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Loneliness and Family Burden: An Exploratory Investigation on the Emotional Experiences of Caregivers of Patients with Severe Mental Illness

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Abstract

We present here an exploratory descriptive investigation about the needs of the caregivers of patients with severe mental illness (SMI) referring to a mental health service of a Southern Italian city. Twelve caregivers were queried, as experienced contacts, about their own emotional involvement and their relationship with the patient by means of a semi-structured interview. Interviews were subjected to a qualitative thematic-categorical analysis. The results reveal painful experiences of anguish and feelings of inadequacy stemming from care-giving, which gravely impact the caregivers' personal well-being and family relations.

Keywords

Family Burden, Communication of Diagnosis, Severe Mental Illness, Sense-Making Process, Qualitative Research

Loneliness and Family Burden: An Exploratory Investigation on the Emotional Experiences of Caregivers of Patients with Severe Mental Illness

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We present here an exploratory descriptive investigation about the needs of the caregivers of patients with severe mental illness (SMI) referring to a mental health service of a Southern Italian city. Twelve caregivers were queried, as experienced contacts, about their own emotional involvement and their relationship with the patient by means of a semi-structured interview. Interviews were subjected to a qualitative thematic-categorical analysis. The results reveal painful experiences of anguish and feelings of inadequacy stemming from care-giving, which gravely impact the caregivers' personal well-being and family relations. Keywords: Family Burden, Communication of Diagnosis, Severe Mental Illness, Sense-Making Process, Qualitative Research

A diagnosis of severe mental illness (SMI) prompts, within the family, organizational efforts aimed at treatment and support which end up inevitably involving the whole family group. (Dicé et al., 2015). It is a critical moment in the medical activity and its understanding can allow transforming steps in the comprehension of illness in the patient and his/her family (De Luca Picione & Freda, 2016a, 2016b, 2016c; De Luca Picione, Dicé, & Freda, 2015). In this paper we intend to observe processes of signification attributed, in the family context, to the psychiatric diagnosis and the consequent possibilities of decline in daily life. As health providers, we consider these aspects as a central point for the doctor-patient relationship, in order to implement best practices for taking care patients and support their families (Freda & Dicé, 2017; Dicé, Dolce, & Freda, 2016; Martino & Freda, 2016a; De Luca Picione, Dicé, & Freda, 2015; Freda et al., 2014; Martino et al., 2013).

In fact, it is becoming an increasingly frequent observation that a specific individual (e.g., a parent or sibling) tends to take on him- or herself most of the duties related to the care of his/her dependent (Hermanns & Mastel-Smith, 2012; Jeanty & Hibel, 2011). Chiu et al. (2013) recently showed how the role of caregiver is often tied to a large amount of emotional work such as meeting patients' emotional needs. These individuals are called on every day to care for their dependents, who often hold no job and require daily assistance to satisfy their needs (Furlong & McGilloway, 2012; Jagannathan et al., 2011; Kate et al., 2013; Wheeler, 2010). Chiu et al. (2013) also showed that relatives of patients with SMI frequently suffer from some kind of emotional disorder. This suggests that the heavy family burden associated with caregiving responsibilities might be a psycho-social risk factor (Van Parys et al., 2014); indeed, several studies show that the role of the caregiver is often associated with anxiety, depression, fears and worries, feelings of guilt or loss, psychosomatic complaints, as well as experiences related to social stigma. Moreover, the caregivers of psychiatric patients often experience emotions pertaining to secretiveness, loneliness, fear, pain, and anger, as well as overwhelming guilt for having borne a child with SMI (Kate et al., 2013).

In light of this scenario, it is generally recognized that family-targeted interventions can improve the relatives' emotional well-being, and support the caregivers in their undoubtedly important role to their dependents. It becomes necessary to focus carefully on the caregiver's emotional state (Caqueo-Urízar et al., 2011; Furlong & McGilloway, 2012; Kate et al., 2013) lest his/her health deteriorate and symptoms should emerge triggered by the inordinate burden of caregiving. This, in turn, will bear beneficially on the treatment of the patient. This is the reason why mental health service providers often include well-being and quality of family relations as indicators of the standard of care provided (Asmal et al., 2014; Caqueo-Urízar et al., 2011; Hansen & Buus, 2013; Kate et al., 2013), and why paramount importance is attributed to the emotional consequences on relatives of living together with and constantly caring for a patient with SMI (Howe et al., 2012; Osada et al., 2013).

It is becoming increasingly apparent in Italy, and in our area of operations in particular, that a need exists for establishing adequate therapeutic settings for both the patients (Laugharne et al., 2012) and their families (Grover et al., 2014); mental health services should devise ad-hoc interventions to this end. Our team operates for one such project aimed to augment the work of a mental health service provider located in a working-class neighborhood of a Southern Italian city. It is a little and isolated suburb, mainly inhabited by people with low levels of literacy and high rates of unemployment. Families, often very numerous, live in palaces in small sites, in close contact with each other; they share a large part of their daily life with their neighbors.

The facility where we work is a day center for psychiatric rehabilitation where professionals of different backgrounds (psychiatrists, psychologists, social workers, community workers) care for patients with SMI and their families. Our work-group deals with providing, through the structuring action-research plans (Dicé & Freda, 2016; Dicé, Maiello, & Dolce, 2016; Freda, Dicé, & De Luca Picione, 2015), multidisciplinary care activities aimed at taking care of users afferent to public health services (Dicé et al., 2015).

In line with this goal, we present here findings of an exploratory descriptive investigation, realized analyzing narrative interviews with a qualitative methodology (Bruner, 1990; Freda, 2008; Freda et al., 2014; Esposito et al., 2015; Freda & Esposito, 2017; Esposito et al., 2016; Martino & Freda, 2016b); this inquiry is aimed to garnering useful information for the improvement of clinical settings which should provide support not only to patients but their everyday caregivers as well. We chose to investigate the process of sense-making linked to the subjective experience of persons dealing with the illness (De Luca Picione, Dicé, & Freda, 2015; Freda et al., 2014), and how this is closely linked to the daily organization in caregivers' lives, their needs, the resources they invested in the dependent's care, and their relationship with the medical team.

Methods

Description of the Participants

Twelve care-givers participated in this exploratory study, 4 parents, 4 siblings, 3 partners, and 1 son, of patients with SMI treated at our facility, most of them (70%) diagnosed with schizophrenia[1]. Participants were recruited by referral by the facility's medical personnel. Particularly, we considered the caregivers of patients who had been in treatment there for at least 2 years, as they had greater familiarity with the service providers. Mean age of the care-

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[1] Other caregivers reported the following diagnoses for their dependents: bipolar disorder (2), and an unspecified clinical condition (1).

givers (82% women, 18% men) was 54.25 years (SD=15.06), while mean age of the patients (75% men, 25% women) was 43.8 years (SD=10.7).

Participants were contacted by phone or during follow-up visits of their dependents. They were asked to participate in a research study sponsored by the medical team, and provide their informed consent. All care-givers queried by us accepted to participate. The research was conducted in accordance with the ethical approval of the Biomedical Research Ethics Committee of the University of Naples "Federico II."

Tools of Analysis

We chose this tool because it is useful to develop processes of signification in interviewed people (De Luca Picione, Dicé, & Freda, 2015; Freda et al., 2014). We consider the narrative process as a useful device for a semiotic interpretation of experiences (Bruner, 1990; De Luca Picione, 2015; De Luca Picione, Dicé, & Freda, 2015; Freda, 2008; Martino & Freda, 2016b). It facilitates the narrating subject to interact with his/her interlocutor, moving between a wide and cultural reference frame and a contingent and restricted contextual frame (De Luca Picione, 2013); both frames define the relevance of his/her speech, allowing him/her to move from an objective to a subjective and inter-subjective logic in the narrative text (De Luca Picione, Dicé, & Freda, 2015; De Luca Picione, Martino, & Freda, 2016b).

Through focused questions, we queried caregivers about the time they realized the mental distress of their dependent, the discovery of the illness, and the beginning of their relationship with the primary medical team (Es: Who did communicate you the diagnosis for your parent/sibling? It was then that you became users of this facility?). They were also asked to talk about their relationship with their dependent, and the needs and wishes of both the caregiver and the dependent (Would you please try to describe, as you can, the clinical condition of your parent/sibling? How did your life change from then? How do you provide to his/her daily needs?), and finally prompted to provide feedback to improve the quality of care.

We administered, audio-recording, interviews at a Mental Health Services of the Local Health Authority "Naples 1," and later transcribed them verbatim. Each interview lasted approximately one hour.

Content Analysis

We chose to qualitatively analyze our interviews by a thematic analysis of categories (Lieblich et al., 1998), realized via a pencil-and-sheet procedure, after reading and re-reading them. On a methodological level, our analysis process was not aimed at the construction of categories through a process to generalization, but a dynamic of the sense-making process (De Luca Picione, Dicé, & Freda, 2015), Reading our interviews, we analyzed some discursive passages useful to understand the specific meaning of narrated contents. In this way, we discerned three thematic categories (detected ex-post), based on their recurrent and common appearance in the experiences as related to us. This organization proved conducive to an in-depth investigation of the caregivers' self-reported experiences.

We read interviews in their entirety, highlighting passages of the discursive state linked to questions and issues proposed by narrators, indicating salience and centrality. We observed cultural-discursive dynamics activated in the experience of mental illness and of the diagnosis as a breakdown in the continuity of experience (De Luca Picione, Dicé, & Freda, 2015; De Luca Picione, Martino, & Freda, 2016; Freda, De Luca Picione, & Martino, 2015), not only deepening contents and representations, but also shared themes and the way to organize and articulate them (De Luca Picione, Dicé, & Freda, 2015; De Luca Picione & Freda, 2016c). Themes were not chosen following arbitrary and categorical criteria, but kept inside a

dialectical tension generated with the same whole text, seizing the forms of signification produced during the interview. In this way, the processes of signification were caught not only including the development of themes and content, but also through the common forms of semio-linguistic organization detecting narrative and discursive trends (De Luca Picione, 2013; 2015; De Luca Picione, Dicé, & Freda, 2015; De Luca Picione & Freda, 2016a; 2016b; 2016c).

Results

Now, we present themes we discerned.

1. Unfathomable nature of the SMI

The first category is about the difficulty that the caregivers experience in understanding, both emotionally and cognitively, their dependent's clinical condition. In spite of the caregivers' protestations that they know their dependent very well, they describe him/her as a mysterious and complex person, a source of preoccupation and confusion for those he/she is in contact with. Specifically, in the following state, it is highlighted how the interviewee describe the impossibility of representing the mental illness, configure it as unclear and undefined.

> *I was yet to understand it.* I used to call home: "A. isn't well; he comes out, screams, doesn't feel like doing anything," I mean, the usual stuff. Sometimes he would go out and not get back home for, I don't know, one or two days. All of this has gone on for years because we didn't understand his disease.

The following state, instead, describes the caregivers' need to receive a support in the definition of the illness, highlighting how its name, even if inauspicious, could be more assuring then uncertainty. "About the disease, after so much time that we'd even had psychotherapy, once I asked: *'Doctor, can we at least give a name to this disorder?* What's wrong with my daughter? Why does she behave like this?'"

The time when a diagnosis is given, is described as full of confusion and disorientation, for the caregivers as well as for the patient and the whole family group. In the following state, the interviewee seems to describe the anguish for the inevitability of the course of treatment that would be undertaken. "Then the physician answered me, and his answer I still carry with me and always will: *'Your sister will never be cured'.*"

The interviewees state that their personal and family life changed dramatically from that time on. These are both emotional and relational changes, as well as changes in everyday routines, as in the following state.

> *Everything changed.* My life has even been wasted. I couldn't do anything anymore. [...] Everything changed. My life is not my own. Not anymore. If I want to go somewhere, I can't bring her with me, because she wouldn't behave or she wouldn't feel like coming.

And the most painful change seems to be the restriction of personal freedom, as described in the following excerpt:

> I managed to get out in the afternoon, her father and me going grocery shopping. But now I don't even go out anymore, except when I have to come here to meet the psychologist for the relatives visit. Or occasions like that. *Because I really*

don't get out anymore. I'm always stuck to the telephone or the mobile. I'm always scared, anxious that the phone is going to ring because something has happened.

The main source of preoccupation with a diagnosis of SMI is, according to the interviewees, the behavioral unpredictability of their dependents, characterized as volatile in mood and actions. For example, the following state shows how their fickle and adamant decision-making can be disturbing and difficult to manage. "I'm scared he's going away [...]. No, nothing can scare or stop him..." Moreover, the depiction of what a "mental case" is, appears heavily influenced by cultural and social connotations. It engenders feelings of inadequacy and shame in the care-givers, which affect their relationship with the dependent.

At this point everybody there knows about it. But in the beginning we used to have strong discussions everybody could hear. *He admitted it himself*: "We are in shame." And it's bad, because then people there say: "She took a husband like that!" Do you know what I mean? They know it now. But in the beginning it was very bad.

The emotional experiences of social stigma outline a deep sense of loneliness. Although they live in close contact with their neighbors, they complain as the condition of the dependent may determine an isolation condition: "People hear schizophrenia is a mental illness, and run away. *They just run away.*" This kind of attitudes causes the caregivers to be constantly in a state of high alert, and experience their own and their family's everyday life as highly precarious, constantly threatened by this kind of behaviors.

...She went on to cause so much trouble, and I mean it. The last time she disappeared she seemed fine. I was at my sister's house with her months-old baby. A. said she wanted to have a cigarette and went outside, even though I told her there was a terrace. Nothing, she wanted to go outside. *And so she disappeared.* We couldn't find her, she wouldn't answer her cellphone. We had to go and file a report with the police. The next day at 5 she calls us: "I'm here, there are no buses coming, would you come and pick me up?" At that time I didn't know what to do, I was scared. This is schizophrenia, you can't trust them alone...

2. Loneliness while caring for a dependent

Caregivers, characterized as those most responsible, within a family group, for caring for and protecting a dependent with SMI, also conveyed their feelings of loneliness and the hardship involved in seeing every day to their burdensome duties.

I don't have anybody. My only other son, he often comes and helps me when I call him... but oftentimes I don't call him, because I can't bother him. He has his own life, his job. If I were to involve him too much in so big a problem, I would destroy him, and I have no right to do that! I'm often told: "You are a brave woman!"

This topic was amply discussed in the interviews, where the participants expressed their distress as well as their related needs:

My wish, as with all of my peers, is to have a fulfilling career, doing what I enjoy, attending to my hobbies, managing to do certain things I want to do despite all the problems. *What are my main wishes? The same as everyone: fulfilling my life, both professionally and sentimentally.*

Caregivers describe themselves as the people most capable of caring for their dependent and fulfilling their needs. "I began to do this, and haven't stopped ever since. *If I didn't care for her in this situation, I don't know how she would end up.*" Furthermore, despite the unpredictable and incomprehensible traits ascribed in their description of SMI, the interviewees presented themselves as those most quickly capable of detecting its signals and manifestations. "*If she sits I notice why she sits that way*, if she gets up, why she gets up, what's happening, if she's thinking, what she's thinking about..." As a consequence, their daily lives seem completely organized in reason to support the needs of the dependent.

Then she asks: "Are we going to get shaved?" She speaks plural, because I *have to shave her*; "are we going to have a bath" because I have to bathe her; "are we getting out" *because we go out together*.

The caregivers also devoted ample time to discuss their worries about their limits, and their difficulties in caring for their dependent. Their inability to ask other relatives for help is a source of discouragement and helplessness, even more so in case of elderly patients. "It's a holiday now and everybody is making his own plans. I'd like to go on vacation alone with her, but I can't, because *if she has a relapse I can't deal with it on my own...*" Therefore, they describe an invasive sense of responsibility tied to perpetual treatment of a pervasive illness, that influences the structuring of the whole life of the person and his/her family.

You need to deal with disorders that are perhaps the most taxing ones... even for those around them, you need to be in this situation to understand it, to understand what one feels and what one must do. They're really wearing because you're not dealing with a torn muscle or a broken bone. *You're dealing with the brain, and when you're dealing with the brain it's not just the person affected who suffers but also, even more, those around him.* It is devastating, truly devastating.

3. Unshakable bond with the dependent

References to a strong bond between patient and his/her caregiver are particularly abundant in the case of smaller families; whatever their relation, this is described as extremely solid and characterized by continuous closeness, both physical and emotional, required of both parties. "At any rate, he always needs somebody to help him, to care for him, and give him affection, warmth, attention. *Because if he's left alone even 5-10 minutes, he panics, freaks out...*" On the other hand, it is evidenced how this bond, sometimes, is characterized by some aspects of reciprocity, in which the dependent can also try to groom in return, as he/she can, his/her caregiver.

About important things, I don't know how to say this, let's hope a physician doesn't need it... for instance, I had breast surgery, I've always worn. *Because I want him with me, because he's my husband. [...] Because he's my husband, I have a bond with him.* He needs to be with me.

The bond between dependent and caregiver is described as singularly compelling; the interviewees presented themselves as constantly preoccupied by the other person's behavior and necessities, so much as to frequently adopt controlling and monitoring attitudes.

> They say here sometimes that they need to live their lives independently. They want them to live alone in their houses. But I don't believe it, what with a disorder and a past like that encumbering you... I don't understand if they tell you that in order to help them or to help you, to help you cope. *I don't trust her to be left alone, not anymore.* I go shopping for groceries, I cook, I iron the clothes, I undress her when she needs to wash. If I let her have the iron I'm afraid she gets burned, what, with electricity... she can't even iron a shirt... she can iron a dishcloth, but I don't iron those. I don't trust her.

The same attitudes seem to be shared by their dependents, who reportedly ask constantly for their caregivers, without whom they feel lost and disoriented. "*He follows me, he's my shadow*. 'When are you coming back? But are you leaving? Are you leaving for the whole of July?'" However, alongside these experiences, it is often reported (however briefly or toward the end of the interviews) that there are needs and wishes for independence, by both the caregiver and the patient. Even in these cases, making such requests seems to leave the other party lost.

> When he goes out, even if you're just after him, he manages to elude you. Yes, I do go after him, but then he wants to go out and I tell him: "Just wait five minutes, I get ready then I'm going out as well." *But no, he cannot wait, he cannot bring himself to wait two minutes*. He goes out, I go after him, can't find him anymore. To go after him, I had to leave everything I was doing. Then I have to run around to try and find him.

Discussion

Detected themes were variously organized in all interviews and showed their cultural nature, although some issues were really related to medical condition. In accordance with other studies (Chieffi et al., 2016; Furlong & McGilloway, 2012; Jagannathan et al., 2011; Kate et al., 2013; Wheeler, 2010), our findings showed feelings of bewilderment, anxiety, uncertainty, confusion, worry, ambivalence, and meanings of processes were shared by all caregivers.

Many of the caregivers we interviewed stated to belong to very small family groups (often comprising one or two individuals), show a rather modest educational attainment, and often hold poor jobs. As a consequence, they are often drawn to devote their everyday activities almost entirely to the care of their dependents with their clinical conditions. The needs these caregivers express seem to relate to finding room to elaborate the painful experiences of loneliness and preoccupation that they lived through. Indeed, references are made very frequently to their sense of duty to their dependent, afflicted with a condition that is difficult to understand and therefore perceived as distressing and dangerous. SMI is described as an extremely worrisome and invasive cultural construct, because of its unfathomable ("who knows what's going on in her head," "he's impossible to understand") and, in most cases, irreversible ("she will never be cured") nature. These emotional factors are further deteriorated by the cultural representation of mental disorders in a highly disadvantaged social context, which magnifies experiences of stigma and shame.

The not always conscious reaction to such feelings is often to take on burdensome care duties (despite the availability of facilities with professional workers), to be drawn to action (for instance, setting their dependent up for several jobs, forming associations, actively cooperating with the social workers), and finally to assume attitudes of omnipotence, ostensibly decisive for their dependent's needs ("I'm the only one who understands," "Were it not for me, he would be lost").

These attitudes are high-maintenance, because of the inherent difficulties of care-giving as well as of avoiding the relevant emotional burdens described before; they also appear to adversely affect the caregivers' social functioning, because they prevent the caregivers from tending to their daily duties without their dependent's involvement. A further consequence is the caregivers being unable to carve out spaces for themselves and the pursuit of their own interests and personal relationships, with important constraints to their independence, and severe repercussions on their personal well-being and relationships with the other family members.

Our analysis certainly shows some limitation: the realization of the research process required considerable difficulties in recruiting participants in the cultural context characterized, as described, of

many social stigma issues; moreover, long time required transcription and analysis of interviews as well as the consequent process of reflection and discussion about the proposed questions. Nevertheless, this analysis process can enrich the understanding of the narrative experience of mental illnesses, describing intra/inter-subjective, local and contextual characteristics of sense-making processes (De Luca Picione, 2013, 2015; De Luca Picione, Dicé, & Freda, 2015; De Luca Picione & Freda, 2016a, 2016b, 2016c; Freda, De Luca Picione, & Martino, 2015).

Furthermore, this inquiry helped us to understand specific forms of the experience of illness and cultural contents related to them. This information can facilitate operators to design, initiate and implement clinical activities aimed to support patients and their families. The severe effects of caregiving on the social, psychological, and physical well-being of our interviewees prompted us to conclude that the implementation is necessary of structured services specifically targeted to caregivers, especially for those facilities serving disadvantaged communities. It is paramount to promote processes of elaboration and comprehension of SMI, support individuals caring for dependents against their feelings of loneliness, and reshape the dynamics of mutual control present in the caregiver-dependent relationship. Specifically, we believe that such services could be enhanced by shared care practices in a multidisciplinary team (i.e., a team comprising different professionals: psychiatrists, psychologists, social workers), suited to provide adequate support to patients and their relatives, in both the therapeutic setting and the integration with the local community.

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