



*“Isn’t it so heartbreaking to see our loved ones decline right before our eyes...”:
Exploring posts as illness stories*

by Marianna Lya Zummo

ABSTRACT: Set in the tradition of studies that look at digital interactions, this paper aims to explore the dimension of illness as referred to by informal caregivers in online exchanges. The research attempts to a) describe posts as mediated illness stories by comparing them to the storytelling in interaction model (Mishler), and b) explore what is revealed about the writer. A data set of 7371 posts (including sub-replies) has been studied as personal narratives in non-clinical therapeutic exchanges by means of Digital Conversation Analysis (Giles *et al.*), and investigated as written emotional disclosure (Pennebaker). Posts are found to convey explicit and implicit messages to be understood and incorporated into health promotion efforts, beliefs and issues. The paper makes a contribution to the field of medical humanities by proposing online posts as third-person accounts of illness experiences, and as the linguistic manifestation of caregivers’ (CGs) state of mind. Although digital settings have already been studied in the context of medical exchanges, this is the first study involving informal caretakers’ exchanges.

KEY WORDS: CMC exchanges; Digital CA; represented health; mediated knowledge



INTRODUCTION

The physician's account of a patient's disease (or medical case history) and the illness narrative (often a patient's first-person description of her/his experience) are considered the most relevant forms of discourse combining medicine and narration. Several studies over the past two decades have provided insights into personal narratives by patients, and Narrative Medicine (Charon) is now used and acknowledged as a way to promote healing.

However, little is said about the mediated experience of illness, as the one encountered by caregivers (CGs). Socio-economic conditions seem to favour caregiving among family members, who are involved in the performance of medical and nursing tasks, and decision-making. Stressed by their condition, many CGs turn to online groups to narrate about their condition. Asking for medical information, they reveal their experience and emotions, especially about dealing with their (new) relationship with their loved ones (LOs) and their disease. The social support that "develops and operates within shared experiences and connections" (Hargreaves *et al.*) fosters a sense of community and promotes empathetic behaviours, which in turn encourage self-disclosure ("the disinhibition effect", Suler). Furthermore, research acknowledges that online communities are a convenient way to exchange information (awareness of the condition and of health literacy, Fage-Butler and Nisbeth Jensen) and support with people experiencing the same circumstances (Bender *et al.*).

This paper considers the platform as a collective/collaborative narrative text, exposed as multiparty conversations. The illness (generally affecting the person) or the disease (affecting an organ or generally a body part) is mediated by a 'third eye', that of a CG, who has the unique position of experiencing the progress of the disease/illness (from dementia to other chronic or temporal illnesses). Since the informal CG is often a member of the family, the (necessary) detachment in the support dynamics between the CG and the disabled/unhealthy person is mitigated or denied. In this sense, the written emotional disclosure produces significant beneficial effects (Schwartz and Drotar), since it contributes to mindfulness skills, such as non-judgemental acceptance of present-moment experiences (Moore and Brody). In addition, narration serves also the goal of exploring an unknown dimension, which causes emotional distress (i.e. frustration, anger and acceptance) experienced by the Self.

Under this premise, this paper studies online posts as third-person accounts of illness experiences in the form of storytelling about strength and resistance. A data set of 7371 posts has been explored as an illness narrative typology (Mishler), and investigated as written emotional disclosure (Pennebaker). The exchanges are analysed by means of Digital Conversation Analysis (an adaptation of conversation analysis for digital settings, Giles *et al.*) and corpus analysis (e.g. Pennebaker and Graybeal).

First the paper reports relevant literature on illness narratives as reinterpretation of facts, and on the online setting as a comfortable space for communication. It subsequently shows posts as narrative episodes that are used, among the other things, to interpret one's changing identity and stress conditions. Finally, it argues that the results may provide some significant indicators for professionals about e.g. remote treatment, failure in health circuits, or group therapy practices. The main purpose of the



work is to show that posts may be relevant to exploring or predicting stress factors (Pennebaker and Graybeal) and thus it proposes digitally-produced texts as (non-clinical) narrative events from a therapeutic perspective. To the author's knowledge, this study is one of the first attempts to investigate the role of posting within the medical humanities.

BACKGROUND

Literature on medical encounters often indulges in the peculiarities of doctor/patient exchanges, particularly when their different roles condition such exchanges (Cordella), and shape the communicative (interactional) context and outcomes (e.g. compliance promoting health outcomes). While interaction in medical practice is structured in a hierarchical relationship where doctors maintain a power distance (regarded as interactional power and credibility, Cordella), illness narratives in doctor/patient dialogues make emotions explicit. They are expressed by subjects, who structure a narrative of their experience that leads to health-related, patient-specific evidence. In Charon's words, "in all of medical practice the narrating of the patient's story is a therapeutically central act, because to find the words, to contain the disorder and its attendant worries gives shape to and control over the chaos of illness" (1898).

Starting from this, narratives can be seen as a means to serve a personal and social function, in that they force the reinterpretation of the facts. Rewording recent studies, illness narratives serve the goal of gaining acceptance of the circumstances and of finding a "meaning to transcend the suffering" (Egnew 258), as well as to "recast reality in relation to the non-ordinary" (Good 164-165). Herzlich distinguishes "illness as destructive" (where personal progress is blocked by illness) from "illness as occupation" (a sick person working at the process of recovery), and from "illness as liberation" (where the person is enriched by the illness). Bury addresses illness narratives differently: if some narratives describe events, their possible causes and their unfolding effects in everyday life (contingent narratives), other narratives introduce an evaluative dimension (e.g. moral narratives and nuclear ones). Illness narratives express, thus, the desire of witnessing the suffering, limiting "the sometimes dehumanising effects of a medicalised society, and the effects of forms of medical practice that [...] fail to offer 'comfort and care' for patients as whole human beings" (Bury 282).

From a clinical point of view, narratives are forms of emotional disclosure (Pennebaker) of stressful or traumatic experiences. These 'revelations' have beneficial effects on physical health-related quality of life (Schwartz and Drotar) both in physical health and psychological well-being, particularly in those whose narratives suggest emotional processing and cognitive restructuring (Warner *et al.*). (Personal) stories of illness are a way to reflect on the physical body and its changes, with implications for the Self. Whereas the doctor focuses on the disease, which belongs to a part of the body that needs to be treated, the patients see the illness as something affecting the whole body. This addresses the distinction between illness and disease: when reporting a symptom or telling the suffering experience in their story, the subjects explain their symptoms starting from 'their' feeling of pain, shaping their description according to the



experience they have (e.g. pain might be, in the same subject, unbearable or tolerable), which is something different from the physio-pathological condition (disease) elaborated in doctors' models, in that patients report a subjective expression (illness).

For this reason, written emotional disclosure research involves the use of linguistic analysis based on adults experiencing a traumatic event. It includes structure analysis of word usage, with contributions from linguistics, sociology, and medicine, that are based on exchanges in primary care (Heritage and Robinson), psychotherapy (Peräkylä *et al.*), and counselling (Silverman). For example, consultations have been treated as a social interaction, with distinctive tasks, goals, and activities (Heritage). Authors have been focusing on the lexical choices speakers make, the turn design, the sequence organisation, or the power distance (Cordella), whereas recent studies focus on theoretical accounts of conversation as cooperation (e.g. Bromme and Jucks).

However, the digital setting has significantly modified health communication, in terms of power dynamics and language. E-patients are found to have more specific medical knowledge than would be expected, expressed by the use of specialised terminology, especially in the case of patients with chronic diseases (Fage-Butler and Nisbeth Jensen); while doctors' language displays similarities with that used in patient-centred models (Zummo).

Furthermore, online communities exchange information among laypersons and find support from people in similar circumstances, taking benefits from the peculiar specificities of the digital space (i.e. anonymity, easy and free access) that make it a comfortable space for communication (e.g. avoidance of stigma). Recent studies have also reported that social media platforms are used by individuals to obtain (first or second) opinions in the form of crowd-diagnosis (Nobles *et al.*), addressing the digital space as an actual medical setting where those with medical expertise and those familiar with particular conditions work together to find the appropriate diagnosis.

DATA AND FRAMEWORK

The aim of the paper is a) to propose posts as (non-clinical) narrative events and b) to study them from a therapeutic perspective.

To define data, the paper adopts and adapts Mishler's narrative typology, namely the storytelling in interactional context model. In fact, as the model proposes, CGs explore their identity by introducing themselves and their situation, and make choices about what and how to describe things (i.e. what they consider to be noteworthy and reportable). Posts allow a direct, open and personal vision of the experience these CGs are enduring in non-clinical settings. They refer to possible transformations in conversation-like environments, since social network group pages seem to offer a space described by users as 'a safe place'. Information and empathy are offered through community-building practices, and narrative practices are fostered by "the disinhibition effect" (Suler) that is experienced in such exchanges.

The group analysed is a closed one, i.e. only participants can read the message board. Users share the most private fears within a one-to-many interactional setting. The posts refer to the response of family and friends to the difficulties due to conditions, the



steps taken to mitigate the effects of symptoms (including the nature of treatments) or the effects illness has on LOs. The group members have in common that their lives have been affected by the necessity of taking care of a LO. This creates a bond of a shared experience and common understanding about what it feels like to live with LOs suffering a serious health condition.

Data are extracted from interactions occurring from 2015 to 2019 by informal (inexperienced until necessity and/or personal choice occurred) caretakers of elderly parents or family members. Opening posts (OPs) were located and archived under tags, and only those containing a selection of terms (related to the semantic fields of e.g. body, disease and illness) were included for analysis. The corpus is composed of 273 OPs, and also considers comments and replies for each OP (total 7098 sub-entries). Permission to investigate and use data from the page has been requested to the admin of the page, which hosts a community of 755 people at the time of study. No users' personal data is used and results come in de-identified form. However, because of Facebook privacy policy, only a few (edited) posts are taken as examples to prevent the possibility of tracing quotations back to individual users.

The exchanges, of a written nature, start with an opening post that is followed by answers and comments, forming one or more threads that can be studied by means of Digital Conversation Analysis (Giles *et al.*). This analytical framework is used to explore the convergence of written texts and talk (conversational-like data) occurring in digital (synchronous and asynchronous) contexts with a conversation analytic approach. In this paper it is employed to explore the interactional strategies used to construct the illness story and to obtain information on the practices that are involved with the digital exchange. During the first stage, posts were selected by using keywords (e.g. 'body'). Posts and threads were read to become familiarised with the site and gain an understanding of group dynamics and specific users. Then, the post is investigated as third-person illness narrative in its interactional nature. Finally, following Pennebaker and Graybeal the corpus was analysed for word counts, sentence lengths, and use of specific categories of words defined by their semantic category. The reason behind this choice is that, other than the doctor/patient exchange, the CG/sufferer interactions are subject to a somewhat 'democratic' impulse (especially if the CG is a member of the family). This reduction of hierarchies and loss of caregivers' credibility leads to renegotiations of roles, and to dimensions of stress and anxiety. The LIWC text analysis program counts words in psychologically meaningful categories, i.e. cognitive processes, and emotional states and provide insights on the linguistic manifestation of stress predictors. The LIWC 2015 software program is thus used to interrogate the corpus on the frequency of occurrence of lexis, and AntConc 3.4.3 to collect examples.

THE POST AS A (THROWAWAY) STORY

The following sections aim at showing posts as narrative episodes with their own characteristics and different functions. These fall into three categories: 1) what CGs do, 2) what CGs know, 3) what CGs feel. The first category refers to the activities directed to LOs, the second category includes the mental processes or the competence they show



in procedures and treatments, the third category involves attitudes and beliefs. First posts will be discussed as personal narrative cells and then, due to space limitation, only the third category will be investigated.

The CG's care is reported in posts dealing with their experience and addressed to an anonymous audience. If a post is read through a narrative lens, a story emerges with an abstract (a), an orientation (b, saying who and where), a complicating action (time sequence in c, or normality breaking in d), an evaluation (implied, both in d and e, for the sufferer and the other family members). While in traditional stories a solution is offered, in posts the solution is requested of the audience (f):

So after reading so many posts on here, I decided that I would like to share as well and try to get out some of my feelings that I can't normally talk about [...]. So here goes my story, (a)
about year ago in February we found out his dad was living in his truck. It was a very cold winter here in Kentucky.[...] (b)

Two days later [...] we brought him out to the country with us, and about *a year later* he started feeling bad. I took him to the dr for a cough and his chest hurting. They did a chest X-ray and bloodwork. Went back *two weeks later* and found out his PSA was in the 4000's. We were referred to an oncologist and found out he has prostate cancer *in March*. (c, my italics)

On August 13th he came and told me he hadn't used the bathroom for 4 days and he was hurting. I rushed him to the ER and they admitted him and continuously found more problems [...] He had a brain bleed, a stroke, a seizure, was sepsis, a UTI, and we had a PET scan and seen where all the cancer was. He's decided that all the chemo meds are what's making him so sick and he's doesn't want them anymore. [...] (d)

[...] None of his kids clean him up, that gets left for me. (e)

[...] How does everybody get through this? How do you find time for you? I know hospice keeps asking what are you doing for yourself, but I don't have any answers. How do you manage? (f)

The use of active verbs emphasises the I as the main actor. The language used when referring to the condition(s) is a mixture of imprecise terminology and medical labels, but is used with confidence among those who has experience with that condition (Fage-Butler and Nisbeth Jensen 2016). The basic narrative syntax changes when CGs express frustration and contrast. Negative sentences highlight what did *not* happen (normal activity/wish as in "So no anniversary dinner out yesterday because dad [...]") with what actually happened, emphasised by meaningful adverbs ("Instead, we were up all night"). The questions serve the interactional purpose (to start a conversation) as well as a functional purpose (obtaining a suggestion and information).

She swears she doesn't have dementia either so I opened up her medical report and showed her it was listed there as one of her conditions. I guess it's really hard for her to accept & admit she's got these issues, maybe she thinks it's a sign of weakness? Have any of your parents resisted accepting that they have issues and start a mind game of denial? How do you deal with it? [...]

Stories promote other stories, told to engage and give support or to tell one's own story:

OP: Took my dad to the ER Thursday he was having trouble breathing. They admitted him oxygen level was extremely low blood pressure was real high. Friday during the day he was alert wanting water that night they say he was agitated so they gave him something to sleep. As of then he has not really been awake [...]. They tell me it's pneumonia [...]



R1: My dad has low blood pressure [...]. Sad to see our parents decline. you're in my prayers [...]
R2: My dad had pneumonia and was septic [...] Once they start IV, it is tricky to keep them in a good spot. Too much liquid, water around lungs and extremities. He needs to walk with physical therapy and may need a diuretic to pull the liquid off lungs. Also, respiratory therapy can give him breathing treatments to open up lungs [...] They monitored dad's blood as though he was a diabetic. We also had to monitor dad's sodium [...] Of course, they had him on 3 antibiotics at first. They took him off too soon and 4 days after discharge his primary found the pneumonia was there [...].

Indeed, as it happens in therapeutic exchanges, the post narrates a 'story in the process' (or, narrative episode), i.e. a post starts a story to be continued by follow-ups in other posts (preceded by the note 'update', e.g. "Update: [x] went in the hospital on Sunday with [his] blood oxygen level at 40%.[...]").

The audience gives continuous feedback, which gives the narrator the possibility to reframe, renegotiate or make continuous changes (e.g. adding details) in her/his story, as it occurs in therapeutic interactions (Mishler):

MK: [...] They are healthy but then longer they are in bed the more the body physically gives out. It is breaking my heart. It is like she has just given up.
RR: How long has this been going on?
MK: About 3 weeks. Health is good on the inside. But the body is giving out in the inside [...]. The Dr has upper depression medication.

In this exchange, the story about a physical failure in MK's first post is reframed (by contrastive marker, *but*) in terms of depression in the second one. The mental illness is only hinted at and the narrator does not seem to share the doctor's view, which adds details for medical insiders (the CG does not recognise the nature of the illness).

In another example, UW tells about how sad it is watching her mom decline. She starts by describing her love and need to save her parent, and she ends the comment by expressing her unspeakable desire of her mother's death. This seems to suggest a development of the user's identity since in her storyline, she proposes a personal change in the acceptance of death. More importantly, she acknowledges her purely observational status and the impossibility of helping (marked by the declarative *pray* that invokes divine intervention for help):

[...] Isn't it so heartbreaking to see our loved ones decline right before our eyes not knowing how to help them. There such a balance between keeping them and letting them go. [...] This journey is getting so difficult and so very sad [...] Her frail body at 98 is breaking down. Her weight loss is significant. I pray for divine intervention.

At times, CGs see and report what they see in emotionally detached, two-words descriptions and short sentences:

Mom seems to be declining. Quickly. [...] No fever. Retaining fluids. Monitoring a flare up of new onset cellulitis on her remaining leg. Exhaustion. Whole body pain. Blood sugars are elevated [...] Difficulty walking even with her walker due to fatigue [...].



The narrator describes a suffering body with short sentences, as s/he sees it and as s/he interprets it, in an objective-like description, and aiming at possible (crowd-)diagnoses. While the perceptual verb *seem* leaves room for hope, the same is eventually minimised by the adverb *even*. That is when the act of seeing must evolve and shared with the others. In fact, the platform allows multimediality, making the body or the illness 'visible'. Pictures, for example, change the subjective act of 'seeing LO's body' to a collective event in which the body is shown on the screen, a 'visible body'. As a result, verbal post is minimised to a rough approximation or inadequate description of the body and/or illness: "[...] My babymomma fell down 3x this week [...]. She's 99, congestive heart failure, early dementia, can't hear, makes big messes [...]"

This post is followed by a picture of a woman lying on a kitchen floor. The woman is quite old, in evident distress, wearing nightwear, a dressing gown and slippers. Her legs have several bruises. The picture is taken after a fall, possibly one of the three times the narrator is describing in the post. Apparently, the necessity of picturing the story is determined by issues of personal credibility, emotive sympathy and modern visual practices that are accepted and employed by users. However, from a different perspective, the woman's body is visible to anyone in the group, described verbally in the post and displayed for anyone to see. This practice not only makes the body visible to others but allows the narrator to put on stage what s/he is narrating.

Beside witnessing the stories, pictures also serve the function of showing the wounds or inflammations, with the CGs asking the other participants to offer their experiential contribution in identifying possible causes, as in:

[...] I did have a question, though. Grandma [x] woke up today with this very intense bruise on her middle finger, with what seems like a blister in the center. [...] No bruises apparent on her hands until today. [...] Any idea of what this may be?

This time, the post produces a shift from the individual's role as narrator to information-seeker and the audience is acknowledged as being medical knowledge connoisseurs, who could provide and negotiate advice (i.e. crowd-diagnosis, e.g. "She could have a UTI or bladder infection but check her temperature first"). This practice has the advantage of having rapid response and multiple opinions but lacks accuracy, in that the audience may have limited knowledge about the subject (the picture and the self-anamnesis cannot replace medical observation) and may lack medical training. Misidentification might be one of the issues, as shown in the next paragraph.

POSTS AS RELIABLE DESCRIPTIONS?

When dealing with a mental illness (i.e. dementia) the narratives found in the posts show a rupture of (semi-)objective descriptions since the 'parenting a parent' experience exposes the CG to a new relationship and personal dilemmas. While body illness is justified by biological causes and accepted, mental illness is often misrecognised and misdiagnosed (as in "If there's a change in mental status, you should make sure she doesn't have a urinary tract infection"). Data dealing with body issues involve reference to medical terms and show CGs' knowledge of clinical procedures and treatments, i.e.



the 'what they know' category. In contrast, mental illness belongs to the 'what they feel' category, since it is not accepted and often addressed as an attitudinal (conscious) repertoire in LOs' response: "[...] the cranky childlike bad behavior, I think about my mother's bad behavior [...] I know, I've spoken to the doctors who are telling me that moms behavior is due to the dementia. I don't really see it [...]"

The lack of identification (i.e. recognition) and awareness (i.e. knowledge of the issues) of the mental disease is also mirrored in the set of vocabulary used in the stories: while CGs' accounts of body failures endorse a set of medical/diagnostic labels, there seems to be a lack of terminological display in cases of mental illness. In data, dementia is thus just labelled an "attitude" of "despotic" or "childish" behaviour. Other than indicating a level of uncertainty expressed about the disease, mirroring the lack of information on dementia, the set of vocabulary associated with the disease (non-specific synonyms) leaves room for other interpretations. Mental illness is difficult to process because of the attitudinal changes ("So far, my experience with dementia is about the change in personality"), and LOs are said to be "emotional", "mental", "self-centred and seems sad most of the time", "fixated on reviewing timeline", "obsessed over certain people", "very confused and jumbled" (also "extremely confused and agitated") as well as "very hyper and mean".

Only a few acknowledge the mental disease and attribute the attitudinal changes to it ("My mother's dementia is extra bad today"). The lack of identification does not help manage the condition nor provide support, and CGs feel at a loss: "My 90-year-old mother (dementia) moved in with me [...]. She has difficulty processing what she is told [...]. She [...] insists that she is 100% "fine." Implying otherwise makes her angry and difficult to live with."

Narrating LOs' illness becomes a way to discuss their own condition (i.e. what they feel). This leads to the next point to be addressed.

A PERSONAL HEALTH NARRATIVE

In this section, CGs' identity constructions, their feelings and their condition are discussed.

When people narrate their stories, the narrative choices reveal how narrators see themselves and what representation they want to give about their identities. The linguistic choices offered in these small stories offer a self-portrait as either a survivor or a victim:

Nobody understands caring for a parent with dementia unless they've experienced it. [...] Will I regret giving up all my free time and these years of my life before I get old myself? [...] This is supposed to be the prime of my life yet I'm saddled here at home with two 87 year olds who cannot really interact in a normal way. Conversations are just them repeating the same thing all day every day. Answering the same questions over and over and reassuring them that they're okay. [...] I don't think I have ever experienced anything more physically and emotionally exhausting in my entire life [...]

But then there's the guilt that I face knowing the only way I get my own life back is for theirs to be over. This is not for the weak hearted that's for sure.



As already noted, posting and commenting in the forum exposes the user to confrontation (Lamerichs and Te Molder). When a CG opens a thread by writing a post, s/he may be subject to accountability, i.e. s/he is making her/himself vulnerable to criticism. By posting the comment in the group, the CG implies that s/he feels safe (group construction) but still makes a difference between those who will understand and those who cannot ("Nobody... unless"). The possibility of understanding is not a cognitive matter but is based on experience. The core of the comment, however, is announced by the question "Will I regret [...]?" She orients herself in time and space ("This is supposed [...] here at home") and describes her life as subjected to (others') mental illness (dementia) and its characteristic communicative dynamic ("conversations are [...]. Answering the same questions [...] and reassuring [...]"). Self-victimisation ("I don't think [...] in my entire life") occurs also if considering the ethical implications of having unspeakable desires, but then the user redefines the Self in opposition to "the weak hearted". CGs are not constructed as heroes or warriors (these metaphoric labels are for LOs, who fight against the disease), but more as victims or survivors through discursive implication and explicit statements: "[Mom] passed away [...] She suffered from dementia, and so did we, because suffering is definitely what it causes. I'm glad she is free [...]"

From this, two considerations are possible: on the one hand, death is welcomed as a way to "[be] free". On the other, dementia is considered as a form of suffering shared with the family in a process of embodiment. The disease seen in the LO's body also affects the narrator's health: "Mom seems to be declining [...]. I know my body has been aching, sleep is weird, I forget to eat. [...]"

The experience of caregiving, in fact, means exploring body deterioration as understood *and endured* by third persons. LOs' body failures (may) determine practical as well as emotional consequences in the management of everyday life activities (i.e. new habits, disruptive events to be repaired):

Today after giving her a shower and lotioned, powdered and put on clean nitie & sheets, my back was killing me from the two times she fell this week and I had to get behind her & pull her up [...] Hearing is beyond help due to her refusal to ever wear a hearing aid. I have to repeat myself 3-4 times by then I'm yelling and she hates that and so do I -Errrr makes me crazy

LOs' illness and attitudes produce frustration and emotive load in CGs, as in:

I am sad. [...] [My mother] cant process things as well [...]. She shuts down. It's so sad to have a conversation with her. And her response is out of left field so to speak. Its frustrating. And hard. [...] I cant fathom what severe dementia is like. [...] So it's hard to know [...] Gosh I miss the mom that used to be here [...] Maybe I'm blaming myself.

The LO's illness is a means to express CG's mind-state condition. By using negative emotion words, cognitive verbs in negative constructions, and by expressing the longing for what it used to be, the CG turns into a sufferer. This is in line with other studies that established an association between caregivers and health variables caused by their relationship with family members (Quinn *et al.*) but in reversed condition:



I am increasingly anxious to the point that my lips get numb and I have to remind myself to breathe. I am mentally exhausted

I am having a tough couple of days. It's not that any one thing is bothering me. It's this mountain of neediness that is building upon my shoulders. Yes, it is now my role as caregiver to provide care and fill needs. I know

Accepting the role ("I know") does not necessarily mean accommodating it, despite (self-)expectations. The initial "yes" in the last sentence acknowledges the understanding of the role. However, the emotional need ("[...] a tough couple of days") needs to be shared, told and eventually negotiated with others.

These posts suggest that caregivers' narratives, while focusing on their LOs' deteriorating bodies/mind, also mirror their own health status. To validate this statement, texts were analysed by means of the LIWC software but, due to space limitation, results are not reported in detail. The analysis of posts (see Table 1) indicates that the exchange among CGs is characterised by a high density of words (mean rate for word count, 194.3 in OP and 51.96 in R), organised in articulated sentences (mean rate for sentence length, 20.48). The high mean rate for first-singular pronouns (I, my, me) suggests a focus for the Self that, in literature, is associated with depression both in private writings and in the semi-public context of social media (Eichstaedt *et al.*). This seems to be consistent with the low values for positive emotion words (e.g. funny, good) and the high values for negative emotion words (e.g. frustrated, angry, tired, confused) which, taken together, are known to predict tension and anxiety (Eichstaedt *et al.*).

VARIABLES	OP (MEAN RATE)	R (MEAN RATE)	AVERAGE FOR SOCIAL MEDIA
I-words	7.3	4.2	5.51
Social words	9.4	3.95	9.71
Cognitive processes	21.0	28.0	10.77
Positive emotions	2.4	2.5	4.57
Negative emotions	3.4	3.95	2.10

Table 1. Language dimensions in opening posts (OPs) and in sub-replies (R)

Source: Adapted from the traditional LIWC dimension, available at <http://liwc.wpengine.com>.

The use of insight words (e.g. know, think, understand, guess, feel) denotes cognitive processes (21.0 in OPs and 28.0 in R) and is explained by the need for CGs to come to terms with their experience. However, this process does not seem supported by a consistent use of causal words (e.g. hence, because, since). These are used when individuals try to reason out the event and attempt to find causes, thus a high mean rate would suggest an active processing of the experience. Apparently, CGs use posts to tell their experience in the form of personal stories and are being honest with these (according to the results for the self-reference variable) but do not come to terms with their personal conditions.



DISCUSSION AND CONCLUSIVE REMARKS

In the digital space, posting has become one of the most recurrent writing practices expressed with written or visual texts, published online by users. In this paper, a particular typology of posts has been discussed as examples of illness narratives, triggered by (in)significant moments and/or activities in everyday life by a closed group of informal caregivers. Post construction involves practices of group-formation (addressing to the community), audience engagement (empathy or knowledge seeking practices), and personal or mediated health accounts, where both positive emotions (hopes, gratitude) and negative ones (hostility, anxiety) are involved.

In the first section of the paper, the post is shown as a selection of a moment, a mood, or a need in the form of micro-stories that have been “thrown away” in the digital space (as adapted from Polanyi 1981). They address illnesses as a destructive occupation (Herzlich), where death is a “liberation from pain” and accepted as biological and ethical congruence with life. While posts reflect on the changes to LOs’ bodies/mind, they also report on the implications, the practical as well as emotional consequences of managing the daily experience. The reports take the form of ‘cases’, in which one’s experience involves personal changes (e.g. death acceptance, parenting role) that are central to the development of an identity.

Rewording Mishler, re-storying one’s experience is the vehicle for identity transformation and mediates one’s understanding of Self, as well as past and present experiences. These “stories in conversation” are also stories in the process, as it occurs in therapeutic exchanges, and have constraints like those found in the storytelling model in interactional contexts, e.g. “telling a topically coherent [...] story that is clearly connected with previous talk” (Mishler 112). When this is difficult, there are specific strategies (e.g. the use of label “Update”) to signal coherence and cohesion with previous texts. Posts are oriented as throwaway stories, where CGs try to make sense of the different issues they face daily, reframing LOs’ illness and changing their beliefs and attitudes (e.g. trust, life visions). The world in which the narrator lives, and talks about, relates to other users, who are engaged in conversational exchanges and multiple practices. Thus, these posts promote a many-to-many type of open-care, where users establish a relational model based on therapeutic alliance (as in crowd-diagnosis, Nobles *et al.*), renouncing the hierarchical doctor/patient relationship. However, if intended as a way to get direct medical responses, the narrative practice of posting is potentially harmful. The verbal descriptions may be replaced by visual practices that are accepted and employed by users, but the response may lack accuracy, causing misidentification of the health issue and thus potential damages. This is particularly true in case of mental illnesses, which are misinterpreted by CGs.

The second part of the paper focuses on how illness narratives are used by CGs to reveal their own issues since, in the digital environment, users are known to tell their experience without filters (Suler). Besides being a way to understand reality and make sense of a problematic experience (e.g. death, chronic illnesses etc.), posts are a means of wording caregivers’ acts of resistance, a space for their silenced personal needs and emotions in narrative processes of self-therapy. CGs construct themselves as victims or



survivors and posts show significant indicators of stress and trauma. In fact, these personal stories seem to be characterised by articulated, self-relevant texts that show tension and anxiety but, despite the need to process the experience analytically, CGs do not seem to organise causes and reasons for the events and emotions they are describing. Combining these results with those for stress and anxiety, it seems that telling others how they feel is not just a call for empathy and may address a serious concern for CGs' health statuses. This confirms that posts may be used in the context of medical humanities, and may help clinicians and medical professionals to deconstruct patients' meanings in therapeutic exchanges.

However, up to now, the possible clinical aspects of these interactions (together with the clinical objectives as e.g. therapeutic adherence, the impact of the disease, and the description of the specificity of the symptoms) are not interpreted in a clinical/therapeutic setting, and are lost. By studying these posts, professionals can identify remote treatment demand or failures in the health circuits (Quinn *et al.*).

Hopefully, this paper will contribute to giving digitally-produced texts the possibility to receive closer investigation in the medical humanities as non-clinical narrative events. The individual story constructs a narrative space that could give room for medical insiders, linguists, narratologists and discourse psychologists for understanding the world of caregiving and CGs as storytellers. Finally, other than a narrative space to study the personal/social (and sometimes cultural) dimension of healthcare (e.g. the reception of health campaigns and education), posting may be addressed as a social practice in the re-signification (and institutionalisation?) of informal caregiving, to be further studied as both a social and cultural product.

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Marianna Lya Zummo is researcher at the University of Palermo. Her research is primarily related to issues in health communication in online contexts and communication dynamics. Recent publications include: *The linguistic construction of confirmation niches in online comment sequences* (*Altre Modernità*, 21, 2018), *A Linguistic Analysis of the Online Debate on Vaccines and Use of Fora as Information Stations and Confirmation Niche* (*IJSCL*, 5, 2017), *New Health Advice: Health Forum Sites as a Change of Discourse Frame, from Doctor-to-Patient to User-to-User* (FrancoAngeli, 2016).

mariannalya.zummo@unipa.it

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