Completing the picture of informal caregiving to individuals with mental illness: An interdisciplinary outline

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ABSTRACT: Despite the particularity of the social context of family caregivers of individuals with mental disorders, most of the existing studies inquiring their situation apply a limited scope of conceptions such as adaptation, burden or emotional management. These are typically applied when studying other categories of informal caregivers. The article discusses the theoretical perspectives, which by shifting from the deficit orientated perspective of an individual in a disadvantageous situation to a strength-orientated one could valuably expand the current discourse and help understand new dimensions of the subjective experience of this category of family caregivers.

1. Introduction

The negative impact of mental illness related stigma on various life domains of individuals afflicted with mental ill-health, as one of the most significant social dimensions of mental health, has received more attention in the academic and clinical discourse in the last three decades. Experiencing stigma due to mental health status results in internalizing negative stereotypes by the afflicted individuals (self-stigma), hinders quality of life (Corrigan *et al*., 2005; Rosenfield, 1997), poses threats to their physical health (Wahlbeck *et al*., 2011), and to their academic achievements (Yang *et al*., 2007) and employment prospects (OECD, 2012). The spoiling consequences have been noted also in the studies of families of individuals with mental health problems (Angermeyer *et al*., 2003; Birenbaum 1992; Muhlbauer, 2002; Phillips *et al*., 2012). Family caregivers accompanying their close ones with mental illness were found to suffer not only from watching the ill relative being

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discriminated, but also from being assigned the guilt for their relative's illness, being ashamed or socially excluded (Angermeyer *et al*., 2003) which makes their experience different from other categories of caregivers.

Two thirds of family caregivers participating in a peer-to-peer taught educational program 'Family To Family' (FTF) from the United States of America (USA) reported thinking about stigma-related caregiving experiences at least sometimes (Muralidharan *et al*., 2016). In a study performed on a sample of family members of first-admission psychiatric patients (parents living with patient, parents not living with a patient, spouses), more than half of the respondents reported making some effort to conceal the hospitalization of an ill relative (Phelan *et al*., 1998). Those who most likely somehow managed the information were parents not living with the patient. Only every twelfth of all respondents spoke about the psychiatric hospitalization with a number of people: these were most often parents living with patients and spouses (Phelan *et al*., 1998).

Despite the above-mentioned particularity of the social context of family caregivers of individuals with mental health problems, most of the existing studies conducted to outline their experience adopt concepts typical for studying other categories of informal caregivers. Social science discourse on family caregivers of individuals with mental disorders has been limited to a few conceptions, such as adaptation, burden or emotional management. Less empirical and theoretical interest has been dedicated to understanding coping strategies, stigma management, factors of resilience or empowerment of individuals accompanying their ill close ones.

By referring to the most informative empirical studies from various countries[1] and contemporary interdisciplinary theoretical works, this article offers a thorough outline of the dominant perspectives used in academic discourse to problematize the experience of providing care to a relative with mental ill-health. Moreover, the article identifies the theoretical perspectives that could valuably expand the current discourse and help understand new dimensions of the experience of this group of family caregivers.

The application of the proposed framework informed the author's doctoral study aimed at reconstructing the subjective experience of courtesy stigma among family members of

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[1] Due to difficulties in accessing the research populations and creating a sampling frame, available studies on families of individuals with mental health problems are all based upon non-probability purposive sampling. Therefore, results taken from the available research cannot be easily generalized for the whole population.

individuals with schizophrenia, engaged in non-governmental organizations devoted to mental health, as well as exploring their positive coping. The concepts hereby presented provided a broad theoretical context enabling the researcher to approach the research problem in an innovative manner by looking at the experience of stigmatization as well as at resources facilitating coping with difficulties that result from adverse social surroundings. Moreover, the conceptual framework helped to grasp the complexity of the studied phenomena with a usage of qualitative methods and analyse the gathered data covering various components of caregivers' experience[2].

2. The processual perspective on accompanying a relative with mental illness

The processual approach to describing the experience of accompanying a relative with mental problems delivers an understanding of how families' attitudes, opinions and emotional responses change over time as the processes of defining their relative's psychiatric diagnosis and treatment progress. This sub-section presents the most noteworthy findings from the available studies whose processual interests were focussed on various aspects of family experience.

Based upon rich material from in-depth interviews with US children, spouses, parents or siblings of individuals with major mental illnesses (uni-polar depression, manic-depression or schizophrenia), David Karp and Valaya Tanarugsachock (2000) argue that there is a predictable schema of feeling frames determining the affective state of family caregivers, as they accompany their relative through time. The researchers claim that this specific dynamics of emotion management is parallel to a discernible career path that a family member follows over time, and that the shift in a caregiver's emotional response transforms as their perception of obligation to the ill relative alters. The dynamics of emotional management comprised four emotional phases: emotional anomy, empathizing with the ill relative, frustration and acceptance. The initial phase entails a strong emotional response to the occurrence of highly confusing behaviour by a relative, and features great uncertainty, anxiety and sheer confusion. A strategy to cope with the emotional anomy that appeals to many family

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[2] At the time of writing this article, future publications of the study's results are still being prepared.

caregivers is to deny the possibility that the relative is mentally ill. The collected material urged the researchers to introduce the metaphor that a psychiatric diagnosis thrusts the whole family into a different culture, which proposes a new perspective for the functioning of the relative and organizes the situation according to its particular norms. The process of ambiguity ends with diagnosis, which provides a feeling of release, greater efforts to learn about mental health, and a strong commitment to finding a cure for the patients by many of their caregivers. No matter how challenging it is, due to the particular difficulties the diagnosed family member experiences, the care-giving relatives try to empathize with him/her. An ill relative's lack of an ability to reciprocate to family caregivers leads to negative emotions. As time passes by, the loss of expectation from before the diagnosis leads to intense frustration and anger. Only the realization that the relative's fate is not the caregiver's fault, and so it is not in their power to fully control the situation, enables the caregiver to renegotiate the boundaries of obligation and once again accept their child, spouse, parent or sibling's situation (Karp & Tanarugsachock, 2000).

A similar dynamic of the phenomenon of accompanying a relative afflicted with mental illness is presented by Monika Frąckowiak-Sochańska (2015) in her analysis of biographical accounts of Polish and German relatives of people with mental illness. She describes the process of affective-cognitive adaptation to the situation of mental illness that relatives experience over time. The process involves four stages. The first relates to early cognitive and affective reactions to the disturbing behaviour of a relative. The stage is also characterized by anxiety at various levels of consciousness, as well as an overt or latent frustration and anger. The inability to remove the cause of those reactions leads to sadness, loss in mental and physical strength, as well as a tendency towards isolation. In order to decrease the level of anxiety, at the second stage of adaptation, relatives make efforts to sustain family life's status quo by denying the fact of a family member's mental problems. A mechanism useful in the second stage is therefore denial. The third stage of the adaptation process involves confrontation with the illness, and introduction of changes in relation to the afflicted relative and the whole family system. It becomes possible only after the conscious experience of losing feelings of security, expectations of the afflicted relative's and one's own future, and one's own vision of the family. As the tension of the third stage is released, the final stage of the proposed adaptation process can commence. As in Karp and

Tanarugsachock's analysis of emotional framework, Frąckowiak-Sochańska also observed the emergent acceptance of their inability to rewind the past (Frąckowiak-Sochańska, 2015).

Another valuable account of family caregiving was provided by Patricia Howard in her qualitative study from the early 1980s in the USA. Owing to the fact that a number of individuals who had schizophrenia diagnosed in their twenties became chronic sufferers, a family's need to accompany them may last decades. A frequently observed pattern of providing care in the family is that parental dedication to the child's needs is prolonged and extended. Care for an adult with schizophrenia is therefore often provided by parents of an advanced age, mainly mothers who dedicated their lives to an adult child. Howard (1994), based on a lifespan perspective and qualitative data from in-depth interviews and respondents' diaries on caregiving, described mothers' perception of engagement in caregiving, from the onset of the child's illness to the time of the research. The material obtained led to conclusion that mothers perceived their prolonged maternal care as consisting of watching (intense vigilance), working (the physical and mental tasks of care giving increased the period normally ascribed to parenting) and waiting (worrying about a child's future after the parents' death). Howard also proposed a model of learning to live with a child who has schizophrenia. It refers to a forward movement of the lifespan trajectory, with possible temporal regression to earlier stages. The process compromises four stages: perceiving the problem, searching for solutions, enduring the situation, and surviving the experience.

The first stage is the period when non-specific signs of the problems are observed and their severity realized, causing a feeling of bewilderment and uncertainty. The next phase has, for most mothers, been the moment of receiving the diagnosis but few details about the disorder. While the lack of information about the illness contributed to tension among the mothers, the second stage typically involved the searching out of information and efforts to understand the nature of schizophrenia. Mothers described their conscious experiences at this stage as 'anguish' and 'living grief' concerning the state of the illness. A daily struggle with the illness required great endurance on the part of the mother. As time passed, and with continual care giving, the mothers experienced progress in managing the situation. The turning point in the third stage is, however, acknowledging the biological aetiology of schizophrenia. The final stage in the model covers accepting the situation and regaining hope,

as well as stimulates determination in facing the challenges of caregiving. One of the participants of the study explained that one constant challenge is the pervasiveness of sorrow connected to accompanying a relative with schizophrenia: "When someone dies, you grieve and then you go on. With schizophrenia, you grieve so many endless griefs" (Howard, 1994: 112). Hope and acceptance occur after a reduction of feelings of guilt, and a reinforcement in mothers' determination with their care giving efforts (Howard, 1994).

An analysis of family caregivers' experiences influenced by having obtained institutional help has been covered in studies by Susan Muhlbauer (2002) and Anita Pejlert (2001), conducted in two settings with differing medical care setups. In her qualitative study, Muhlbauer investigated experiences of families of individuals with schizophrenia or bipolar disorders living in the USA, who participated in psycho-educational programmes. The experience of 26 interviewed family caregivers was reconstructed in six phases and presented as an analogy of 'navigating through the hurricane'. It starts with a phase of developing awareness, which incorporates increasing concerns about problematic behaviours of a relative and inefficient effort to seek help. Next, relatives move on to a phase of crisis.

The second phase is characterized by traumatic episodes and entering mental health services. Institutional care is connected to encountering various inconveniences, such as financial troubles resulting from the cost of medical help, as well as insufficient and/or inadequate provision of information by medical professionals. On the other hand, getting a medical diagnosis seems to be a relief for the relatives. Further experiences of families were metaphorically presented as 'a drift on perilous seas', which reflects continuous instability, failure to search for explanations, further financial problems, dissatisfaction with mental health services as well as experiences of stigma (Muhlbauer, 2002).

The other study illuminates parental experience of care giving to an adult child with a severe mental illness in a Swedish community-care setting. Using a phenomenological hermeneutic perspective, Pejlert analysed parents' narratives regarding placing their ill children in a group residence/flat. Her study revealed components of the experience of being a parent of a child receiving professional care: living with sorrow, anguish and constant worry, living with guilt and shame, relating with carer/care; comfort and hardships; coming to terms with difficulties and hoping for a better life for the adult child.

The first element of the pattern consisted of grieving for the lost child and being constantly worried about the child's poor health condition. It was also typical for parents to blame themselves of being responsible for their offspring's illness and experiencing shame due to rule-breaking behaviour of the ill child.

The second component of Pejlert's respondents' experience was ambiguity towards formal carers: on the one hand they were satisfied with their work, on the other hand, the lack of full control over the process of care giving caused feelings of dissatisfaction. Pejlert pointed out that parents dealt with the situation in different ways: either by concentrating on the advantages of the situation, or on the drawbacks and efforts to take hold of some actions and influence them. Finally, the year-long experience leads to the development of a hopeful attitude and concentrating on the positive moments while accompanying the ill child (Pejlert, 2001).

3. Family Burden

The processual perspective on the experience of families accompanying their relatives with mental health problems exposes a long-term struggle to accept a relative's mental condition and how burdensome this experience may be. Even in cases of receiving substantial support in caring for an ill adult child, parents termed their involvement 'endless parenting' (Pejlert, 2001). The costs of prolonged care and dedication of parents or other family members, has been studied as family burden. It is conceptualized as the sum of objective losses and disruptions to family routines and subjectively experienced worries and tensions related to the process of caring (Schene *et al.*, 1998). Numerous studies on this phenomenon demonstrate that, for a significant proportion of relatives, care giving to a family member with a mental disorder results in the emergence of feelings of loss, worries about the ill relative's future and feelings of not being able to bear the situation any longer (Hadryś *et al.*, 2011; Magliano, 1998).The most recent exploration of this problem among families of individuals with mental illness was accomplished in 2015 within "The Caring for Carers Survey"[3]. The burden of care was conceptualized here as occurring in several life domains:

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[3] The study was conducted by an academic research team from the Centre for Care Research and Consultancy of KU Leuven in cooperation with EUFAMI with a self-completion questionnaire administered on paper, by

emotional, social, physical, financial, concerning safety, and relationships. For a large number of family caregivers, the relationship with the person they care for was of serious concern. More than half of all respondents in the survey worried that the ill relative would become too dependent on them in the future. Around four out of ten family members worried that he/she was too dependent at that moment and were distressed with strains in the relationship with the ill relative or with upsetting things he/she said. Around one-third of families were concerned about reaching a 'breaking point' when one cannot carry on with the situation or felt irritable with the ill relative. The second most bothering aspect of care giving for a relative with mental health problems were financial issues, including the situation of the ill relative, of the caregivers themselves and the extra costs connected with caring.

Another life domain in which they experienced a sense of burden regarded emotional coping. More than one third of the respondents reported that constant caring, lack of sleep due to stress or worrying, feelings of depression, and the negative effect of exhaustion of one's ability to function were all troublesome. A less common tendency was to perceive things negatively and to lack sleep because of having to provide care to the ill relative at night.

Physical burden was also declared as causing serious concern by one in three family caregivers. Moreover, some of the relatives' worries regarded safety. Nearly one in four caregivers had concerns about a relapse or deterioration that could put a relatives' safety in danger, and nearly one-third worried about their close ones getting themselves into dangerous situations or self-harming. Less family caregivers declared being concerned about the ill relative becoming aggressive towards the caregivers or accidentally doing something dangerous to them.

Finally, every third family member who provided care to his/her ill relative worried about feeling isolated, not getting the support needed from their close ones, or losing contact with family and friends because of their responsibilities. One in five was concerned about conflicting roles as a result of the caregiver's duties. Burden from at least two domains is experienced by nearly four out of ten family caregivers, while burden from three or more domains is experienced by every third. Only 28% of the respondents in the study did not

email and online in Australia, Austria, Belgium, Canada, Cyprus, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Malta, Netherlands, Norway, Portugal, Russia, Spain, Sweden, Switzerland and UK (Vermeulen *et al.*, 2015).

report any burdening experience. Some particular characteristics of family caregivers are associated with a higher level of experienced burden, such as being female, of a young age, not getting by financially, a higher number of hours of care giving in the previous week, and being the only caregiver (Vermeulen *et al.*, 2015).

A study conducted by Tomasz Hadryś and colleagues (2011) on burden of caregiving, describes the situation of families in Poland. In the inquiry, burden was operationalized as a sum of the subjective burden covering worrying and tension, and the objective burden covering supervision and advice. A vast majority of the responding family caregivers reported worrying about a relative's general health (82%), his/her future (74%) and financial status (66%). A substantial proportion of the caregivers (65%) struggled with urging relatives to undertake any kind of activity during the day. Another study conducted in Poland reported that, due to the mental burden, 22% of the caregivers needed professional support from a psychologist and/or psychiatrist (Wojciechowski *et al.*, 2015). The type of psychiatric diagnosis was proven not to be associated with the level of family burden of caregiving. Caring for patients with anxiety or personality disorders was just as burdensome as caring for patients with schizophrenia or depression (Hadryś *et al.*, 2011).

However, a difference in the experience of burden was observed when comparing family caregivers of individuals with mental disorders with those caring for individuals with intellectual disorders.

A study from the USA tested the impact of mental disorders and intellectual disabilities in adults on the experience of lifelong caregiving responsibility among mothers aged 64 and over. It demonstrated that mothers who have taken care of their adult children with either mental (mainly schizophrenia) or intellectual (mainly Down syndrome) disabilities, tended to use the same coping strategy, i.e. problem-focused coping. However, those two groups of mothers differed in their ability to reduce their risk of depression. While the mothers of adult individuals with intellectual disabilities were able to decrease the risk, mothers of adult individuals with mental illnesses were not.

The researchers pointed at the context of caregiving as a significant variable here. They claim that little control over stress related to the irregular, cyclical nature of mental illness, in comparison to the stability of the states of adult children with intellectual disabilities, determined the difference (Seltzer *et al.*, 1995). Moreover, the mothers of individuals with

mental illnesses had a smaller social network, and their close relations were more often established with other women with mentally ill children. Nearly seventy percent (65.7%) of their friendship network represented women with a similar family situation, as compared to a half (51.1%) of friendship network of mothers of individuals with intellectual disabilities (Greenberg *et al*., 1997).

Additionally, some later studies revealed that mothers of adults with mental illnesses felt significantly more pessimistic about their children's future. They also reported greater caregivers' burnout than in mothers from the other group (Greenberg *et al*., 1997). What also determines family burden is the patient's degree of impairment in daily life, as well as the carer's characteristics (Wittmund *et al*., 2002).

Furthermore, the contextual factors connected to healthcare systems in various countries, including accessibility, scope and quality of institutional assistance provided to an individual with mental health problems, as well as different levels of mental health awareness and culturally varying coping strategies, have been discussed as crucial factors impacting the international variations in the level of burden on caregivers. The available research on family burden revealed that Polish families of individuals with mental health conditions are distinct in this respect from families in Western European countries. Namely, in Poland family caregivers experience more burden of caregiving when compared to those in Western European societies.

In case of caring for individuals with schizophrenia, the difference is 13% (74% caregivers in Poland and 61% in Western Europe reported burden) and in cases of caring for relatives with depression, 22% more Polish families declared experiencing burden (66% vs. 44% respectively) (van Wijngaarden *et al*., 2004; Hadryś *et al*., 2011). The researchers interpret this dissimilarity mainly as resulting from the worse accessibility to community services and extensive institutional neglect of patient's family needs in Poland, compared to societies with a better-developed Welfare state (Hadryś *et al*., 2011). Moreover, research from the United Kingdom indicates that the support offered to family carers needs to be of an adequate quality. A lack of cooperation, reciprocal distrust and disrespectful treatment by mental health professionals towards the family caregivers increases a sense of burden and distress, and causes feelings of being ignored and marginalized amongst the carers (Askey *et al*., 2009).

Another conceptual approach to describe the particularities of this caregiving experience emphasizes this activity's stressfulness. This particular research perspective discusses parents', spouses' or children's experiences of taking care of their ill relatives either as a chronic stressor – some symptoms are maintained over a long period of time, or as discrete life events – when a specific situation, i.e. hospitalization or encounters with the police, is taken into account (Avison & Comeau, 2013).

In the Polish study from 2015, taking care of a relative with schizophrenia has been indicated as one of the strongest sources of stress. On a scale from 0 (not stressful at all) to 10 (the most stressful) the responding relatives assessed their situation of providing care on average at 7.9 (Wojciechowski *et al*., 2015). Chronic stress and strain connected to caregiving of individuals with another mental disorder – bipolar disorder – has been analysed by Deborah Perlick and colleagues in relation to the caregivers' risk of developing depression. It has been found that 40% of family caregivers reported experiencing some depressive symptoms. Depression in caregivers was then associated with the perception of courtesy stigma. Families anticipating rejection and/or embarrassment tend to adopt ineffective coping strategies, such as avoidance, or retreat from social support, which may lead to depression as a result (Perlick *et al*., 2007). Experience of courtesy stigma among family caregivers of individuals with Alzheimer's disease was also found to increase caregivers' burden (Werner *et al*., 2012). Also the caregivers' thoughts about stigma-related experiences, i.e. secrecy, concealment and being stigmatized, were associated with caregivers' distress (Muralidharan *et al*., 2016).

4. Managing stigma and positive adaptation

The concepts of stigma management, coping strategies or caregiving satisfactions provide a different perspective on the experience of accompanying a relative with a highly stigmatizing condition. Erving Goffman (1963) argued that the management of stigma depends on the visibility of the stigmatizing attribute. Management strategies typical for discredited individuals are those particular daily arrangements, undertaken by stigma carriers, to reorganize their engagement mainly in a public life, interactions with strangers or mere acquaintances. Relations characterised by intimacy, i.e. within a close family, are typically

free from those additional efforts. Since these easily visible attributes are particularly crucial for interactions with strangers, a strategic breaking through aims at the normalization of the discrediting characteristic by reaching more personal levels between stigmatized and stigmatizing. Gradually, the discredited individuals start to feel sheltered among those with whom they interact on a regular basis.

Goffman (1963) illustrated the variety of stigma management strategies by drawing a continuum between stigmata that are unknown to anyone, including their carriers, at the one end, and stigmata that are familiar to everyone associated with the carrier, at the other. On the continuum between those extremes of complete secrecy and full transparency, there are stigmatized individuals who pass their stigmatizing attribute from one social group, and expose it to another. There are also others whose tabooed traits are generally firmly concealed, but which are shared within some very close relations. There are also others whose stigmatizing attributes are apparent, yet in certain situations some of those who encounter the individual do not realize the stigmatized status.

The dominant tendency is, however, to conceal the secret of the carried attribute. Independent from the scale of passing, it requires having a double life, which consists of contact with those to whom the stigma was disclosed and with those who, lacking this knowledge, assume the individual's normalcy. The individual biography available to each of these groups differs. Concealment carries the risk of being discredited should the individual have a slip – a shameful incident. Goffman (1963) also noticed that passing is connected with high personal costs, including experiencing the anxiety associated with the danger of others learning about the concealed truth. On the other hand, Goffman discusses that deciding on a strategy of passing could be the result of an individual having problems identifying with a new group, and at the same time disdaining themselves for not reacting to insulting comments addressed at the category of people that individual may belong to. A positive stigma management strategy in Goffman's theory is one that results in positive outcomes, understood as gaining social acceptance as well as regaining some degree of normalcy:

> After laboriously learning to conceal, then, the individual may go on to unlearn this concealment. It is here that voluntary disclosure fits into the moral career, a sign of one of its phases. It should be added that in the published auto-biographies of stigmatized individuals, this phase in the moral

> career is typically described as the final, mature, well-adjusted one – a state of grace (Goffman, 1963: 124)

Yet, Goffman's elaboration on the techniques of controlling, hiding and passing does not cover individual's ability to challenge the consequences of unequal treatment resulting from the processes of labelling and stigma theory.

In psychology, on the other hand, a great body of research addresses the problem of external and internal requirements by applying the concept of coping, typically defined as strategies aimed at tackling hardships and handling stressful events (Heszen, 2013: 61). The majority of psychological research on coping suggests that measures applied in response to stressful events are emotion-orientated or task-orientated (Lazarus & Folkman, 1984). Reactions to particular life events, i.e. the loss of a spouse, comprise loss-orientated coping and restoration-orientated coping, as for example the death of a wife or husband causes both emotional and cognitive challenges to the widower or widow, as well as financial, legal and organizational difficulties.

Classical psychology approaches coping as an individual's disposition to behave in ways that extend the regular possibilities of that individual. Individuals respond to stressful events by applying different coping styles or strategies, which have been categorized as: information seeking or information avoidance strategies (Carver *et al*., 1989); task-oriented, emotion-orientated or avoidance-orientated styles of coping (Endler & Parker, 1994), as well as active coping, planning, instrumental seeking of support, seeking emotional support, concentration on emotions, disengagement, denial, acceptance, religion or humour (Miller & Kaiser, 2001). In the rich body of psychological research on coping strategies, psychologists confirm that some particular conditions determine the probability of applying particular strategies. For example, having control over a stressful situation brings about a more confrontational coping style, compared to uncontrolled situations, in which individuals tend to apply avoidance coping strategies (Heszen, 2013).

In the last decades, the discourse has broadened the conceptualization of care giving outcomes to advantages of engaging in caregiving. Some studies indicated the experience of gratification by family caregivers for providing assistance to their close ones (Bulger *et al*., 1993). In the Polish study from 2015, the family caregivers reported seeing a positive impact of their assistance on the mental health state of their relatives. On average respondents

evaluated it at 8.4 on a scale from 0 (no impact on the mental health state of the relative) to 10 (very positive impact on the mental health status of the relative) (Wojciechowski *et al.*, 2015).

This emphasis of internal and external resources supporting informal caregiving has attracted a relatively small number of studies so far. It is still unpopular to research a family's potential for – and resources that foster – empowerment in the encounter of various adversities in accompanying a relative with mental problems. For example, the factors of resilience, defined as "potential for recovery, repair, and growth in families facing serious life challenges" (Walsch, 2007: 399), facilitate positive coping and adaptation to hardships individuals encounter, as well as enabling recovery and growth.

The subject of resilience can be both an individual and a family unit. A single available study on resilience with regards to family caregivers of individuals afflicted with severe mental illnesses has been conducted recently by Melanie Bishop and Abraham Greeff (2015). They applied a mixed-method approach to explore factors supportive to families' adaptation after a member had been diagnosed with schizophrenia. The performed quantitative measurements suggest a relation between the ability to positively manage the situation of a relative's psychiatric diagnosis and relatives' psychological qualities, their soft-skills, family-life practices, environmental resources, as well as the family's social status. Moreover, the following nine quantitative measures relate positively with a family's resilience and its ability to adapt: family hardiness; style of communication during a crisis; commitment to the family; positive reframing; supportive communication patterns; special events and family time; degree to which the family finds support in their community; internal locus of control and family income.

The first factor, family hardiness, indicates how much a family is able to resist stress and endure a demanding situation, and has been found to be the strongest predictor of the ability to adapt after the psychiatric diagnosis of a relative. Secondly, since clarity of communication facilitates problem solving, an effective form of communication between family members is highly important to adapt to unknown conditions of crisis. Thirdly, being involved on behalf of a family group remains crucial for solving its problems and staying supportive for each other. Fourth, being able to learn about the new situation and approach it as a challenge has been found to be a vital cognitive feature of family caregivers. Fifth, sharing experiences and

views among family members in stressful conditions enables the whole family group to remain together and support each other despite the crises. Sixth, customary family gatherings and spending time together unites the family and enhances its internal resources. Seventh, accompanying a relative with mental problems is so burdensome for a family that receiving support for the family caregivers themselves in the form of support and/or educational workshops is essential. Eighth, a psychological readiness to feel in control over the situation and perceive meaning in life fosters better coping. Finally, a psychiatric diagnosis may become a source of financial burden to family caregivers. Having financial support empowers family groups to better adapt to the challenge.

In the qualitative part of the inquiry, Bishop and Greeff (2015) found that there are also some factors related to functioning of a diagnosed individual, as well as his/her family's attitude toward the relative's health condition, that determine the level of a family's resilience. The former category includes: the extent to which the ill relative adheres to medication, independence, involvement in the community, having some responsibilities, certain routines and activities, as well as a positive attitude and attending support groups for people with schizophrenia. The other category covers the ability of a family to accept their family member's diagnosis. Other studies proved that the better the communication between community services and the patient's family, the stronger the resilience of the relatives (Bishop & Greeff, 2015).

Some studies, which I present briefly below, suggest that planned educational interventions can enhance coping capabilities with a relative's mental disorder. Recognition that therapeutic endeavours aimed at modifying dysfunctional families of individuals with symptoms of schizophrenia were ineffective gave birth to psycho-educational programmes addressed towards relatives. This change of therapeutic perspective required professionals to transition from an approach that excluded and blamed relatives for the destructive impact on an ill family member, to one of engaging families, sharing information about the illness with them, educating and teaching them how to cope with the burden of care giving. This new perspective evolved into various models of cooperation with relatives: individual family consultation, single-family and multifamily group formats, traditional family therapies, professionally-led family psycho-education or short term family education, as well as family-led information and support groups (Dixon *et al*., 2001; McFarlane *et al*., 2003).

A number of studies conducted since the 1980s have demonstrated that meeting the needs of a family improves patient's prospects. A treatment that includes family intervention is clearly superior to the usual care of patients with schizophrenia. A meta-analysis of 25 studies, examining the effectiveness of intervention programs to educate relatives and help them cope better with patient's illness, has demonstrated that patient's relapse rate was reduced when his/her family caregiver/s participated in psycho-educational initiatives. A significant worsening of symptoms or re-hospitalization in the first years after hospitalization has been found to be reduced by 20 percent when family members have received support. The effect was especially evident when help to the family continued for more than 3 months.

Whether the effects of psycho-educational intervention remain stable over a longer period of time has not yet been established. Regardless of the orientation of the intervention (psycho-educationally or therapeutically oriented), significantly better results were observed when family intervention was offered additionally, compared to when standard medication-only treatment was provided ($p<0.0001$ and $p<0.001$) (Pitschel-Walz *et al.*, 2001). A recent experiment conducted in Jordan on a group of family caregivers of individuals with schizophrenia, demonstrated the benefits of psycho-educational intervention devoted to increasing awareness about neuroleptic medication. This finding proves that enhancing family caregivers' understanding of the illness might help in the reappraisal of caregiving demands, and facilitate coping with problematic behaviour (Al-HadiHasan *et al.*, 2017).

5. Conclusions

Taking into account estimations from the WHO according to which one in four families has at least one member currently affected by mental or behavioural disorder (WHO, 2001), accompanying a relative with mental health problems is not a rare experience. However, despite the potential number of individuals related to somebody with mental illness, accompanying some close person struggling with mental illness remains a cultural taboo (Angermeyer & Matschinger, 2003; Coppens *et al.*, 2013), which might impact informal caregiving in a large part of the population. Therefore, further works on family caregivers' experience are necessary in order to enrich our understanding of their situation.

The dominant approach to describe the experience of relatives accompanying their close ones concentrates on caregiving burden. Little theoretical and empirical attention has been given to the resources of the families and their potential to tackle the outcomes of mental illness related stigma. To complete the understanding of the experience of caregiving to individuals with mental health problems it is crucial to shift the approach from the deficit-orientated perspective of an individual in a disadvantageous situation to a strength-orientated one. Indeed, a perspective grasping relatives' involvement in non-governmental organizations and their efforts to tackle the adverse social context is beneficial for learning about factors facilitating families' empowerment and conditions conducing to constructive coping with the challenges brought up when accompanying individuals with mental health problems.

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