


BMJ Open Multicentre narrative research on major depression to integrate the experiences of patients, their caregivers and healthcare providers in Italy

Paola Chesi ¹, Claudio Mencacci,² Matteo Balestrieri,³ Maurizio Pompili,^{4,5} Salvatore Varia,⁶ Ubaldo Sagripanti,⁷ Luigi Reale,¹ Maria Giulia Marini¹

To cite: Chesi P, Mencacci C, Balestrieri M, *et al.* Multicentre narrative research on major depression to integrate the experiences of patients, their caregivers and healthcare providers in Italy. *BMJ Open* 2022;**12**:e052744. doi:10.1136/bmjopen-2021-052744

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2021-052744>).

Received 23 April 2021

Accepted 01 June 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to

Paola Chesi; PChesi@istud.it

ABSTRACT

Objective This research aimed to investigate the experience of major depression by integrating the perspectives of patients, caregivers and healthcare providers through narrative-based medicine (NBM) to provide new insights to improve care relationships.

Design and setting The research was conducted in 2019 and involved five Italian psychiatric centres and targeted adult patients, their caregivers and healthcare providers to address data source triangulation. A sociodemographic survey and a narrative plot, based on Natural Semantic Metalanguage were collected. Narratives were analysed through NBM classifications, NVivo software and interpretative coding.

Participants Thirty-six patients with a diagnosis of major depression, 27 caregivers and 33 healthcare providers participated in the research.

Results Among the 96 collected narratives, 'lonely' was the word patients used most frequently, while 'sad' and 'lifeless' were used most respectively by caregivers and healthcare providers. A positive care relationship was crucial for 84% of patients in relation to their care pathway, and nature (36%) and the arts (28%) were the most frequent resources. Caregivers expressed feelings of powerlessness and inadequacy, and 21% of them reported a declining social life while providing care to a loved one with depression. Thirty-one percent of mental health professionals experienced difficulties in their first encounter with patients; however, their emotions progressively moved towards trust and satisfaction. Furthermore, 89% of patients and healthcare providers and 58% of caregivers evaluated writing the narrative to be a positive experience.

Conclusion Findings suggested the possible role for language in understanding major depression, thereby improving care relationships between patients and physicians. Care pathways might also be more attentive to caregivers, to reduce their risk of burnout. Finally, narrative medicine could be integrated with the care pathway as an additional space of expression, dialogue, reflection and development of empathy.

INTRODUCTION

With 300 million people diagnosed with depression worldwide, the WHO ranked

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The research integrated perspectives from patients, caregivers and healthcare providers.
- ⇒ The narrative-based medicine approach allowed new insights.
- ⇒ Participants did not equally represent all levels of severity for major depression.
- ⇒ The research involved a limited number of centres of care.

depression as the single largest contributor to global disability and the largest contributor to suicide deaths, which number close to 800 000 per year.¹

Major depressive disorder involves changes in mood, interests, pleasure and cognition lasting at least 2 weeks. Appetite disorders, sleep disturbances, energy loss and diminished self-esteem can also occur.² The aetiology of the disorder is multifactorial, and environmental factors are strongly associated with the risk of developing major depression: abuse during childhood,³ absence of a partner, negative life events (eg, illness or grief), financial or social problems and unemployment.⁴

Major depression occurs approximately twice as frequently in women than in men and affects one in six adults in their lifetime. Its course varies considerably in remission and chronicity; however, around 80% of patients with remittance experience at least one recurrence in their lifetime. Heritability is approximately 35%.⁵ The most common management strategies comprise psychotherapy and pharmacological treatment, although the significant heterogeneity of interventions depends on clinical severity, course, comorbidity and treatment response in patient prognosis.⁶

Stigma, either towards oneself or from other people, can lead to suffering in silence, resulting in undisclosed symptoms, avoidance behaviours and delayed help-seeking.⁷⁻⁹ Furthermore, the disease can imply consequences for caregivers as well, including possible distress, anxiety, and depression.¹⁰⁻¹²

Previous studies suggested that a narrative approach to therapy could be fruitful in the treatment of depression, improving the understanding of the living with this condition and physician empathy.^{13 14}

Narrative-based medicine (NBM) refers to relationships between the healthcare professional and the patient, from the collection of information on events before the disease, to how it has been diagnosed, with a keen emphasis on the psychological, social and ontological implications for the patient.¹⁵ In research, NBM suggests potential interventions for a specific condition and its care pathway by integrating the point of view of all actors, including healthcare professionals and caregivers, with the twofold aim to mediate the patient's context and understand their perspective.^{15 16} While evidence-based medicine (EBM) concentrates on clinical processes and problem-solving, NBM includes the personal experience in coping with distress.¹⁷ The integration of EBM and NBM provides clinicians with fresh methods to strengthen their clinical practice with narrative competencies.¹⁸ WHO recommends the use of narrative research to improve healthcare policies at the level of the individual, the health professional, the healthcare organisation and the healthcare system'; in addition, the collections of multiple perspectives are encouraged.¹⁹ NBM can be applied to four fields of care:²⁰

- ▶ Education to develop healthcare professionals' narrative competencies.^{21 22}
- ▶ Clinical practice to facilitate efficient and personalised care pathways.^{23 24}
- ▶ Research to investigate new elements to improve services of care.²⁵
- ▶ Communication to inform, sensitise and increase awareness.^{26 27}

Although the application of NBM to psychiatry and mental health has been increasing, literature investigating simultaneously patients with major depression, their caregivers and healthcare professionals is lacking. The present research aimed to investigate the experience of major depression in Italy through the analysis of narratives and the integration of these three target groups' perspectives.

METHODS

Research design and setting

The research was conducted in 2019 and involved the patients association National Observatory on Woman's Health (ONDA), and five Italian public Psychiatric Centres—namely two general hospitals, one hospital-based centre and two local healthcare services—equally representing northern, central and southern Italy: the

Mental Health Department at Azienda Ospedaliera Fatebenefratelli e Oftalmico (Milan), the Psychiatric Clinic at Health-University Friuli Central Authority—University of Udine (Udine), the Department of Psychiatry at Sant'Andrea Hospital—La Sapienza University (Rome), the Mental Health Department at Palermo Health Authority (Palermo) and the DSM3 Department at Marche Health Authority (Civitanova Marche). All the referents of the association and the Psychiatry centres composed the Steering Committee of the research and underwent training conducted by scholars from ISTUD on NBM and the project aims, design and data collection tools.

A diagnosis of major depression and a clinical follow-up in one of these centres represented the patients' eligibility criteria; no other inclusion criteria were employed, except for the willingness to share their experience by writing, and the ability to communicate in Italian.

Data collection

Data collection tools were proposed by three NBM researchers from ISTUD, and then discussed within the project multidisciplinary Steering Committee.

A sociodemographic survey and three different narrative plots, namely plots related to the illness experience, were addressed to the three target groups (online supplemental material). These plots were structured by using the Natural Semantic Metalanguage (NSM), which is based on 65 semantic primes, empirically identified as concepts universally present in languages, and a set of their combinatorial properties. Researchers chose to use NSM assuming that a neutral, culture-independent metalanguage might facilitate the expression of individual experiences and allow a confrontation between them.^{28 29}

Narrative stimuli were used to ask the patients to describe their experiences with major depression, from the first symptoms they noticed in the past, moving towards the present until their perspectives on the future. The caregivers' narrative plot included another section to collect their experiences with caregiving, while the healthcare providers' narrative plot collected information on their experiences during the care relationships with the corresponding patients.

Narratives were integrated with the patients' Hamilton Depression Rating Scale, which measures the severity of depressive symptoms differentiating among normal cases (absence of depression), mild, moderate and severe depression.³⁰ Clinicians supplied the corresponding score for each patient. This integration aimed to individuate possible differences in narratives among levels of major depression.

From March to September 2019, clinicians from the five medical centres directed the participants to the dedicated website <https://www.medicinanarrativa.eu/fuoridalblu>, in which, after being informed on the project design and purpose, they could write their narratives. A coding system was developed to allow triangulation among patients, their caregivers and healthcare professionals while maintaining anonymity: an alphanumeric

code identifying the psychiatric centre and the target group was assigned by clinicians to patients and their caregivers so that researchers could triangulate the narratives without knowing the identity of responders. Therefore, data and narratives were collected anonymously through the Survey Gizmo online survey platform (www.surveygizmo.com); at the end of data collection, raw and anonymous data were downloaded as an Excel spreadsheet (Microsoft, Redmond, WA, USA).

Patient and public involvement

ISTUD researchers developed the research questions moving from the healthcare professionals' interest in narrative medicine as a tool to improve the care relationship with patients with major depression and caregivers. Moreover, ONDA association expressed the intention to promote the research to collect narratives from people suffering from major depression. Patients did not participate in developing the research design and tools and were not engaged in interpreting and discussing the results. They were invited to participate in the narrative activity from their medical centres, and, at the end of the research, they could attend the online presentation of the results, or watch the video of the presentation uploaded on the project website after the dissemination event. Patients were not involved in the writing or editing of this manuscript.

Ethical considerations

The research was performed in accordance with the principles of the Declaration of Helsinki. The materials and methods of analysis were agreed on by the project Steering Committee.

All participants were informed of the research aim and submitted their narratives voluntarily. Written informed consent was obtained in compliance with current Italian data privacy laws³¹ and the General Data Protection Regulation of the European Union 2016/679.³² No patient-sensitive data were reported.

The Ethical Committee of the Mental Health Department at Azienda Ospedaliera Fatebenefratelli e Oftalmico (Milan) approved the project.

Data analysis

Researchers analysed the sociodemographic survey through descriptive statistics. Participants' narratives were entered into the semantic evaluation software NVivo 10 (QSR International, Melbourne Australia)^{33,34} for coding and analysis. Then, researchers applied Kleinman's classification, which distinguishes between disease-centred, illness-centred or sickness-centred narratives: specifically, disease narratives focus on the clinical evolution of a condition, using highly technical language, whereas illness narratives highlight an individual's emotional and relational experiences in an open and flowing narration; sickness narratives reflect society's perception of a given condition.¹⁷

The analysis investigated also coping strategies, considering active coping as the process of trying to remove or circumvent a stressor or to ameliorate its effects: planning, seeking for support or acceptance, can activate coping, while elements such as denial or disengagement can deactivate coping strategies.³⁵

Moreover, researchers traced metaphors related to major depression that emerged within the narratives, in the effort to uncover spontaneous meaning associations used within daily language.

Researchers analysed narratives both as individual respondents and through triangulations to evaluate similarities and differences.

Researchers shared the results from the analysis with the Steering Committee to collectively address emerging issues and data interpretation and followed the Standards for Reporting Qualitative Research reporting guidelines.³⁶

RESULTS

Sociodemographic characteristics

Overall, 96 narratives from people with major depression (n=36), their caregivers (n=27) and their healthcare providers (n=33) were collected. The coding system allowed for 27 triangulations to be individuated, which were narratives about the same case from the three perspectives, plus six couples composed of patients and healthcare providers (without caregivers) and three individual testimonies from patients (without any caregivers and healthcare providers).

Patients and caregivers showed similar median ages, of 54 and 50 years respectively, while the healthcare professionals presented a median age of 40 years. Among the target groups, there were more women than men (table 1).

Findings from people with major depression

The main cited causes of depression were the patients' or family members' experiencing other diseases (17%), job issues (15%) and family or affective problems (both 13%). Ten percent of patients stated they had always lived in a depressive state.

'Loneliness' was both the most common feeling described when patients referred to their past and the most frequent word in their narratives.

Dualism between the desire to die and at the same time to be cured appeared in 60% of the narratives. This theme also appeared in reference to patients' bodies between carelessness and care. Patients reported their weight to be the main cause of the difficult relationships with the bodies (23%), followed by general negligence (20%), weakness (20%), psychosomatic reactions (10%) and sleep problems (7%). Along the care pathway, these percentages decreased, with improvements in one's physical condition (35%) and renewed interest in caring to one's body (15%) referred in relation to the present.

According to patients, the main element that helped them to recover from depression was the relationship

Table 1 Participants' characteristics

	Patients	Caregivers	Healthcare providers	
Gender % (n)				
Women	69 (25)	67 (18)	64 (21)	
Men	31 (11)	33 (9)	36 (12)	
Mean age (min–max)				
Age	54 (20–73)	50 (25–71)	40 (28–65)	
Marital status % (n)				
Single	31 (11)	30 (8)	NA	
Married/cohabitating	46 (16)	56 (15)	NA	
Divorced	20 (7)	7 (2)	NA	
Widow	3 (1)	7 (2)	NA	
Education % (n)			Medical specialty % (n)	
Primary school	3 (1)	4 (1)	Psychiatry	64 (21)
Secondary school first level	22 (8)	18 (5)	Specialising in psychiatry	27 (9)
Secondary school second level	47 (17)	41 (11)	Mental health	6 (2)
Degree	28 (10)	37 (10)	Psychologist	3 (1)
Occupation % (n)			Institution % (n)	
Employed	25 (9)	59 (16)	University hospital	40 (13)
Free-lance	14 (5)	8 (2)	Hospital	40 (13)
Unemployed	19 (7)	0 (0)	Local health authority	20 (7)
Student	6 (2)	0 (0)	Free-lance	0 (0)
Retired	25 (9)	26 (7)		
Homemaker	3 (1)	7 (2)		
Other*	8 (3)	0 (0)		

*Apprentice, occasionally employed, waiting for layoffs.
NA, not applicable.

with their healthcare provider (84%). Forty-seven percent of patients described an initial period of ineffective attempts, mainly due to their reluctance in participating in treatment. The perceived humanity from carers was the most frequently reported 'turning point' responsible for the decision to follow the care pathway. Besides clinical care, other elements emerged due to their important roles in patients' recovery: nature and animals (36%, mostly represented by walking in natural environments and caring for domestic animals), culture and arts (28%, reading, studying and creative activities), sport (14%) and travel (10%).

In the first part of the care pathway, isolation and closing oneself off to others were recurrent themes (72%). In the last part of the narratives, positive social relationships (29%), and efforts to reconnect with others (41%) prevailed. Realising the improvements, 53% of the patients expressed they were afraid to 'fall again' and experience depression relapse.

Furthermore, 89% of the patients appreciated the opportunity to write their story, reporting that it helped them experience tranquillity, reflection and relief (table 2).

Eighty-three percent of patients expressed their feelings through metaphors, recalling the following main images:

- ▶ Emptiness and falling (13%): 'drugged in a dark hole'; 'fallen in a never-ending vortex'; 'out from this abyss'.
- ▶ Fight against the disease (12%): 'interior fight'; 'get up again and fight'; 'survived'.
- ▶ Torture and punishment (11%): 'living was torture', 'future as a sentence'.

The care relationships were the main coping strategies and prevailed over the deactivating coping elements, including lack of acceptance of the one's own condition, closure off to others and anger.

Findings from caregivers of people with major depression

Almost all the caregivers were family members, mostly represented by spouses (37%), followed by sons and daughters (22%), parents (19%), siblings (11%) and brothers-in-law (4%); friends were involved in 7% of the cases.

'Sad' was the word more frequently used to describe their loved one with depression, while 'have to' and 'helpless' were the most frequent expressions caregivers used when referring to themselves.

Caregivers confirmed the care pathway patients described: the dualism between the search for help and isolation, a difficult relationship with the one's body and weight, gradual improvements in one's social life,

Table 2 Patients' narrative fragments

Topics	Patients' narrative fragments
Loneliness	'I felt lonely, without a support, with all the things to do on my shoulders'; 'I felt lonely, as the world and people didn't exist'; 'I had lost everything: a husband, a friend, a lover'.
Dualism (willingness to die and wanting to live)	'I wanted to die, I attempted suicide with many pills. I wanted to escape, run away'; 'Maybe I was expecting somebody to save me, care for me. I wasn't able to do it by myself'; 'I wanted and didn't want to fight and hope for a better day'.
Relationship with one's own body	'I neglected myself, washing up only when strictly necessary and eating less than I needed to do'; 'I completed rejected myself; I put on weight 18 kilos'; 'Today I feel fit; I resumed taking care of myself'.
Care relationships	'Before encountering Prof. X I had not followed the care pathway with confidence'; 'My carers are human people; I wasn't an easy patient'; 'The biggest help came from a person who not only cured me with medication but offered me love and listening that I had never received before'.
Relationships with others	'I didn't want to see anybody, I had the impression I was a bad friend, a bad classmate, a bad sister, a bad person because I was always sad and worsened the mood of whoever was with me'; 'I don't like talking about me. But I am trying to be a little more open. I don't want to continue to be isolated, even if I feel good on my island'.
Afraid to 'fall again'	'I wouldn't lose all that I reached, my balance'; 'I wouldn't fall again in the dark tunnel'; 'I don't want to live this nightmare again'.
Writing experience	'While I was writing, I felt calm'; 'It was an opportunity to reflect and feel relief'; 'I want to continue to write'.

importance of cultural and artistic activities and nature, good relationships of care and fear of falling again into depression.

While their loved ones were improving their relationships with others along the care pathway, caregivers' social lives tended to be limited to those within the family or reduced to total introversion (both 21%).

Fifty-eight percent of caregivers appreciated the writing activity for the sense of freedom they felt, while 42% found it difficult to relive bad memories (table 3).

Eighty-eight percent of caregivers used metaphors, which were partly similar to those written by patients: the fight against the disease (14%), also referred to their fight and emptiness (11%). They also introduced different metaphors to depict the burden (14%), isolation (9%) and 'the trap' of their perceived lack of freedom (8%).

Deactivating elements of coping such as closure off to others, pessimism, anxiety and anger, prevailed in their activated strategies.

Findings from healthcare providers of people with major depression

Most of the healthcare providers were psychiatrists (64%) or future psychiatrists in training (27%) and operated within public health services.

The expressions most frequently used to describe their patients were 'without life' and 'without hope', while 'suffering' was the most frequent word found in the first part of their narratives, regarding the patient's initial medical visits. Some healthcare providers expressed feelings of helplessness (24%) and concern (17%) when first encountering patients, while others felt trust and

Table 3 Caregivers' narrative fragments

Topics	Caregivers' narrative fragments
Patients' sadness	'I perceived suffering, bad moods, closure off to others, sadness'; 'She felt tired, sad, discouraged'; 'Now she feels less sad'.
Sense of duty and helpless	'I couldn't have worries, I had to manage his worries and the kids'; 'I felt helpless in front of the severity of the situation, always in a state of tension'; 'I felt helpless, unable to give her support'.
Relationships with others	'I didn't talk too much about this situation, just with my father, brother, and sister-in-law, the only ones who could understand'; 'I changed a lot with other people: with my family, I became harsher because they didn't help me, with friends I was no longer the joking and smiling person I used to be. The door of my house was closed for everyone'.
Writing experience	'I felt free to tell and write my emotions. Thank you for this opportunity'; 'I feel released from so much pain misunderstood by everybody, including my loved ones'; 'It was difficult. I had to think about unpleasant episodes and situations'.

Table 4 Healthcare providers' narrative fragments

Topics	Healthcare providers' narrative fragments
Patients' emotions	'The patient's eyes looking down seemed to express a strong suffering, almost anguish'; 'She was in a severe condition of suffering and told me, crying, as she tried to get it over with'; 'She was very weak, disintegrated and lacerated from pain, overcome by adverse life events, unable to react'.
Healthcare providers' emotions during the first encounter	'I felt helpless and discouraged in front of that colossal and unmovable silence'; 'I felt almost helpless in front of such a suffering'; 'I felt concerned, nervous. She expressed a clear pessimism, sense of guilt, and demoralisation'; 'I felt confident I was able to help the woman'.
Healthcare providers' emotions in the present	'I feel confident compared to the situation at the beginning. I can investigate emotions and I feel we have built a good therapeutical relationship'; 'I trust her and her abilities. I hope that the deep grey areas will be easier to manage'; 'I am happy, satisfied, and glad to have been helpful and I am happy that she got back to her life'.
Writing experience	'I appreciated the utility to retrace the patient's story. While I was telling the experience, I realised some elements that I would deepen together with her during the next visits'; 'It was useful to organise my ideas'; 'I paid attention to things I have never reflected on'.

motivation (both 17%). Along the care pathway, trust (44%) and satisfaction (33%) increased over time.

The healthcare providers confirmed the care pathways patients and caregivers described, reporting on patients' gradual improvements from silence to communication, from 'lifeless bodies' to more relaxed gestures, from isolation to more social behaviours, the achievement of acceptance of the therapeutic path, the key role of pleasant activities and the patients' fears to experience a relapse of depression.

Of this group, 89% appreciated the narrative experience, mainly evaluating it as a useful opportunity to reflect and find new elements of knowledge (table 4).

Among the healthcare providers, 85% of the narratives contained metaphors, some of which were already used by patients and caregivers and some that were specific to their perspectives:

- ▶ Path (11%): 'taking a new way', 'upward path', 'therapeutical walk'.
- ▶ Fight against the disease (9%): 'she felt like a war veteran', 'going down by barricades', 'bringing peace'.
- ▶ Isolation (9%): 'locked in a nest', 'in a shell', 'a wall of suffering'.
- ▶ Freezing (9%): 'frozen anger', 'dissolving rigidities', 'defrosting'.
- ▶ Trap (9%): 'being in a trap', 'entrapped', 'imprisoned'.
- ▶ Emptiness (6%): 'emerging from the oblivion'; 'thousand-yard stare'.

Attention to the care relationship was the most recurrent coping strategy, which was acted out through patience, listening and reassuring. The only deactivating

element was represented by the need for more time to establish trust in the care relationship.

Table 5 shows a comparison of the main findings from patients, caregivers, and healthcare providers.

Findings from aggregate analysis

Kleinman's classification showed that sickness, identified through the evolution of social relationships, was the most recurring element (38%), followed by a balance between the elements of disease in detailed descriptions of depression and illness shown through intimate reflections and family life (both 31%).

Twenty-one percent of the cases showed more than one person suffering from depression within the same family (eg, a parent and a son, or both the spouses).

Finally, considering the Hamilton scale, cases of remission (29%) and mild depression (26%) were common, followed by moderate (17%) and serious depression (11%); 17% of patients had undetermined Hamilton score. No patterns were observed between the severity of depression and the narratives reported.

Coping strategies revealed to be present independently from the level of depression, as well as the deactivating elements of coping. The same result was found regarding the appreciation of the narrative experience.

DISCUSSION

The analysis of the language and contents of the narratives allowed to integrate, for the first time in Italy, the perspectives of patients, their caregivers and their healthcare

Table 5 Main findings from all the target groups

Most recurrent elements	Patients	Caregivers	Healthcare providers
Words	Lonely	Sad/have to/helpless	Lifeless/suffering
Metaphors	1. Emptiness 2. Fight 3. Torture	1. Fight 2. Emptiness 3. Burden	1. Path 2. Fight 3. Isolation/freezing/trap
Coping strategies	Activating element: care relationship	Deactivating element: closure off to others	Activating element: care relationship
Appreciation of the writing process	89%	58%	89%

professionals and provided new insights to improve care relationships. The comparison among the three target groups highlighted the risks of misalignment in understanding the perception of depression. The collected narratives revealed the important role of care relationships to begin the healing process and showed the caregivers' burden in taking care of the person with major depression. Finally, the healthcare professionals could benefit from the writing activity, suggesting a possible role of narrative medicine in their clinical practice as a mean to improve their empathy and managing of emotions.

Language

The aim of structuring narrative plots using NSM was to invite target groups to discuss depression while avoiding clinical terms and focusing on the expression of their inner thoughts. The 96 collected narratives, especially those from the participants with major depression, showed the willingness to tell their disease experience, breaking the 'unmovable silence' physicians described at the beginning of the care pathways. Even if closure and isolation are characteristic of depression, patients voluntarily decided to express themselves and communicate their intimate feelings, reflections, needs and expectations fostered by simple and non-judgemental words. Aside from the higher percentage of women, the participants' ages, status and settings varied, to represent a heterogeneous scenario: younger and older adults; daughters, sons and parents; people who experienced job loss, grief or another disease; and people who did not report specific triggering events. The number, content and openness of the narratives suggested the potential of NSM as a cross-language tool able to encourage the sharing of different human experiences.³⁷

Additionally, more than 80% of each target group used spontaneous metaphors to describe the care pathway from the acute phase to the healing process. Metaphors such as 'dark hole', 'oblivion', 'internal fight' and 'new way' represented what could not be expressed by mere words, to communicate a kind of suffering usually unable to be explained. This confirmed the pivotal role of metaphors in illness narratives^{38 39} and suggested a more immediate and inclusive language should be introduced and used both in clinical practice and in society to refer to depression.

Content interpretation

Describing their feeling, the most frequent word used by patients was 'lonely', differently from their family members and healthcare providers who used expressions such as 'sadness', 'lifeless' and 'without hope' to describe the person with major depression's feeling. While patients are in the 'to be' dimension, their carers are in the 'to do' dimension, more based on 'performance adequacy', as suggested in the definition of depression DSM-5.⁴⁰ This difference showed that patients experienced intimate loneliness, and the distinction between 'loneliness' and 'solitude'^{41 42} was not perceived. Moreover, this

misalignment could explain the loss of reciprocal understanding, creating the feeling of loneliness. However, this result suggested that major depression remained not entirely understood or recognised, confirming the difficulties in understanding the experience of depression.⁴³

Another interesting element that emerged from the content analysis was the prevalence of sickness, which revealed the weight of society's perception of depression, stigma and social exclusion, also impacting the care pathway.

The caregivers' narratives showed how the burden of caregiving can affect their lives, increasing their own risk of depression. Too many tasks, a sense of duty, helplessness, tendencies to decrease social relationships, neglect of their well-being and difficulty in writing displayed their hidden suffering. Specifically, 89% of patients and healthcare providers appreciated the narrative experience, while that percentage decreased to 58% for caregivers. The care pathway for major depression should also include supports directed towards caregivers, as applied for other mental conditions,^{44 45} to avoid the impacts of caring.

Finally, through narratives, both junior and senior healthcare professionals revealed their sense of helplessness and difficulties in facing the first medical encounters with patients. Even if trust and satisfaction in the care relationship increased over time, they could benefit from specific emotional skills training to be able to face patients' suffering from the beginning of the care pathway.

Limitations

The research involved a limited number of centres of care. Moreover, the psychiatric centres involved in this research invited patients and their family members to voluntarily participate in the narrative experience. Data on the number of patients unwilling to participate, the severity of their depression and other reasons for not taking part were not collected; this could have resulted in a bias for the lower representation of the more severe cases of depression. Nevertheless, 11% of the participants presented with serious depression and wrote narratives even if they were at the beginning of their care pathway.

The collection of narratives was carried out within a one-shot phase. It would be interesting implementing the research foreseeing more narratives of different moments in the care pathway, to follow the evolution of the living major depression along the therapeutical process.

CONCLUSION

The use of universal and evocative words from NSM referring to major depression and other mental illnesses could improve the care relationships between patients and healthcare providers—both psychiatrists and also family doctors and all healthcare professionals involved in mental health—being a key to open oneself.



In addition, the integration between narrative medicine and the Hamilton test suggested the potential for including individual experiences in diagnostic analysis, thereby providing a deeper explanation of numbers from standardised conditions and behaviours. Narrative medicine supplies tools to apply in clinical practice and integrate with quantitative scales. It also can play an effective role in the development of empathy, reflection, listening and perspective-sharing among medical students and senior healthcare providers.^{46–48} Moreover, narrative competencies fortify resilience and inner motivation, which are the main strategies to reduce the risk of burnout.^{49–50} At the same time, the acceptance of the narrative practice, including linguistic discipline, to foster empathy could be taught in pregraduate students, postgraduate doctors and specialists for mental illness.

The combination of these tools might allow a better alignment in the care relationship, a pillar for quality of care.

Author affiliations

¹Healthcare Area, Fondazione ISTUD, Baveno, Italy

²Neuroscience Department, ASST Fatebenefratelli Sacco, Milano, Italy

³Medical Area Department DAME, University of Udine, Udine, Italy

⁴Department of Neurosciences, Mental Health and Sensory Organs, University of Rome La Sapienza, Roma, Italy

⁵Suicide Prevention Center, Sant'Andrea Hospital, Roma, Italy

⁶Mental Health Department, Azienda Sanitaria Provinciale di Palermo, Palermo, Italy

⁷Mental Health Department, ASUR 8 Civitanova Marche, Civitanova Marche, Italy

Acknowledgements The authors wish to thank the patients with major depression, their caregivers and healthcare providers who released their narratives, the Italian Society of NeuroPsychoPharmacology (SINPF), the Italian Society of Psychiatry (SIP) and the National Observatory on Women's Health (ONDA) for their active contribution. We would like to thank Editage (www.editage.com) for English language editing, and Alessandra Fiorencis for the revision of the manuscript.

Contributors MC, BM, PM, VS and SU met the ICMJE criteria for authorship contributing to the survey design and dissemination, data interpretation. CP, MMG and RL met the ICMJE criteria for authorship, contributing to research management, survey design, data collection, data analysis, writing of the present manuscript. All authors contributed to the manuscript review and read and approved the final draft for submission. CP is responsible for the overall content as the guarantor.

Funding Lundbeck Italia unconditionally supported the Healthcare and Wellbeing Area of Institute of Management Study (ISTUD) for the realisation of the project, the MW of ISTUD and fee submission.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting or dissemination plans of this research.

Patient consent for publication Not required.

Ethics approval This study involves human participants and the study was approved on 28 February 2019 by the Ethical Committee of the Mental Health Department at Azienda Ospedaliera Fatebenefratelli e Oftalmico, Milan, Italy. 2019/ST/069. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data are available upon reasonable request. All data relevant to the project are included in the present manuscript. Original narratives are available in Italian upon request at the email areasanita@istud.it.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and

responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Paola Chesi <http://orcid.org/0000-0002-7664-9258>

REFERENCES

- WHO. Depression and other common mental disorders global health estimates, 2015. Available: <https://www.who.int/emergencies/diseases/novel-coronavirus-2019>
- American Psychiatric Association. DSM-5. In: Biondi M, Cortina M, eds. *Manuale diagnostico E statistico dei disturbi mentali*, 2014.
- Otte C, Gold SM, Penninx BW, et al. Major depressive disorder. *Nat Rev Dis Primers* 2016;2:16065.
- Risch N, Herrell R, Lehner T, et al. Interaction between the serotonin transporter gene (5-HTTLPR), stressful life events, and risk of depression: a meta-analysis. *JAMA* 2009;301:2462–71.
- Vos T, Haby MM, Barendregt JJ, et al. The burden of major depression avoidable by longer-term treatment strategies. *Arch Gen Psychiatry* 2004;61:1097–103.
- Kraus C, Kadriu B, Lanzenberger R, et al. Prognosis and improved outcomes in major depression: a review. *Transl Psychiatry* 2019;9:127.
- Jorm AF, Reavley NJ. Depression and stigma: from attitudes to discrimination. *Lancet* 2013;381:10–11.
- Manos RC, Rusch LC, Kanter JW, et al. Depression Self-Stigma as a mediator of the relationship between depression severity and avoidance. *J Soc Clin Psychol* 2009;28:1128–43.
- Bell RA, Franks P, Duberstein PR, et al. Suffering in silence: reasons for not disclosing depression in primary care. *Ann Fam Med* 2011;9:439–46.
- Vescovelli F, Cesetti G, Ruini C. Optimal well-being, depression, and caregiving: an explorative investigation. *Clin Gerontol* 2020;43:572–84.
- van Wijngaarden B, Schene AH, Koeter MWJ. Family caregiving in depression: impact on caregivers' daily life, distress, and help seeking. *J Affect Disord* 2004;81:211–22.
- Jeglic EL, Pepper CM, Ryabchenko KA, et al. A Caregiving Model of Coping with a Partner's Depression*. *Fam Relat* 2005;54:37–45.
- Robertson A, Venter C, Botha K. Narratives of depression. *S Afr J Psychol* 2005;35:331–45.
- Lewis B, Bradley L. Narrative and psychiatry. *Curr Opin Psychiatry* 2011;24:489–94.
- Greenhalgh T, Hurwitz B. Why study narrative? *BMJ* 1999;318:48–50.
- Charon R. *Narrative medicine: honoring the stories of illness*. New York, NY: Oxford University Press, 2006pp.: 155–74.
- Kleinman A. *The illness narrative, suffering, healing and the human condition*. NY: Basic Books, 1989.
- Charon R. At the membranes of care: stories in narrative medicine. *Acad Med* 2012;87:342–7.
- Greenhalgh T. *Cultural contexts of health: the use of narrative research in the health sector. who regional office for Europe; health evidence network (HEN) synthesis report 49*. Copenhagen, 2016. http://www.euro.who.int/__data/assets/pdf_file/0004/317623/HEN-synthesis-report-49.pdf
- Marini MG. *Bridging the gap between evidence-based care and medical humanities*. Switzerland: Springer International Publishing, 2016.
- Charon R. Narrative medicine in the International education of physicians. *Presse Med* 2013;42:3–5.
- Cappuccio A, Sanduzzi Zamparelli A, Verga M, et al. Narrative medicine educational project to improve the care of patients with chronic obstructive pulmonary disease. *ERJ Open Res* 2018;4. doi:10.1183/23120541.00155-2017. [Epub ahead of print: 04 05 2018].
- Kalitzkus V, Matthiessen PF. Narrative-based medicine: potential, pitfalls, and practice. *Perm J* 2009;13:80–6.

- 24 Langellier KM. Performing narrative medicine. *J Appl Commun Res* 2009;37:151–8.
- 25 Monsted T, Reddy MC, Bansler JP. The Use of Narratives in Medical Work: A Field Study of Physician-Patient Consultations. In: Bodker S, Bouvin N, Wulf V, *et al*, eds. *ECSCW 2011: proceedings of the 12th European conference on computer supported cooperative work*. Aarhus Denmark: Springer, London: 24–8.
- 26 Marini MG, Chesi P, Mazzanti L, *et al*. Stories of experiences of care for growth hormone deficiency: the CRESCERE project. *Future Sci OA* 2016;2:FSO82.
- 27 De Vincentis G, Monari F, Baldari S, *et al*. Narrative medicine in metastatic prostate cancer reveals ways to improve patient awareness & quality of care. *Future Oncol* 2018;14:2821–32.
- 28 Goddard C, Wierzbicka A. *Words and meanings: lexical semantics across domains, languages, and cultures*. Oxford: Oxford University Press, 2014: 215–27.
- 29 Peeters B, Marini MG. Narrative medicine across languages and cultures: using Minimal English for increased comparability of patients' narratives. In: Goddard C, ed. *Minimal English: improved communication using fewer words (note 5)*, 2018.
- 30 Trajković G, Starčević V, Latas M, *et al*. Reliability of the Hamilton rating scale for depression: a meta-analysis over a period of 49 years. *Psychiatry Res* 2011;189:1–9.
- 31 Personal data code protection. Legislat. decree no.196 of 30 June 2003. published on the Italian official Journal n.174, 29th July 2003, supplementary n.123. Available: <http://194.242.234.211/documents/10160/2012405/Personal+Data+Protection+Code+-+Legislat.+Decrete+no.196+of+30+June+2003.pdf>
- 32 General data protection regulation. Published on the official Journal of the European Union L 119, 2016. Available: <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679> [Accessed 15 Jun 2020].
- 33 NVivo 10. QSR international. Available: http://www.qsrinternational.com/products_nvivo.aspx [Accessed 30 Jan 2014].
- 34 Welsh E. Dealing with data: using NVivo in the qualitative data analysis process. *Forum Qual Soc Res* 2002;3:1881.
- 35 Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol* 1989;56:267–83.
- 36 O'Brien BC, Harris IB, Beckman TJ, *et al*. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;89:1245–51.
- 37 Ragusa L, Crinò A, Grugni G, *et al*. Caring and living with Prader-Willi syndrome in Italy: integrating children, adults and parents' experiences through a multicentre narrative medicine research. *BMJ Open* 2020;10:e036502.
- 38 El Refaie E. Looking on the dark and bright side: creative metaphors of depression in two graphic memoirs. *alb: Auto/Biography Studies* 2014;29:149–74.
- 39 Coll-Florit M, Climent S, Sanfilippo M, *et al*. Metaphors of depression. studying first person accounts of life with depression published in blogs. *Metaphor and Symbol* 2021;36:1–19.
- 40 American Psychiatric Association (APA). *Diagnostic and statistical manual of mental disorders (DSM–5)*. Washington: American Psychiatric Association Publishing, 2013.
- 41 Tiwari SC. Loneliness: a disease? *Indian J Psychiatry* 2013;55:320–2.
- 42 Hipson WE, Kiritchenko S, Mohammad SM, *et al*. Examining the language of solitude versus loneliness in tweets. *J Soc Pers Relat* 2021;38:1596–610.
- 43 Hajela S. The monster within: understanding the narratives of depression. *Psychol Stud* 2013;58:10–19.
- 44 Egan KJ, Pinto-Bruno Angel C, Bighelli I, *et al*. Online training and support programs designed to improve mental health and reduce burden among caregivers of people with dementia: a systematic review. *J Am Med Dir Assoc* 2018;19:200–6.
- 45 Donath C, Luttenberger K, Graessel E, *et al*. Can brief telephone interventions reduce caregiver burden and depression in caregivers of people with cognitive impairment? - long-term results of the German day-care study (RCT). *BMC Geriatr* 2019;19:196.
- 46 Remein CD, Childs E, Pasco JC, *et al*. Content and outcomes of narrative medicine programmes: a systematic review of the literature through 2019. *BMJ Open* 2020;10:e031568.
- 47 Charon R. Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA* 2001;286:1897–902.
- 48 Chen P-J, Huang C-D, Yeh S-J. Impact of a narrative medicine programme on healthcare providers' empathy scores over time. *BMC Med Educ* 2017;17:108.
- 49 Wald HS, Haramati A, Bachner YG, *et al*. Promoting resiliency for interprofessional faculty and senior medical students: outcomes of a workshop using Mind-body medicine and interactive reflective writing. *Med Teach* 2016;38:525–8.
- 50 Winkel AF, Feldman N, Moss H, *et al*. Narrative medicine workshops for obstetrics and gynecology residents and association with burnout measures. *Obstet Gynecol* 2016;128 Suppl 1:27S–33.