



## Aging With Schizophrenia: A Lifelong Experience of Multidimensional Losses and Suffering



Hila Avieli <sup>a,b</sup>, Peli Mushkin <sup>b</sup>, Tal Araten-Bergman <sup>c</sup>, Tova Band-Winterstein <sup>b,\*</sup>

<sup>a</sup> Department of Criminology, Ariel University

<sup>b</sup> Department of Gerontology, University of Haifa

<sup>c</sup> School of Social Work, University of Haifa

### A B S T R A C T

The aim of this study was to explore the subjective experience of suffering in aging individuals with schizophrenia. Qualitative interviews were conducted with 18 participants aged 60–69. Phenomenological content analysis was performed. Nine dimensions of suffering emerged: social rejection; familial rejection; the symptoms of schizophrenia; hospitalisation; the side effects of medication; loss of employment potential; loss of independent accommodation; loss of social life, and loss of hope to be a partner and a parent. The suffering of aging people with schizophrenia is cumulative and ongoing and thus evokes issues such as existential loneliness and feelings of homelessness.

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The number of older adults with severe mental illness is expected to increase dramatically in the next 20 years due to the aging of the general population and the decrease in mortality rates among adults with psychiatric disorders (Palmer, Heaton, & Jeste, 1999). Despite this anticipated increase, little is known about the lives of aging people with schizophrenia (APWS) (Folsom et al., 2006). Previous studies of APWS revealed lifelong deprivation due to poverty, abandonment and drug use (decreased quality of life (Bartels & Pratt, 2009) and social isolation (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006). However, the negative aspects of schizophrenia often present a broken and fragmented reality and poorly reflect the holistic experience of the suffering involved in living with a severe mental illness (Geanellos, 2005). Virtually absent from the literature are studies that offer narratives of APWS who talk about their life experiences (Adame & Hornstein, 2006). Therefore, the aim of the current study was to explore and comprehend the subjective experience as expressed by persons with schizophrenia reaching old age, thereby improving the social visibility of this excluded group of individuals.

### SUBJECTIVE EXPERIENCE OF AGING PEOPLE WITH SCHIZOPHRENIA

Schizophrenia, as a chronic condition, usually begins with a premorbid phase that is manifested in developmental, emotional and cognitive problems accompanied by socio-behavioural deterioration in functioning. The disease develops into the prodromal phase that is manifested in psychotic symptoms. This is followed by a psychotic phase characterised by recurrent psychotic episodes, and finally, the stable

phase, which is characterised by general dysfunction in all aspects of life (Walker, Kestler, Bollini, & Hochman, 2004). In this fourth and final stage, people with schizophrenia usually enter their aging years.

Research of aging people with schizophrenia (APWS) has generally focused on the course of the illness and its symptom manifestation in old age (Cohen, 1990). Studies indicate that, in old age, people with schizophrenia experience fewer positive symptoms, such as hallucinations, delusions, and thought and movement disorders (Davidson et al., 1995), whereas the intensity of negative symptoms, such as flat affect, lack of pleasure in everyday life, poor executive functioning, trouble focusing or paying attention, might increase (Cohen, 1990) or decrease (Davidson et al., 1995). Cognitive changes are parallel to those seen in the general aging population (Berry & Barrowclough, 2009). Social functioning of APWS, including marital and parental status, social contacts, residential status and occupational status, is usually well behind that of healthy peers at a similar age (Meesters et al., 2010). In line with these findings, studies of quality of life among APWS reveal significantly lower quality of life than that of persons of a similar age without schizophrenia (Jeste et al., 2003). The controversy over this heterogeneous picture of schizophrenia in old age cannot be complete without the subjective experience of the persons with schizophrenia themselves, which is currently missing from the debate (Adame & Hornstein, 2006).

The subjective experience of APWS has been scarcely investigated (Larsen & Gerlach, 1996). Few qualitative studies have focused on the way that APWS perceive their lives in old age, including the positive and negative changes brought on by aging (Shepherd et al., 2012), feelings of increased vulnerability (Martinsson, Fagerberg, Lindholm, & Wiklund-Gustin, 2012), loss of dignity and identity, as well as loss of family, friends and other aspects of “normal” life (Martinsson et al., 2012) and hopes and fears for the future (Shepherd et al., 2012).

\* Corresponding Author: Tova Band-Winterstein, Ph.D., Department of Gerontology, University of Haifa, Mt. Carmel, Haifa, 3498838, Israel.

E-mail address: [twinters@research.haifa.ac.il](mailto:twinters@research.haifa.ac.il) (T. Band-Winterstein).

Whereas these studies offer a glimpse into specific domains in the lives of APWS, the current study offers in-depth insight into these individuals' experience of suffering.

### THE CONCEPT OF SUFFERING AS A THEORETICAL FRAMEWORK

Suffering is an important, yet illusive phenomenon in healthcare (Rodgers & Cowles, 1997). It has been defined in medical, psychological and religious idioms as "a state of severe distress associated with events that threaten the intactness of the person" (Cassel, 1982, p. 640). This all-encompassing definition refers to the nature of suffering as a threat to an integrated existence, which affects the individual on many fronts, and may reach and consume the core of the self (Black & Rubinstein, 2004). In the Western medical model, suffering is usually connected to bodily pain, as a symptom of illness or disease. The sufferer, however, often states that suffering is multidimensional and more encompassing than pain (Black & Rubinstein, 2004). Therefore, it has been claimed that suffering is a lived experience of the total person and not an isolated behavior (Duffy, 1992). Existential philosophy (Frankl, 1963) and nursing research (Rodgers & Cowles, 1997) have engaged with the concept of suffering. However, only few studies have explored this phenomenon from the perspective of persons who experience it (Pilkington & Kilpatrick, 2008). This personal perspective is lacking from the overall discussion of suffering (Black & Rubinstein, 2004; Pilkington & Kilpatrick, 2008) and thus exploring the subjective experience of suffering among APWS may enrich our knowledge of the phenomenon.

### NARRATIVES OF SUFFERING AMONG AGING INDIVIDUALS

Suffering accrues across the age spectrum from childhood to old age (Starck & McGovern, 1992). However, the experience of suffering might be especially familiar to older persons, considering the heightened incidence of chronic and acute disease, physical pain, depression, decline in mobility, more frequent loss and nearness to death (Pilkington & Kilpatrick, 2008). The literary discussion regarding suffering in old age is assembled from studies that have focused on specific aspects, such as losses in old age (Black & Rubinstein, 2004), loneliness (Savikko, Routasalo, Tilvis, Strandberg, & Pitkälä, 2005) or pain and disease (Duggleby, 2000). Other studies attempted to explore the holistic nature of suffering in old age (Pilkington & Kilpatrick, 2008; De Medeiros, 2009). These studies pointed out that suffering cannot be localized, and claimed that the experiential content of suffering is ambiguous and complex and thus is a question of meaning rather than a clinical issue (Black & Rubinstein, 2004).

Old people's narratives regarding suffering and losses provide a multidimensional perspective of the experience, rather than flattened out unidimensional constructions (De Medeiros, 2009). It emphasises diminishing dimensions of the self, such as cognitive awareness and physical strength (Rodgers & Cowles, 1997), social suffering due to the cultural bias against old age (Kleinman, Das, & Lock, 1997, and suffering as a result of loss (Black & Rubinstein, 2004).

### NARRATIVES OF SUFFERING IN LIVES OF PEOPLE WITH SCHIZOPHRENIA

A large body of literature has acknowledged the negative consequences of mental illness on lives of people with schizophrenia. These studies referred to various aspects of the disease such as social isolation (DeNiro, 1995), stigma (Jenkins & Carpenter-Song, 2009), diminished ability to acquire and maintain employment (Walkup & Gallagher, 1999) and loss of accommodation (Ogden, 2014).

The experience of suffering in schizophrenia has been investigated by several authors (Martinsson et al., 2012; Baker, Procter, & Gibbons, 2009; Baker & Procter, 2014). The language and metaphors of the medical model that has a dominant place in mental health discourse might marginalise the subjective experience of suffering (Adame &

Hornstein, 2006). Thus, descriptions of the negative aspects of schizophrenia often present a broken and fragmented reality and poorly reflect the holistic experience of the suffering of living with a severe mental illness. It seems that the subjective voice of the suffering person can easily become lost in the impersonal and sometimes dehumanising medical discourse (Adame & Hornstein, 2006).

However, studies on experiences of suffering among APWS are currently lacking. Narrating the experience of suffering is significant at this point of life as it may enable life review processes (Reker, Birren, & Svensson, 2013), which include resolutions of conflicts, insights regarding life events and better understanding of past events (Butler, 1964). Thus, life review enables an identity exploration process that allows people to answer the question of "who am I?" and may provide closure (Clarke, Hanson, & Ross, 2003).

The data presented in this article were drawn from a wide-scale study. The research questions were as follows: 1) How do the APWS describe their life with the illness; 2) What is the meaning attributed to schizophrenia at this stage of their lives?

The aim of the present article was to explore the experiences of suffering as narrated by APWS.

### METHOD

An existential phenomenological tradition was utilised for conducting this study (Spinelli, 2005). The descriptive power of this approach enables in-depth understanding of these individuals' life experience and what it means to them (Rehorick & Bentz, 2008).

The research sample included 18 participants, 11 men and seven women. All the participants were purposefully sampled (Patton, 2002) to meet the following criteria: current age over 60, diagnosed with schizophrenia before the age of 40, living in the community, with verbal, cognitive and mental state capacities that enable conducting face-to-face in-depth interviews. Age range of the participants was between 60 and 69, with an average of 63, and the average age of onset was 22.3. Most of the participants were single or divorced at the time of the interviews and were living in hostels and some of them participated in a sheltered employment arrangement (Table 1).

The final sample size was determined according to the theoretical saturation principle (Morse, 2000). Saturation was achieved by the recurrence of identified themes. As suggested by Bowen (2008), the interviews continued until no new themes or subthemes emerged from the data throughout the initial coding process. In this case, after 18 interviews, the data obtained were rich and deep enough to achieve saturation (Bowen, 2008).

Data collection was performed using semi-structured face-to-face in-depth interviews based on an interview guide designed to cover the key subject (King & Horrocks, 2010). Four main content categories were covered by the interview guide: description of the self and significant others (e.g., Tell me about yourself); self-narration of schizophrenia (e.g., How would you describe your life with schizophrenia through the years?); everyday life with schizophrenia (e.g., Describe your everyday life (activities and interests). How has it changed through the years?) Aging with schizophrenia (e.g., When you think about your age and schizophrenia, what comes to your mind?).

Following approval of the research by the Israeli Ministry of Health, and the ethics committee of the University of Haifa in Israel, potential participants were located by professional managers of rehabilitation facilities, who approached the participants initially. Subsequently, one of the researchers, who also conducted the interviews, contacted the participants directly by telephone, introduced herself, asked for their consent to be interviewed and set an appointment for the interview. This introductory telephone conversation was essential for informing the participants of the topic of inquiry and establishing an initial rapport and trust.

The interviews took place in a location chosen by the participants and the duration of each interview was suited to the needs and abilities

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