normal issues.	

Themes	Most frequent word	Percentage of covered text	Sub-themes	Description	Citation
Adaptation	Disease (n = 35)	9,5% of the fifth; 9% of the first	Acceptance of the pathology	Participants often referred that was not easy to accept this illness. Psychologists often invited patients and caregivers to focus on the difference between acceptance and adaptation. It is impossible to accept ALS, the only thing you can do is to adapt to.	<< <i>I don't accept my illness.</i> >> (I.D. 2, Patient)
			Elaboration of a loss	Participants often expressed a difficulty in accepting the loss of their daily routine, as it was before the onset of ALS. It was very difficult to accept that it is no longer possible to walk on your own legs or eat everything you want to. Caregivers instead referred that it was a problem to empathize with patient's feeling about loss of functionality. Caregiver often used negation as defence mechanism.	
			How to fight ALS	Everyone finds his own strategies: some cited <i>living day by day</i> as a good strategy; it consists on content of what it is still possible, of the activity patients can still perform without worries about patient's worsening; other used <i>isolation</i> as a strategy to face the challenges posed by ALS.	

Themes	Most frequent word	Percentage of covered text	Sub-themes	Description	Citation
Family and relationships	Brother (n = 28)	13,5% of third; 12,5% of the seventh	Family	In some families (n = 3), the duty of care was equally divided between caregivers; in these families, relationships were better, and no family member felt alone in the fight against ALS. In other cases (n = 2), this division of tasks was not possible, and it created pain and suffer among family members. It seems that care of the seek family member has awaked an old pain an old rancour in these families.	<i><< Thanks to the disease I have seen who a friend is and who is not. Many got away, both relatives and friends.>></i> (I.D. 2, Patient)
			Friendship	After the onset of ALS also friendly relationships changed. Some (n = 3) reported that they have friends who take care of the patient, trying to encourage him. Others (n = 4) referred a loss of friends after the onset of ALS; this was often reported sadly by participants and linked to the friends' difficulty in accepting patients' illness and patients' loss of functionality.	
			Loneliness and choice of isolation	For some (n = 4) loneliness was an uncomfortable condition; experienced as something negative and it seemed that there was no one to count on. Others (n = 4) told about loneliness as something chose to protect themselves from the reactions that other people might show; isolation seems to be functional to protect against the feeling of shame.	

Themes	Most frequent word	Percentage of covered text	Sub-themes	Description	Citation
			Exit from home	Caregivers often complained about patients who do not want to leave their houses. The group was useful to show how similar this difficulty was present in many patients and to normalize the situation.	
Being caregiver of oneself	Must (n = 10)	4% of the first; 4% of the third	Need to protect oneself and to find time for oneself	Caregivers often showed the need to protect their psychological world from a situation perceived as damaging for their own physical and psychological health. They reported a severe difficulty in taking time for themselves, as if they were stealing this time from patient care.	<< <i>It is important to protect yourself. It is important to have the opportunity to take care of yourself. You cannot delate yourself.</i> >> (I.D. 20, Psychologist)
			Duty of care	Caregivers often felt obliged to spend time, which could be spent on self-care, with the patient. Then, when they finally succeeded in having time for themselves, guilt took over.	
Sharing	Group (n = 33)	14% of the third; 10% the sixth one	Sharing patient care	Since it was impossible to survive with the burden of patient care, many (n = 5) caregivers reported a need of sharing care with others. Group has been recognized as a safe place where it was possible to ask for helps and to receive it, feeling less isolated in the caring process.	<< <i>If I hadn't had the opportunity to confront with people who live my same situation and to share with them, maybe I would have gone out of my mind!</i> >> (I.D. 1, Caregiver)

Themes	Most frequent word	Percentage of covered text	Sub-themes	Description	Citation
			Sharing life experiences and difficulties	Participants often described life experiences, reporting experiences about the diagnostic process and the difficulties with diagnostic communication, with the adaptation to the disease and with the use of some tools as NIV.	
			Sharing as an opportunity	Participants understood that they were not alone in this situation. In this process, a key point was the help of professionals who gave information and advices to better cope with the ALS. They made participants feel less alone and more supported.	

Connections between themes also emerged. First, the themes *Recognition of emotions* and *Family and Relationships* were both most present in the third and the seventh group meetings; it also emerges that the emotional theme and the relational theme are present together in meetings one, two, three, five, six, seven and eight; while *Family and Relationships* is present alone in the fourth meeting. That could suggest a link between the two themes (Fig. 1). Secondly, caregivers often linked the theme *Being caregiver of oneself* to the relational one, because they find it extremely difficult to maintain their own relationships after the onset of ALS in their relative, this connection is shown in Fig. 2.

Themes and Sub-themes emerged from semi-structured interviews

Interviews' analysis allowed to understand participants' perceptions and satisfaction about group meetings. The 3 themes and 4 sub-themes emerged from analyses are shown in Table 6. The emerged themes concerned the reasons why patients and caregivers took part in the psychoeducation program and the positive/negative aspects of participation. Moreover, participants generally felt satisfied with group's attendance and expressed appreciation for this activity. Some (n = 6) also expressed the will to carry on group meetings.

Table 6
Themes and sub-themes emerged from interviews

Theme	Percentage of covered text	Sub-themes	Description
Reason for the choice to participate/leave the group	20%	Reason for participating	<ul style="list-style-type: none"> - Seek information about the disease and the disease progression or about patient care (n = 6); - Confront with others who are all in the same situation (n = 3); - Desire for a comfortable place to share emotions and difficulties (n = 2); - Share a route with the patient they care for (n = 2); - Need of a place to be listened to without being judged (n = 2).
		Reasons for leaving	<p>The reasons why participants have left group's attendance could only be asked in one single case. This person referred that she was forced to interrupt group's attendance because of an extremely negative emotional reaction after the first two group meetings and because of the worries about what other participants could think listening her stories about her husband's disease (this patient was in a severe ALS condition, more severe than the other participants' one).</p>
Positive and negative aspects	27%	Positive aspects	<ul style="list-style-type: none"> - Opportunity of sharing and of support that the group can provide; - The big amount of information shared in the group; - The group could be a reference point, that can help in facing difficulties.
		Negative aspects	<ul style="list-style-type: none"> - The difficulty in participating in a group in which levels of disease progression were different. Most of the conversations, in fact, were about disease progression and listen to this was very difficult for patients at the first stage of ALS. Participants often referred that they were distressed after group meetings. - The joint participation of patients and caregivers.

Theme	Percentage of covered text	Sub-themes	Description
Which advices to improve?	8%		<ul style="list-style-type: none"> - Participation of other professional figures that could be important in ALS management, such as a nutritionist and an otorhinolaryngologist which could provide important information. - Restrict participation only to caregivers in order to inform them about the disease and its progression more in detail.

Discussion

The present study explored the needs emerged in psycho-educational groups for patient with ALS and their caregivers as well as their experiences of participation. Analysis of the group sessions and of the interviews showed that many participants chose to attend the groups to find information about their own illness or their caregiver's one, as also highlighted in previous studies (Madsen et al., 2018; Passoni et al., 2014). Having received information about ALS and ALS's progression was a crucial point, especially for caregivers, who referred to feel more confident and peaceful after group participation. Passoni et al. (2014) also highlighted this point, showing that when caregivers were sufficiently informed about their patient's illness, they felt less anxious. There was no previous literature on why participants leave groups for patients with ALS and/or for their caregivers; this was a new element proposed by the present study.

Practical advices was one of the emerged themes and one of the participants' most appreciated element, as Locock and Brown had previously showed (Locock & Brown, 2010). Locock and Brown (2010) and Passoni (2014) highlighted the importance of sharing in a group composed by people that live a same situation. This theme emerged also in the present study both as a frequent topic in the transcripts and as a positive aspect reported in the interviews (Locock & Brown, 2010; Passoni et al., 2014). Practical advices (18% of covered text in session 2 and 19% in session 6), Explanation of pathology (35% of covered text in session 4 and 27% in session 2) and Sharing (14% of cover text in session 3 and 10% in session 6) represented the most common topics participants told about; so, they probably were the basic themes, respect to which the others were consequent. Previous studies didn't analyse much the familiar and relational theme, which instead was analysed by the present study. Locock and Brown focused on *Isolation* as a choice made by patients with ALS to protect themselves from negative emotions, as shame. This theme also emerged from the analysed group sessions (Locock & Brown, 2010). Moreover Cipolletta et al. (2018) analysed support groups for caregivers and found that caregivers often referred to patient care as a duty. The present study, which highlighted the *Duty of care* as a sub-theme, was coherent with this previous qualitative research (Cipolletta et al., 2018). *Adaptation* was the last important theme in this study. Previous literature about group interventions for people with ALS and/or their caregivers had analysed this theme. Marconi et al. (2016) showed that a meditation training for people with ALS and their caregivers improved their acceptance of the disease and the restrictions due to symptoms (Marconi et al., 2016). Later, Cipolletta et al. (2018) referred to the caregivers' acceptance of

ALS; their groups were not organized for patients, so they didn't refer to patient adaptation to the illness (Cipolletta et al., 2018).

There were no studies in previous literature that investigated aspects that patients found negative in participating to group's sessions, nor about advices to improve the group's meetings.

Strengths and limitations

One of the most relevant strengths in this study was the novelty of the topic because there was no previous literature about psycho-educational group for people with ALS and their caregivers. Another positive element was the nature of the analysed data, which came both from transcripts of group meetings' sessions and from interviews. As regard interviews, their novelty was represented by questions about reason why participants decided to participate or to leave the group.

The main limitation of this study was the limited number of participants and the restricted geographic area from where they come from. It was not possible to interview all the participants, so we hadn't a feedback from all patients and caregivers. Having more data to compare would have made it possible to strengthen the conclusions.

Future implications

There is a need of further studies to better understand the experience of participation in groups for people with ALS and their caregivers. These studies might be conducted with a larger sample and in different geographic areas or using a quantitative research method. It could offer the possibility to make confronts between different times about important issues as anxiety, quality of life and caregivers' burden. It could be useful also administering a semi-structured interview before the beginning of the group's meetings to better understand participants' expectation. Last, future research might compare the different themes that could emerge in other types of groups for patient with ALS and/or their caregiver.

Clinical and Research implications

The intervention based on psycho-educational groups represents a possible help for patients and caregivers facing ALS. Perceived benefits support the use of the program as an intervention and identified challenges can be used to tailor it to improve inclusivity and manage group dynamics. Indeed, an intervention that keeps together the element of support and the element of multidisciplinary could be very useful in addressing the complex needs of ALS patients and their caregivers.

On the other hand, our knowledge about psycho-educational groups for people with ALS and their caregivers need to be expanded. This study showed the difficulties found in carrying on researches that involves participants who fight against a neurodegenerative illness. Future researches are essential to verify the efficacy of this type of intervention.

Conclusions

This study of psycho-educational groups for patients with ALS and their caregivers indicates the utility of this type of intervention in supporting people who fight against ALS for two main reasons: first for the element of psychoeducation provided by professional; second for the possibility of sharing experiences and emotions with people in the same situation.

List Of Abbreviations

Amyotrophic Lateral Sclerosis, ALS; non-invasive ventilation, NIV; Grounded Theory, GT; Interpretative Phenomenological Analysis, IPA; percutaneous endoscopic gastrostomy, PEG; Revised Amyotrophic Lateral Sclerosis Functional Rating Scale, ALSFRS-R; ID: Identifier (of the participant)

Declarations

Ethics statement

This study was conducted in accordance with the principles of Helsinki Declaration and approved by the Ethics Committee of IRCCS Fondazione Don Carlo Gnocchi of Comitato Etico Regione Lombardia, Milan (Italy) on 21th June 2018. All the participants were informed that the meetings would be audio-recorded. If they accepted, they were invited to read and sign in the Consent Form for data collection and pseudonyms were used to preserve their anonymity.

Consent for publication

All the participants provided written informed consent for publication.

Availability of data and materials

The datasets generated during and/or analysed during the current study are available from the corresponding author on a reasonable request.

Competing Interests

The authors declare that they have not competing interests.

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The authors received no specific funding for this work.

Authors' contributions

EV designed the study; VAB together with EV and FP analysed the data and interpreted the results. VAB and EV drafted the manuscript and FP and PIB critically revised it. All authors approved the final version of the manuscript, they are accountable for all aspects of the accuracy and integrity of the manuscript in accordance with ICMJE criteria.

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Figures

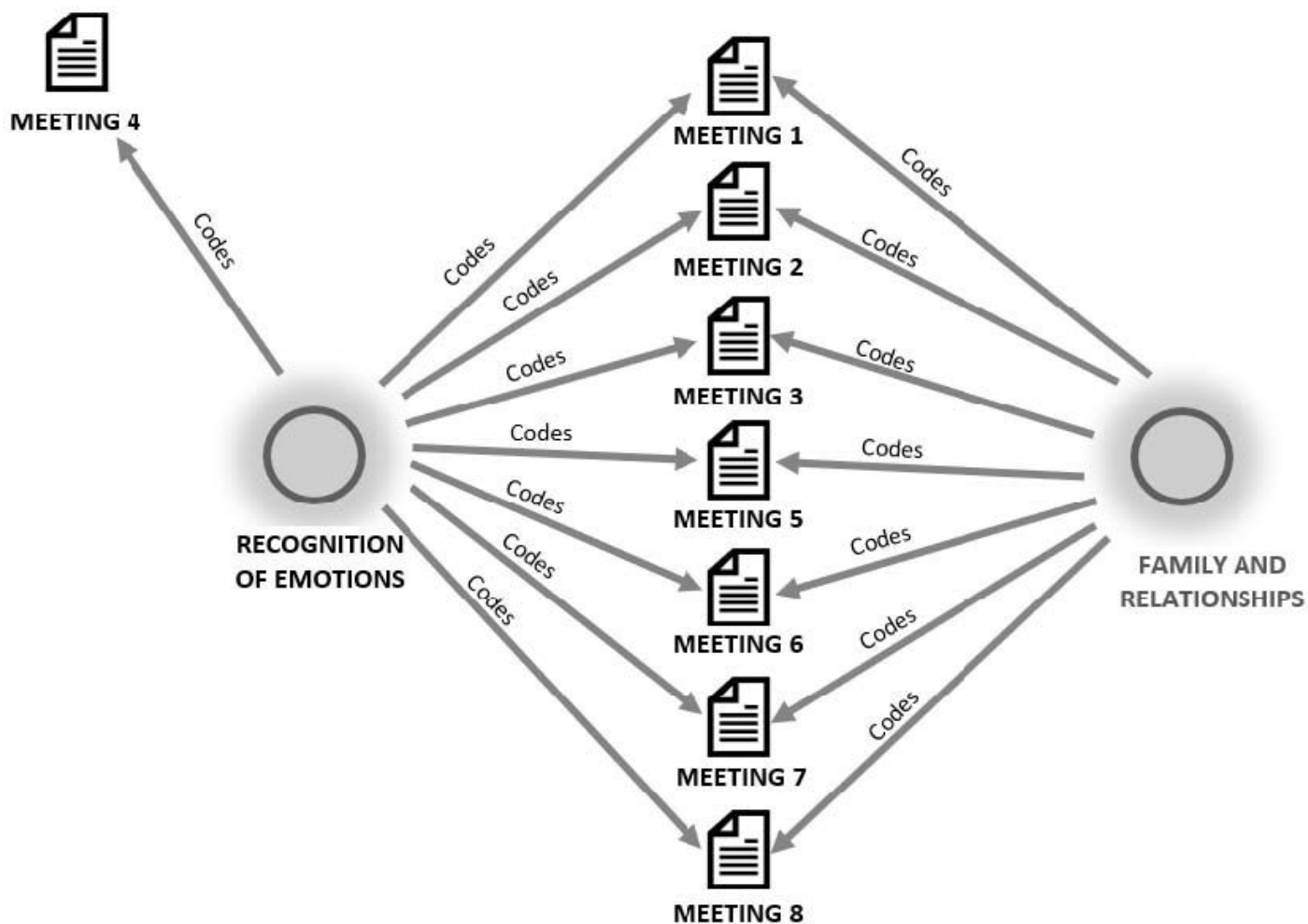


Figure 1

Comparison between Recognition of Emotions and Family and Relationships

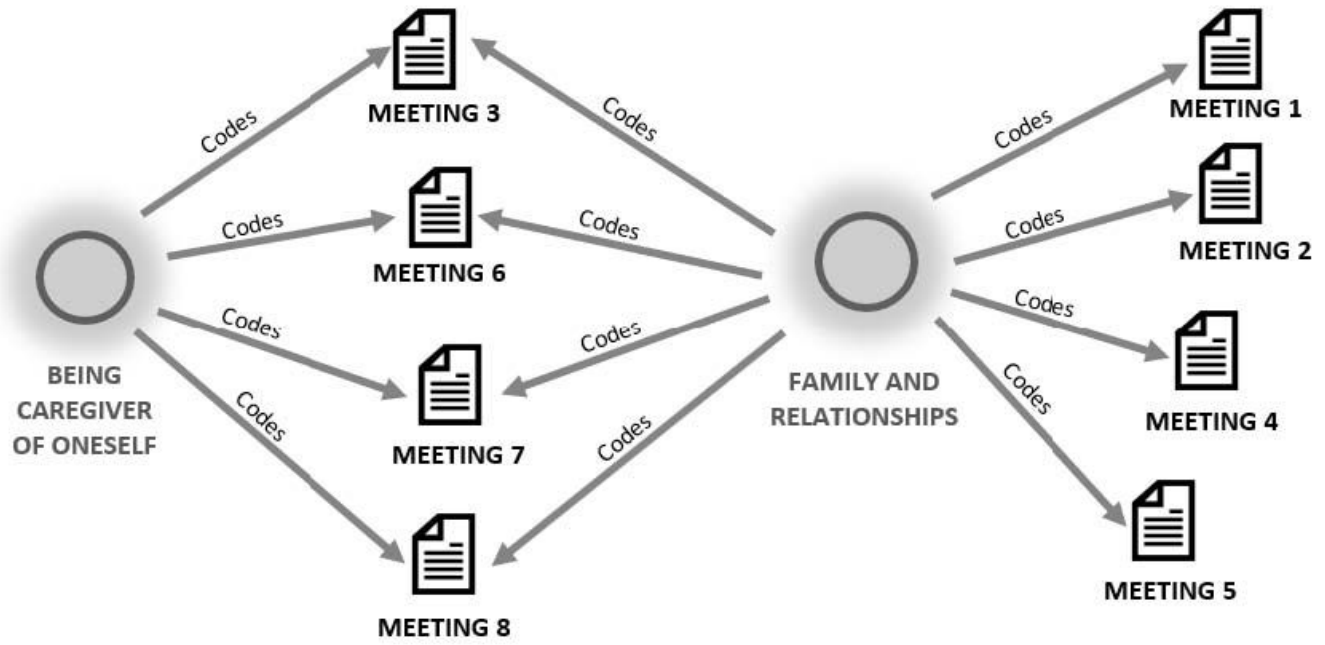


Figure 2

Comparison between Being Caregiver of Oneself and Family and Relationships