Exploring the Language of Chronic Pain Stories Through a Facebook Page: A Qualitative Study on Narratives and Unmet Needs

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Abstract

Background: Dimensione sollievo (Dimension of Relief) and its Facebook page is a patient-centered social media initiative in the field of chronic pain, providing its users accurate resources on the medical condition and importantly a virtual space for peer-interaction for a condition which often lacks proper recognition.

Objective: The primary objective of the study on patients with chronic pain was to analyze contents in relation to unmet needs. The secondary objective was to explore the role Narrative Medicine in this form of social communication.

Methods: All the posts with replies and comments from the Facebook page from 2020 to 2023 were analyzed in terms of thematic analyses by Frank, Kleinmann, Launer classifications and by Berne's transactional analysis. Language styles, semantics, word frequency and metaphors were also analyzed.

Results: Users welcomed the Facebook page Dimensione sollievo as a safe space for peer interactions, where they found understanding and relatedness, in contrast to what they experience outside the community. Interactions were characterized by short comments but became more intense around issues where injustices were perceived, such as scarce recognition of their medical condition by medical professionals and family, and access to benefits.
Narrations expressed difficulty in coping with disease and lack of recognition. Thematic analysis of contents showed the most evident dimension emerging from the descriptions and stories to be the dimension of disease. Stories also revealed a state of steadiness or regression, that is lacking clues to coping strategies, with few stories of progression or resolution.

Conclusions: Application of narrative medicine (NM) tools in the analyses of these contents allows to highlight topics relevant to patients and unearth less obvious unmet needs. This is the first study to explore potential of NM in chronic pain. It is conceivable that a knowledgeable implementation of NM tools by moderators leveraging on the community's collective experience, has the potential to lead to an evolution in the culture of pain management, while elevating the community's experience.

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Original Manuscript

EXPLORING THE LANGUAGE OF CHRONIC PAIN STORIES THROUGH A FACEBOOK PAGE: A QUALITATIVE STUDY ON NARRATIVES AND UNMET NEEDS

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ABSTRACT

Background and aim: *Dimensione sollievo* (Dimension of Relief) and its Facebook page is a patient-centered social media initiative in the field of chronic pain, providing its users accurate resources on the medical condition and importantly a virtual space for peer-interaction for a condition which often lacks proper recognition. The primary objective of the study was to analyze contents in relation to unmet needs. The secondary objective was to explore the role Narrative Medicine in this form of social communication.

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Keywords: chronic pain, quality of life, humanistic burden, narrative medicine, illness experience

INTRODUCTION

It is estimated that chronic pain affects up to approximately 21% of the population in advanced countries, and another 7% in its severe form known as high impact chronic pain (i.e., chronic pain that results in substantial restriction to daily activities) [1,2]. It may follow diverse temporal patterns, either episodic, chronic-recurrent (with intermittent pain-free periods), constant, or even fluctuating in intensity. Its manifestation is multifaceted, often deriving from overlapping types of pain mechanisms (nociceptive, neuropathic, or nociplastic) – being most likely a spectrum of mechanisms (rather than a single pathological entity), across which physical symptoms interact with underlying physiological, psychological, and social factors [1]. Such aspects make the patient's overall pain experience and burden an extremely personal experience, variably affected by intensity, temporal manifestation, and the degree of discomfort of the pain [3]. Moreover, despite these dimensions being generally expected to be highly correlated, pain dimensions may modulate independently with no obvious underlying causal relationship.

To date, in fact, the clinical assessment of pain by clinicians still remains challenging [4]. The difficulty of an objective clinical assessment of the condition and the lack of a clear identification of the triggering factors heavily delay the delivery of effective long-term treatment [5]. Yet, is it widely acknowledged that the use of multimodal, multidisciplinary interventions can potentially change the course of pain and improve outcomes for patients [1].

In recent years, such gap has encouraged the development by users and healthcare providers of many on-line self-management and patient outreach programs, support groups, and the publication of an extensive body of health-related patient literacy sources [6 -12]. Today, sharing contents and personal stories on social media (such as Facebook, Tik-Tok, Instagram and Twitter/currently X) has become so widespread to naturally pervade daily lives, visibly affecting individual and group behaviors. From the perspective of Narrative Medicine (defined as a comprehensive approach to care and cure through the narrative voices of those directly involved – patients, physicians, family-members/caregivers) [13,14], this wealth of contents and intense communication offers interesting study areas. So far, few isolated studies have begun to explore social interaction through these media, mainly Facebook, in diverse pathology settings (multiple sclerosis, cancer, diabetes, cardiovascular disease and respiratory disease, mental health) [6-8,11,12] to understand aspects spanning from peer-to-peer interaction, levels of engagement, and belonging, to patient literacy, awareness and empowerment.

With specific reference to Facebook, this social media platform has become over the past three decades a virtual crossroad of people and meeting venue, where its pages represent the natural extension of traditional communities, or fertile ground for new ones connecting individuals who have never physically met before but who share common interests [7].

Here we describe a pilot study on the implementation of a Facebook page on chronic pain *Dimensione sollievo* (*Dimensions of Relief*) specifically developed as a dedicated venue for people to share personal experiences and exchange information on chronic pain. In particular, the study aimed to analyze the ways the platform has been used, interactions and relationships between users, reaction to contents and level of engagement, and health-related literacy in relation to chronic pain. Accordingly, the analysis was carried out by means of qualitative approach to the phenomenon known as Narrative medicine, which allows to explore subjective truths of those living the disease through the analysis of their stories.

METHODS

The present study was an exploratory qualitative assessment with three primary objectives: (i) analyze the language of pain, (ii) analyze interactions of the community (tone, conversation dynamics, relevance of topics and language used), (iii) identify unmet needs. Secondary objective was to explore the role Narrative Medicine in this form of social communication.

The social platform

The Facebook (FB) page *Dimensione Sollievo: la Community sul Dolore Cronico* (in English: The Dimension of Relief: the Community on Chronic Pain) [15] was launched in 2020 as part of a broader digital initiative by Grünenthal Italy, to promote comprehensible and accurate information about chronic pain and related topics. The initiative evolved around the website *Dimensione sollievo* (in English: *Dimensions of Relief*) [16] dedicated to chronic pain, and providing online resources including podcasts hosting a panel of specialists on chronic pain, references to medical publications, all developed around three core user-centered principles *Know, Act, Share* [16]. Further information on the site is provided in the Supplementary material (See *Supplementary material*, for further information on the *Dimensione Sollievo* website).

Contents of the FB page were managed by a multidisciplinary team for medical communication and social media appointed to the project that developed an editorial plan of opening posts / topics, providing information on chronic pain (definition, prevalence, symptoms, diagnostic assessments, management) as well as services, such as Ask the expert, Chatbot service, and a web survey on information needs. The same group was also in charge of the daily management and moderation of reactions and responses. Moderators generally welcomed new users with an invitation to share their personal story with other users.

The page is in Italian language and does not publish any, advertisement inserts, nor endorsement, for use of specific medication or pharmaceutical treatments.

Users of the platform were random internet users, who accessed the page, with no external endorsement or invitations, and signed up to the group on a voluntary basis. Users could read the posts on the Facebook page as they were public. In addition to writing comments, users could also add links to other websites / pages, can post images and emoticons (*aka* "*emojis*").

Data collection

The study dataset was made up of the verbatim texts of 181 posts on the FB page available for the first four years of operation (2020, 2021, 2022, 2023). No demographical or personal data of FB page users were collected. Narrations were analyzed in confidential and pseudonymized form. Names and other direct identifiers were deleted to prevent direct links with the identity of the users involved.

Content analyses

Contents of the posts were analyzed as aggregate form in terms of contents, disease narration styles and thematic and in terms of word usage and semantics. Narrations were classified according to the main classifications used in Narrative Medicine, namely the those by Launer [17], Frank [18], Kleinmann [19] (Table 1) and Berne's transactional analysis [20], which identify the narrator's role and different states of self –child, parent, and adult (See *Supplementary Material* for a detailed explanation of these classifications). Coding for emerging themes and subtopics was performed independently by two researchers with expertise in the field of Narrative Medicine and aided by calculation and word processing software for word frequencies, metaphors, and semantics.

Table 1. Thematic classifications of narrations employed in the study

Frank [18]	restitution (restoration of health);	chaos (list of negative events, lack of control and awareness)	quest (narrator's/hero's journey towards awareness)
Kleinmann [19]	illness (disease-centred descriptions)	disease (being ill health; person identifies oneself with lived experience)	sickness (sickness-centred, the social role a person with illness or sickness)
Launer [17]	regressive (mainly focused on the past)	steady (traversing the journey from past to present)	evolution (moving forward towards the personally valued goal)

RESULTS

Characteristics of the social platform users

In the period under study, the number of the page's users grew very rapidly, going from 0 to over 7100 from October 2020 to December 2020, and then increasing constantly over the years to reach over 18000 in December 2023. The pool of users mainly consisted of adult women (> 85%) mostly over the age of 60 years of age who have a prolonged experience of chronic pain, some beyond 10 years. Men, which represented a minor proportion were generally family members or a caregiver of a person suffering from chronic pain. Some user posts were also made by health-care professionals such as therapists (physical rehabilitation, psychological, art). Ninety percent of users posted an average of 1 to 3 posts, while less than 1% of users interacted with at least 10 posts on the same thread within the four years of observation.

General Content

Overall, the study covered 181 posts for a total of 9792 comments, for a total of 5733 users engaging on-line from October 2020 to June 2023 plus 590 replies to the posts from the moderators of the FB page. In detail: there were 16 posts for 2020, 63 post for 2021, 62 for 2022, and 40 for 2023.

The posts contained spontaneous narratives (i.e., without any prompt beside those offered by the opening posts by the board of *Dimensione Sollievo*) and reactions to posts by other users. The narratives/ stories analyzed accounted for 160.000 words, of which 1400 were considered key words. The narrations were traced back to 181 conversations (aka, *threads,* a series of replies to a single post).

Aside from the user's personal story developed with a relatively longer text (two or more paragraphs, most comments left by users consisted of short replies to posts of other users (*Me too; I've been suffering for years*) or status emojis (*likes* and *smilies*), generally unrelated one from one another and distant in time, while a smaller portion presented more elaborate replies, providing personal considerations, advice, encouragement. Some posts dealing with specific topics triggered a visibly higher number interaction in time among users giving rise to conversation-like threads, with a greater number of experiences shared and more articulated stories.

Thematic analysis of narrations and classifications

From the thematic analysis perspective, the most evident dimension emerging from the descriptions and stories is the dimension of *disease* (as defined by Kleinmann), i.e., centered around the physio-pathological aspects of ~~the~~ pain.

Following is the dimension of *sickness*, the subjective experience of chronic pain and the social rejection /non-recognition of chronic pain, and stigma. This dimension is mainly expressed through related feelings and impacting aspects that in part transcend individual conditions.

Most stories are *stuck* or in *regression* (as defined by Launer) and lacking clues to coping strategies and future planning or *resolution* (Textbox 1).

Textbox 1

Chronic pain for at least 25 years. Tried everything medication and physical therapies. There is nothing left to try.
There is no alternative, there is no cure they should grant me disability benefits
I'd like to fall asleep. And wake up as I was years ago. Otherwise, it's not worth waking up.
"*I've consulted so many doctors and specialists also far away, but it never led to anything*"

Nonetheless, occasionally, there are stories of coping strategies, where the individuals grow in their level of awareness and seek ways to overcome future challenges, portraying narrations of *change* (as defined by Launer) and of *quest* (as defined by Frank). These latter stories are generally oriented to master or tolerate emotions and stressful situations, diverting their focus elsewhere like for example to leisure activity, family life, and hobbies or seeking meaning through religious faith (Textbox 2).

Textbox 2

I've been suffering from chronic pain since 2012, I've learned to live with it and manage it, I have learned that " it must follow me" and not the other way around. It is not easy but I want to and I must succeed every morning I wake up with a mission to walk and do all I can to be happy... I carry a medical device ì [...], the pain doesn't go away "it's chronic" but I lead a " decent" life. I had to work on myself first, though, accept my new self and then move on... after the implantation a year after the wedding day I wore my heels again (shortly) went through a

pregnancy with so many doubts; for a " normal" person this will be normal for a 30-year old girl who finds herself with a " dead" body part it is not...
Life has changed, chronic pain changes you, for the better or worse, but that is our choice. For six years now I have had to give up work, too much medication, too much everything! In this timeframe I've broadened my horizon, discovered I love writing, a CSM (mental health center) women's-only group: autobiographical writing. Now creative writing in a library near my small town. Theater, I had a part in a theater group. Where was the pain in the creative moments? ALWAYS BY MY SIDE!!! I cried, I couldn't learn the part by heart, they encouraged me; it was so emotional! I was stuffed with medication, but I made it through. I go to sleep stuffed with benzodiazepines (of course we know, fibromyalgia makes you sleepless) I thank God for this day, I wake up clumsy, I rejoice for the new day, I start over, today I'm meeting someone, I'm visiting a cancer patient, I'll phone an old aunt of mine who loves to talk. Evening comes, I'm bushed, my daughter who lives a bit far away calls me: mom, how 's it going? WELL!!! You know I sewed some beads to an old pair of jeans; you must see how awesome!!!

Another recurrent feature across stories is the tangled narrative plot and lack of linearity, where persons speak about themselves in an abrupt, disorganized manner reflecting an inner turmoil of emotions, which finds relief by venting their distress and frustration inside the community. Descriptions in these stories may detail list of symptoms, or a chronological sequence of events, but are void of articulated reflections on attribution of meaning, outlining a typical *chaos* narrative (as defined by Frank), where the individual sees no clear way out.

From the perspective of Berne's transversal analysis, the stories present shifts from silence to active dialog, from affectation to aggressiveness, that provide keys to deciphering the different degrees of relationships possible through comments, from isolated and individual responses to proactive or altruistic interventions.

Semantic analyses and narration styles

The semantic analysis evidenced a prevailing reference to distress and pain, described with abundance of personal qualifiers (*my, mine*) and totalizing statements (*everything has changed; I tried everything; nothing has changed*) and universal quantifiers (*everybody, all, everyone else*)*;* likewise time, which is mostly depicted as inexorable (*all day, all night, for years, forever*) [13] (Figure 1. Words and the emerging dimensions of pain). Verbs are mostly in the past or present and very seldom in the future. Descriptions of symptoms are frequently expressed by means of figurative terms (burning sensation, weight, pins, knife, fire, knots) while the relationship with pain are often emphasized by metaphors recalling images of war, hell) (Figure 2. Chronic disease. Use of Metaphors). Personal stories of pain generally include in a mix of medical jargon of *disease* and lay-terms. Cervical pain, fibromyalgia, hernia, and arthrosis are the most frequent ailments mentioned (Figure 3. Conditions and aspects linked to descriptions of pain), whereas legs, arms, muscles, spine, heart, brain, neck, foot are among the most frequently mentioned anatomical references (Figure 4. Reference to body districts).

Central, Recurrent and Emerging themes

Personal stories mostly describe the physical symptoms (fibromyalgia, extreme fatigue, lack of concentration, electrical shocks) and comorbidities, the duration of their condition and their clinical journey and resignation to not finding a solution (Textbox 3).

Textbox 3

Two years ago I was in great pain, I had to undergo surgery on both knees, I couldn't even walk, I was hospitalized for 10 days, I was diagnosed with spondyloarthritis, calcific enthesopathy on my right foot (I had excruciating pain) and unspecified dryness (basically I have all the symptoms of Sjogren's syndrome, without having the aforementioned syndrome). For the latter there is no cure, there are too few of us, in Italy to waste money on research and in the meantime the

immune system destroys all the glands, no more tears (and this makes me very angry), no saliva, and other dryness that I won't mention, the process of destruction obviously continues not to mention the surgery for a herniated disc which switched off sensitivity from my left leg (I had been resting on my sacral nerve and it caused adhesions to form, girls believe me for 4 months I had to stand pain similar to those of childbirth, just thinking about it makes me shiver) and not to mention the shoulder surgery 5 months after the first one, I couldn't wait any longer. And not to mention my nightmarish neck pain. In any case, I wanted to tell you that despite everything we are able to move forward, I have changed our lifestyle for years,...
After a very bad car accident the only thing healthy left was my right arm, the legs were supposed to be amputated up to the knee but a doctor defied the odds and rebuilt them after a number of operations, the chest was opened trying to fix what could be fixed, the left arm was operated on at [PLACE] where there is the only doctor able to fix an elbow if could still be called an elbow, putting a prosthesis that very little bone to hold on to; after a few months they had to change it with one made especially for me. In short, they put me back together like a puzzle, you can only imagine the pains that accompany me daily !!!

Above all, posts revolve around the distress of living with chronic pain, the obstacles experienced over the years and still encountered in daily routine. In particular, among the most recurrent themes are those of not feeling understood, and of being labelled as having an excessively low pain threshold by family members, friends and clinicians as well. In some cases, they even feel accused of having an imaginary condition, leading them to hide their pain and discomfort to prevent any judgement or avoidance. Several users perceive they are invisible, and that they have not been adequately listened to. Many describe the discomfort deriving from these attitudes, as an additional element to their physical burden (Textbox 4).

Textbox 4

I've been living with rheumatoid arthritis for 45 years now, that forced me into a wheelchair at the age of 25. Chronic pain was my lifelong companion, but I always kept it to myself. Communicating it to others was not only difficult, but alienating since people do not enjoy the company of those who complain.
For years I repressed and showed only my smile plastered on my face. Now I've finally reached the realization that if I have to say I'm hurting I'll say it, and if they don't want to listen to me it's their own damn business, but I don't pretend anymore. And it makes me feel good."
@Dimensione sollievo: I have always suffered in some way since childhood. I was always labeled as the DELICATE one, I always got sick often and easily, delicate inside out and all around.
Often the suffering of others is not believed, many people feel one exaggerates or fake it to be pitied and thus the inappropriate use of painkillers or a choice of isolation.
Chronic pain is wearisome and limiting, I fully understand your words in saying that you don't want the pity of others, I have experienced this feeling for most of my life, even with a partner I was with for 20 years, but I want to invite you to think about it Why do you think others, all others would feel pity? How can we complain that others don't understand if we don't explain to them how we feel? Especially to our family, to those who love us? And mind, I am not talking about the complaint for its own sake but about the feelings, limitations and emotions we experience every day as we deal with our condition. Not everyone will listen, but one would be enough to make us feel better. Most importantly: what does it cost you to keep it all inside?

Such lack of understanding is also described across the stories associated to the change of relationships with friends or people in one's inner circle and how others deal with someone suffering a medical condition or with state of distress and suffering. The concepts that emerge are a perceived lack of empathy, and as lack of willingness or interest to understand the causes of distress of the person affected (Textbox 5).

Textbox 5

As a lady before me said, NO ONE LIKES TO TALK ABOUT DISEASES, as long as they are not personally affected by them because the disease scares (as if everyone is exempt from it) and it bothers one to complain, because the model of our society is based on WINNING, efficient, healthy, fit people, who have to hide their frailty, must not cry in public, must always be perfect and functioning, if not, down the cliff of Sparta. Doctors, specialists, with very rare and precious exceptions, treat patients as numbers, cases to be entered into the computer, they don't even look you in the face, they draw up the report, they make you take tests and explain almost nothing about the disease. Family members bury their heads in the sand, not all of them obvious, there are those who are close, they don't even want to inquire about what the disease is, they don't even look at videos even if you send them to them and as long as you are standing and breathing, they are convinced you are fine. Friends –for goodness sake, unless they're sick and therefore have developed some empathy– run away like you're a leper. This fast-paced society does NOT have time to listen in general, let alone have time to listen to those who are sick and "whining." The model, even in sickness, is that of a kind of "super hero" who alone, like a warrior in armor, fights alone against sickness, in silence and otherwise: lx' best and most respected hero or warrior is the one who not only does not complain, but SMILES ALWAYS and always and goes on working stoically until he falls to the ground and dies at work. It is not us sick people who do not know how to communicate ! It is the interlocutors who DON'T WANT to listen. To be listened to, or receive empathy, you have to pay a psychologist. That's how we are in this society based on the frenzy of work and consumption. I don't hide my illness or play super heroine because that would be untrue. If one is sick one says so. If he is well he says so. We are not immortal robots. When illness drops on someone overnight who was fine before, suddenly he realizes it. You have to talk about this nonempathetic society, not about patients' inability to communicate pain. Turn the perspective upside down, otherwise, we're

not going anywhere.

Community interactions

Conversely, users expressed feelings of relatedness and belonging with others in the online community, trust, empathy, and gratitude. There is a pervasive sense of bonding both among users of the page and between the users and the board *Dimensione sollievo,* which users appear to have personified in their trusted ally.

In general relationships among peers were polite and attitudes were supportive, although not all users showed appreciation for other user's opinions, minimizing the severity the other person's pain compared to theirs and arguing no-one suffered more than they did. (Textbox 6)

Textbox 6

@Dimension Relief: the Community on Chronic Pain Good morning and Many Thanks to you Mr. Alex and the Community for the support and solidarity. You are so kind.
@Dimension Relief: please find a solution for us suffering from fibromyalgia!

Community interactions can be also interpreted through the use of emojies, memes, Gifs, and other types of images that often accompany their words to better express their mood and feelings. Other times they replace the need for words that the user might not have time to write o might not feel comfortable expressing. They may be considered by users as visual aids to the interpretation of narrations. As seen in Figure 5, there are a variety of icons; some expressing closeness (hearts, flowers), emotions (crying faces, and smiling faces, tears, rage, friendly animals) and then motivational one (clapping hands, thumb up, flexed arm, and winking eyes).

Gender-related aspects

In reference to the markedly prevalent rate of women users, the narrations also highlight an additional gender-related burden, as comments often mentioned how the condition interfered with their capability of performing daily chores and family-related tasks. Interestingly, the comments reflected the traditional female role in conducting the household despite disease and treatment burden (Textbox 7).

Textbox 7

I enjoy painting! I'd spend my days painting all the time! Unfortunately, I can't; being a woman we have so many things todo!
It's been 5 years of ordeal, between doctors, medicines, tests, and various research... I have 3 children, a house, a job to maintain in addition to the strenuous work at home and 4 grandparents to look after...

DISCUSSION

The present study aimed to explore interactions among users, reaction to contents and level of engagement on a popular and widespread social platform media specifically dedicated to the topic of chronic pain. Overall, the dynamics observed were those typical of FB pages of disease-related support groups, where people from very different geographical location find themselves connected in a familiar place beyond temporal and spatial restraints [6,7;9-11; 21,22]. In general, users expressed the sense of belonging to the community and of being understood by other who share similar pain experience in contrast to the rest of the world, outside the community.

Most stories highlighted the frustration of years of pain and the difficulties this posed in activities of daily life, both in the family, and professional environment. Of note, is the intense user interaction (higher number of comments with short turn-around time) which was generated around topics where a sense of injustice was felt, like the lack of recognition of chronic pain as a condition, perceived prejudice or stigma, or patient rights and access to welfare or occupational benefits. As new users posted their stories, a large portion of interactions were in reaction to these, either with personal anecdotes or short two-word replies or *emojies* which were extensively used to express approval, compassion, distress, resignation, and even happiness.

Nonetheless, beyond this apparently basic communication, characterized by a brief fragmented style of narration and the extensive use of intuitive status emoticons, the comments and narrations posted represent a wealth of contents for study that allow to gain insight on expected primitive needs (recognition, sharing, finding support, trusted point of reference, solutions to practical issues like access to affordable specialistic consultations) as well as less obvious unconscious and more complex needs.

The set of narrations and interactions provides a new field of application of Narrative Medicine tools that enable a deeper reading of stories through the interactions among users, and their perspectives, and that cannot be gained through surveys or patient questionnaires [23]. The classification of narrations performed using the approaches by Kleinmann, Frank, and Launer outline clues on the personal attitude of users in dealing with their personal condition, attribution of meaning, processing and coping–or lack of. Moreover, the lens of transactional analysis proposed by Eric Berne, drew attention to two important elements. First, the need to avoid forms of 'plastic strokes,' [20], inauthentic acknowledgments that may communicate neutral condescension as well as emphasize a sense of unrecognition. In this sense, personalized and non-generic responses seem to offer a more effective opportunity for support and facilitate online threads than standardized or automated moderations. Second, while most sections of threads represent non-dialogues, a first level of narration composed of isolated, individualistic or 'venting' comments, significant exchanges have shown to trigger 'Adult' responses (in the terms of transactional analysis), able to generate or propose active action for the improvement of self and others. Such examples mainly entail active requests for clarification or possible solutions but may, in some cases, reach a higher stage of awareness, conveying willingness to change and actions aimed at helping not only oneself but also others. Thus, this work has offered an exploratory view on the potential for 'activation' of patients through shared digital narration, as well as guidance for a more effective role in facilitating individual trajectories by means of moderating comments that can support such interactions.

Future perspectives

Comments and narrations posted online represent a significant resource to gain insight on expected as well as invisible, undervalued, and complex needs. The application of a narrative-based approach to the study of chronic pain can allow a deeper understanding of conditions and related social interactions. Classifications of languages and narrative styles, as well as the study of interaction through the transactional analysis proposed by Berne, shed lights on personal experiences, socially relevant meanings and issues, and the presence or absence of coping strategies. In this perspective, this pilot study based on the *Dimensione Sollievo* program can be useful to set the premises for future implementation in user services, leverage on user's experience to accompany individuals, where possible, toward full utilization of the community relationships even in the medium to long term. It can stimulate sharing of pain facilitating processes, i.e., 'coping' or daily 'relief,' contributing to an 'activating' and evolutionary space.

'Progressive" narratives, though a minority, are an important reality for observing the potential of the community dedicated to chronic pain. The (digital) space that can be created around evolutionary type stories go to draw and share the horizon of potential, through the direct words of those who suffer, or have suffered. In practical terms, findings from the study point to the opportunity of a new role of facilitators and moderators, embracing for example the idea of active group facilitators with communicative competences in narrative medicine. This type of moderator would be able to elicit narrations from a large portion of users and stimulate those who have opened-up to sharing, to consider elements that can lead them to embrace stories of evolution. The participants could become more assertive about the possible actions to produce self-care, diminishing their anxiety of being included and acknowledged by who is unlikely to understand their pain and instead move on with a better selection of connections and friends.

Finally, it is worth mentioning the paramount value these narrations cover, representing a useful navigation compass for healthcare providers, researchers, and decision-making. Indeed, the levels of interaction and the language used in the comments around specific topics can be used as symptomatic of specific areas of unmet needs (such as failure of social recognition), as red flags of critical issues in the patient/user journey (unequal access to care) or in doctor-patient relationship (information gaps, misunderstanding, attitude towards patient issues) –and thus of potential improvement.

In developing such strategies for the future, consideration should also be given to the sociodemographic analysis of user basin so to provide further context to research findings and maximize opportunities of patient/user-experience [10]. Despite this aspect being beyond the scope of our study, it is well known that Facebook users typically belong within specific demographic groups (like, over 30 years of age) [10] and could in some way influence access to contents, and levels of engagement (indeed, this platform was purposely chosen to reach the age-group typically suffering from chronic pain). Also, autobiographic narration is primarily approached by women who, in general, are more incline to sharing personal experience, to psychological introspection and reflection. Accordingly, it is worth considering what more can be drawn by this means of communication to benefit the patient. One example is the corpus of recurrent posts stressing the additional emotional and physical burden carried by women in their role of family organization, which reminds the opportunity for gender-related approach to pain medicine, and the need for targeted interventions (occupational therapy, support nets).

CONCLUSIONS

In the setting of chronic pain, online Patient Support initiatives like the *Dimensione sollievo* and its Facebook page represent a forum where users can find recognition and relatedness. The narrations posted by special interest group users on social media platforms represent a valuable resource of insights into personal experience, elaboration, and attribution of meaning. The application of narrative medicine tools in the analyses of these contents allows to highlight topics relevant to patients and unearth less obvious unmet needs or underrepresented populations/subgroups.

It is also conceivable that in a next future, the knowledgeable implementation of NM tools could represent a driver for advancement of the culture of pain. By leveraging on the community's collective experience, moderators could foster new ways of patient engagement elevating the community's experience.

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Conflicts of interest/Competing interests

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Figure 1. Words and the emerging dimensions of pain

Figure 2. Chronic disease. Use of Metaphors

Figure 3. Conditions and aspects linked to descriptions of pain

Figure 4. Reference to anatomical districts

Figure 5. Emoji: chronic pain beyond words