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## EMPIRICAL STUDIES

**Struggling for existence—Life situation experiences of older persons with mental disorders**

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**Abstract**

Older persons with mental disorders represent a vulnerable group of people with extensive and complex needs. The older population is rapidly increasing worldwide and, as a result of deinstitutionalization in mental health care, older persons are remaining at home to a greater extent. Although they constitute a large proportion of the population, older persons with mental disorders have been neglected in research as well as in care organizations. As there is little previous knowledge concerning older persons' experiences of their own situations, this study aimed to illuminate the meaning of the life situation as experienced by older persons with mental disorders (excluding dementia disorders). Interviews were conducted with seven older persons and the text was analyzed using a phenomenological hermeneutical research method, inspired by the philosophy of Paul Ricoeur. "Struggling for existence" emerged as a main theme in the older persons' narratives, understood as a loss of dignity of identity and involving being troubled and powerless as well as yearning for respect. The older persons fought to master their existence and to be seen for who they are. The study highlights the importance for caregivers, both formal and informal, to avoid focusing on the diagnoses and rather acknowledge the older persons and their lifeworld, be present in the relation and help them rebuild their dignity of identity. This study brings a new understanding about older persons with mental disorders that may help reduce stigma and contribute to planning future mental health care.

**Key words:** *Aged, gerontology, mental disorders, municipal care of the old, phenomenological hermeneutics, psychiatry*

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Older persons constitute an increasing proportion of the world population and are affected by mental (Martinsson, Wiklund-Gustin, Fagerberg, & Lindholm, 2011; Meesters et al., 2012; Prina, Ferri, Guerra, Brayne, & Prince, 2011; Wada et al., 2011) and/or physical disorders (Garcia-Garcia et al., 2011; Lin, Zhang, Leung, & Clark, 2011) to a high extent; the prevalence of such disorders will likely increase in the aging population. As a direct result of the push for deinstitutionalization, initiated in Sweden in the 1990s with psychiatric care reform (National Board of Health and Welfare [NBHW], 1999), a larger proportion of persons with mental disorders, defined as psychotic, anxiety and affective disorders, are living in their own homes

with support from the municipal home help services, psychiatry or both. The home is regarded as important to both younger and older persons with mental disorders as it is closely linked to their sense of security and safety (Granerud & Severinsson, 2003), and older persons frequently express a wish to remain in their own homes (Ryan, McCann, & McKenna, 2009). However, older persons with mental disorders often have very specific needs involving both physical and mental aspects (Krach & Yang, 1992). As the size of this demographic increases, so will the proportion of older persons living in their own homes with complex disorders and in need of adequate care and assistance.

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Previous studies on older persons with mental disorders have focused on the experiences of either professional (Hassall & Gill, 2008; Martinsson, Wiklund-Gustin, Lindholm, & Fagerberg, 2011) or informal caregivers in providing care (Chang & Horrocks, 2006; Tryssenaar, Tremblay, Handy, & Kochanoff, 2002). Young or middle-aged persons with mental disorders frequently participate in research focused on their subjective needs (Middelboe et al., 2001), their experience of their own daily lives (Erdner, Magnusson, Nyström, & Lützen, 2005), and of their integration in the community (Granerud & Severinsson, 2006). However, although constituting a large part of the community, older persons with mental disorders have been neglected in research (Moyle & Evans, 2007) as well as social services and health care (NBHW, 2012). The extent and quality of municipal home help services for older persons with mental disorders has been described as inadequate; for example, older persons suffering from depression receive very little home help service (Larsson, Thorslund, & Forsell, 2004) and those with severe deficiencies are the most dissatisfied with the care and services they receive (NBHW, 2011). This indicates that older persons with mental disorders are not currently receiving adequate care and support.

In order to further elucidate the present situation for older persons with mental disorders and help fill the knowledge gap concerning this demographic, it is important to explore their life situation from their perspective. By deepening the understanding of how older persons with mental disorders experience their own life situations, we may help develop a new understanding about this vulnerable and neglected group of people. Furthermore, such new knowledge may serve to reduce associated stigma and form the basis for much needed discussions on the changes in care and health care provision for older persons with mental disorders that are necessary in order to meet the challenges ahead.

## Aim

This study aimed to illuminate the meaning of the life situation as experienced by older persons with mental disorders (age  $\geq 70$ ) living at home and receiving assistance from home help service and/or psychiatry.

## Methods

The study used a lifeworld approach in order to explore older persons' experiences of their life situation while suffering from mental disorders and living at home. The lifeworld is our basic reality and

the world that shows itself to our consciousness. The lifeworld approach reduces the distance between science and daily life and provides an opportunity to develop new knowledge through understanding (Dahlberg, Dahlberg, & Nyström, 2008). To understand what shows itself to our consciousness (phenomenology) it has to be interpreted (hermeneutics), that is, there is no understanding without explanation. Therefore, to increase the understanding of older persons' being in the world and to describe the phenomenon the present study used phenomenological hermeneutics for the analysis (Lindseth & Norberg, 2004).

## Setting and participants

One urban and four rural districts in Sweden formed the geographical basis of this study. Invitations for participation were forwarded to the caregivers of older persons fulfilling the inclusion criteria (outlined below) by the heads of four psychiatric wards specialized in psychotic disorders. Potential participants were approached by the caregivers with whom they had the most regularly contact. The caregivers then either returned the willingness to participate to the interviewer, including a set date and time for the interview, or provided a phone number by which the interviewer could directly contact the potential participants. The interviewer contacted all persons that had provided phone numbers and more thoroughly explained the study. All potential participants were given another opportunity to ask further questions or to decline participation.

The sampling was convenient and seven older persons, two men and five women, agreed to participate. The inclusion criteria of this study were as follows: aged 70 years and older; currently receiving treatment or under examination for, mental disorders by primary health care or psychiatric care; current or previous contact with home help services, caregivers in primary health care or psychiatric care; not subjected to compulsory institutional care; not diagnosed with a dementia disorder; and able to communicate in Swedish. All participants were living in their own homes and receiving support from the municipal home help services and/or psychiatry. Their ages ranged from 71 to 75 years at the time the interviews were conducted, with a mean age of 72.6 years. All informants were diagnosed with (or under investigation for) schizophrenia, schizotypal and delusional disorders (F20–29 International Classification of Diseases, version 10 (ICD-10)). Three of the older persons included were also diagnosed with affective disorders (F30–39 ICD-10).

### *Data collection*

Data was collected, October 2009 to March 2011, via interviews with the seven older persons. All of the older persons invited to participate accepted and determined the time and place for the interview. Three interviews were conducted at the psychiatric outpatient wards with which the older persons were familiar, and four interviews were conducted in the older persons' own homes. At the beginning of each interview, the interviewer orally provided thorough information about the purpose of the study and voluntariness. Though they were given yet another opportunity to decline participation, each of the older persons agreed and their participation was considered informed consent.

The older persons were asked to narrate daily situations and various situations in which they had encountered their caregivers. Clarifying questions, such as "What do you mean by that?" or "Can you tell me more about that?", were then asked to encourage further narration. The interviews lasted from 55 to 110 min and were transcribed verbatim by the interviewer. In order to ensure confidentiality, all personal information was replaced with specific codes; the codes and transcripts were stored in locked cabinets in different locations at the university.

### *Analysis*

In order to interpret the interview texts and illuminate the meaning of the life situation as experienced by older persons with mental disorders, a phenomenological hermeneutical research method was used, inspired by the philosophy of Paul Ricoeur (Lindseth & Norberg, 2004). The analysis began with naïve reading, progressed to explanatory structural analysis, and ended in a new understanding or comprehension.

During the naïve reading phase, the whole text was read in order to grasp a first understanding. After verbalizing the naïve reading, the text was structurally analyzed with the naïve reading in mind. The text was then divided and represented by meaning units, which were condensed by thorough analysis (see Table I). The condensed meaning units were analyzed and compared with respect to differences and similarities, and subsequently abstracted to sub-themes, themes and then one main theme. In relation to the naïve reading, the sub-themes, themes and main theme were reflected on to make sure the naïve reading was validated. Finally, the naïve reading, structural analysis, relevant literature and the authors' pre-understandings were brought together to develop a new understanding about being in the world as an older person with mental disorders.

### *Ethical review*

Interviewing vulnerable older persons stricken by severe disorders may pose a threat to their integrity. By narrating situations from their daily lives as well as from their encounters with the caregivers, they may be sensitized to their physical and mental state; this could consequently evoke detrimental, sometimes destructive, thoughts and feelings. In order to alleviate the older person's mind and/or prevent destructive thoughts from unfolding, the interviews all concluded with off the record conversations in which the participants were able to express their thoughts about what the interview involved. The older persons were then also encouraged to talk to their caregivers whenever they felt it necessary. Additionally, all participants were scheduled appointments with their caregivers, either with psychiatry or municipal home help service, shortly after the interviews.

The caregivers were informed about the study in advance, and read the inquiry of participation together with the older person at the next regular appointment and remained available for questions and/or referral to the persons conducting the study. The caregivers were informed about the risks associated with the interviews and were encouraged to be observant for any changes in the individual needs of the older persons. The participants were informed about the voluntariness and the fact that declining participation would in no way impact the care they receive.

Although there are several ethical challenges involved in interviewing older persons with severe mental disorders, it is important to note that the participants may simultaneously benefit from the interviews (Wiklund-Gustin, 2010). For instance, the interviews gave them the time necessary to verbalize their thoughts and provided the opportunity to be heard and listened to while discussing their situation with someone outside their daily life. Importantly, it may have provided some clarity for the older persons by raising their awareness about the good things in life, as well as knowing that one can make a difference, contribute something significant, and over the long term affect the care of others. This study was revised and approved by the regional ethics board (Dnr 2008/345).

## **Findings**

### *Naïve reading*

To be an older person with mental disorders meant to be alone, both socially (no close friends) and mentally (alone within). One was typically encumbered with thoughts concerning why the disorders had

Table I. Examples from the structural analysis of meaning units and their corresponding condensation.

Meaning units	Condensation
<p>Interviewer (I): How would it be if, you said that you haven't figured her [caregiver] out yet, what would be better if you figured her out?</p> <p>Interview person (IP): To talk as I did with the two previous ones.</p> <p>I: Can you tell me about that?</p> <p>IP: You know, from the heart and such, tell her how I feel and, but she rarely answers . . . She doesn't come to any conclusions. No, she just listens, but you want some advice and so from her . . . No . . . It doesn't result, no . . . Yes well, it is how it is.</p>	<p>I would like to get advice from my caregiver but she just listens.</p>
<p>I: Did you get an offer on meeting someone else when your current caregiver retires?</p> <p>IP: No I haven't.</p> <p>I: How does that feel?</p> <p>IP: It was a disappointment because I was thinking that they would say that if I wanted to continue I could meet with, for example. Ehm . . . it was sort of and maybe because I didn't get that offer I sort of took the decision myself that I well, ok then it is over then, but I'm not sure that it would be over if I got an offer to continue, but now I don't want to say to them that I want to continue and then get a no. No.</p> <p>I: What do you think about that?</p> <p>IP: I think I will get a no and that I don't want to, but then I rather, rather take the decision myself than letting someone else take it for me and say no to me.</p>	<p>I don't want to ask for more help and risk getting a no, I prefer to make my own decisions.</p>
<p>IP: Well, I can't go out on my own, not without a girl from the home help service. And I am supposed to have 1–2 h of social activity in the afternoon, so that they can go out with me or we can go and shop for example.</p> <p>I: So you have 1–2 h scheduled?</p> <p>IP: That's the schedule. So it . . . But, you know, being able to go out for yourself when you feel like it. It's hard just sitting inside. So it is.</p> <p>I: What is hard then?</p> <p>IP: You feel alone . . . It is a bit lonely. Not being able to, you see, don't have anybody and not being able to visit them. My sister, she lives here, and I can't go there because then I need one of the home help service personnel with me . . . and . . .</p>	<p>It feels hard and lonely to not be able to go out alone without being referred to the caregivers.</p>

developed, what to do and which potential resources were available. One was dejected, troubled and saw life as being without meaning; this was further reinforced by a continuous listlessness and helplessness. Worries about the stigma and restrictions associated with a mental disorder diagnosis resulted in a fear of being labeled. One was weak and decrepit, and aware of the own mental and physical changes.

The own home provided a sense of security and the freedom to act according to the own will, whereas contact with others left one feeling misunderstood, cheated and helpless, and generally excluded from conversations. One was at mercy of others; powerlessly watching while others controlled one's life. The need for advice and knowledge was immense as one attempted to understand the causes leading up to the present situation. Furthermore, being limited to the own knowledge and not able to profit from the knowledge of others was frustrating. Needing and asking for help evoked a troubled

conscience; although not wanting to trouble others, one longed for the help needed as well as the security, companionship and attention such help entails.

### *Structural analysis*

The main theme “Struggling for existence” emerged from the structural analysis. It constituted three themes: *Being vulnerable*, *Being powerless*, and *Wanting to be respected as a person*, as well as the 13 sub-themes, listed in Table II. The main theme and the three themes are described in the following sections.

### *Struggling for existence*

The struggle for existence represented a struggle against futility, decrepitude and invisibility. Various difficult questions arose; for instance, why is a life entailing only meaninglessness worth continue

Table II. Structural analysis. Sub-themes, themes and main theme that emerged from the narratives of the older persons.

Sub-themes	Themes	Main theme
Being feeble Fearing not being able to be oneself Being alone and isolated Stepping back Being dejected	Being vulnerable	
Being in the power of others Being left in a state of uncertainty	Being powerless	Struggling for existence
Being dependent on others Needing help Searching for one's sanctuary Shielding one's sanity Wanting companionship Being able to be oneself	Wanting to be respected as a person	

living? Though aware of the fatalistic prospect of life, one seeks sanity, security and safety. The management of daily life was under the jurisdiction of others, which resulted in being deprived of the possibility of being one's true self. Although excluded from decision-making, one longed for the help necessary to take an active role in managing the own life and to facilitate the recognition of the own existence. To not disappear from the mercy of others one submits oneself to them taking charge of one's own life. The struggle for existence involves being vulnerable and powerless, yearning for respect while simultaneously dreading to bother family, friends or caregivers. Although being discouraged by the fear of being labeled, one opposes oneself to the categorization supplied by others in order to maintain one's dignity. Struggling for existence meant wanting and trying to obtain respect and help in order to facilitate the mastering of the own existence.

*Being vulnerable*

Being vulnerable meant being restrained by fear: fear of being excluded, of bothering others, of being negligible and labeled. Labeling diminished the sense of self and restricted the opportunity to be oneself; in effect, such labeling implied being less worthy, despised, alienated and forlorn. One retreated in order to avoid bothering others and the risk of losing the access to help. Being inferior to

others meant not deserving to take space or be heard.

... Maybe I've been helped for so long that I have to be satisfied. [Crying] [...] I don't dare ask for anything else. [...] If I ask for something more they [caregivers] might think, it might be, you know, convenient for them not to make an effort. If they were to fill the space that I myself am not aware of, then they have to make an effort and I am afraid that they won't. It feels like a minor accusation against them, and that is why you take it on yourself instead of demanding things from others and so, you know, it is just that common sense that "Now you *have* to be satisfied!". Little me. Ya. So, I guess I have to ...

Lacking mental strength entails lack of physical strength and vice versa. This lead to a vicious circle in which one is enfeebled and dejected, lacking the will to live and struggling with destructive thoughts. Being vulnerable meant being alone and powerless against a constant deterioration.

*Being powerless*

Being powerless meant being in the power of others and left in uncertainty. Despite a strong desire to have answers to the various questions that had been raised, such answers were left untold. In order to resolve situations and understand the effects of certain disorders, one tried to access the knowledge of others.

...I am not embarrassed to be labeled as a madcap but, hell! I have been trying to get a new mental exam, but to, or at the same time get access to the first mental exam I went through. I don't even know where I should search for it. I was recommended by the psychiatry that I search for it myself, well, how many should I call? You know, it was a man, he tested, the only thing I remember of the test was that he, we sat around a table and he had a paper and pen. "Draw a tree and sign your name", he said, and then I did that. That's all I remember. I would like to know more. [...] Those were the previous theories but now, I know of at least five different mental exams. [...] I would like to know how mad I am, if the first test was right or completely wrong, or, I don't know, I was, yes ...

Conversations among caregivers and family members are generally held without regarding the will, interest or ambitions of oneself. Being denied access to the knowledge of others was frustrating and one

must be self-sufficient in order to maintain sanity. Paradoxically, one must also rely on others for adequate care and decision-making; without the help of the caregivers one is left alone, isolated and resigned.

#### *Wanting to be respected as a person*

Wanting to be respected as a person meant to both want and ask for help in coping with life and facilitating the ability to be oneself. One was aware of the own needs and held on to the help of others for maintaining the sense of being human.

... I would, well I've tried to explain to them [care personnel] that I, I feel, I feel, that I don't feel well. I feel restless and anxious and I would like some peace of mind but I can't get to it. I would like help to find that peace. Because I, I don't feel, I don't know what it is but I feel overall discontented and not, well, at ease. I am not at ease and I cannot be my own master and say that I am at ease. No, there is frequent disturbance in my way of thinking and I don't get any peace. [...] Perhaps you can't find your peace but I am searching for it. I don't want to give up on it ...

Desiring respect for oneself meant yearning to be a part of something bigger, be confident and safe, and to be seen as an equal human being. When shielding the own sanity one attempted to decrease worries about the future and to maintain the hope that life will improve with time. To be a part of something, to contribute and be seen as a human being made life easier as one strived to avoid being disparaged, diminished or forgotten. Wanting to be respected as a person meant to build strategies for oneself and to try to finalize things that needed to be done in order to cope with the challenges of daily life.

#### **Comprehensive understanding and reflections**

The life situation of older persons with mental disorders involved struggling for existence. Although the older persons tried to protect their sense of self, they were often defeated by the lack of self-respect and the subjectively experienced views and attitudes of others.

This struggle for existence may be further understood with respect to Nordenfelt's philosophy concerning dignity of identity (Nordenfelt, 2004). Dignity can be understood as a state characterized by balancing willfulness and obedience (Aristotle, 1952). It entails value, respect and is grounded within the subject (Nordenfelt, 2004). Although the concept of dignity has been challenged and its

relevance is under debate (Gallagher, 2011), it is a very prominent feature in policies for old age care and legislation; for instance, the National Social Services Act in Sweden states that older persons should be able to live a dignified life (SFS, 2011). Dignity of identity is inextricably linked to the older person's body, mind and self-image and is affected by the changes within oneself as well as the acts of other persons in close proximity (Nordenfelt, 2004). Dignity of identity is particularly relevant for older persons with mental disorders; they are subjected to both the natural processes of aging and severe mental disorders. Maintaining dignity of identity thus becomes an important aim for both the older persons and their caregivers.

A previous study suggested that the loss of dignity of identity is not primarily due to the changes within oneself, such as being struck by disorders, but rather that dignity is lost as a consequence of the cultural stigma surrounding the disorders (Edgar, 2004). This is supported by the findings of the present study, in which dignity of identity of older persons with mental disorders was not necessarily diminished by the disorders themselves, but rather by the anticipated prejudice of the people nearby. Worthiness, an aspect of dignity, was shown to be strongly associated with how a person was viewed by others (Statman, 2000). The struggle for existence involved fear of being stigmatized and labeled; in fact, the label in itself entailed both demotion (less worthy) and restrictions (denied the opportunity to be oneself). The objectification of older persons can violate their dignity; interestingly, this can arise from either the caregiver's attitude or the older person's own perception of themselves as non-existent and mere objects in the eyes of caregivers (Moody, 1998).

In line with the Aristotelian works on friendship, Ricoeur suggested that we are all dependent of one another; self-esteem and friendship exist in a dialectic state in which one must first befriend others in order to befriend oneself (Ricoeur, 1992). The older persons experienced objectification and being equated to their disorder; they were not permitted to participate in conversations and experienced an existential vulnerability. Although the older persons of the present study suffered from different disorders, the findings are in agreement with research on older women with depression demonstrating the tendency of the women to resign as a result of their own self-pity and firm conviction that their caregivers depreciated them (Allan & Dixon, 2009). An older person's personal belief that they lack dignity and worth in the eyes of others can intensify their existential vulnerability. However, degradation by others could also help contribute to the inability to appreciate oneself. Previous studies have shown

that older persons with mental disorders are subjected to stigma and discrimination (Carlos, Levay, Jacobsson, & Rutz, 2003) and that humiliation impairs one's self-esteem, thereby reducing the ability to appreciate oneself and the own life (Edgar, 2004). Consequently, the older persons may be defeated in their struggle to be acknowledged, as the acts of surrounding people can hinder their achievement of a higher self-esteem and self-respect. The struggle for existence involved the desire for recognition, respect and the opportunity to understand and participate in decision-making; this suggests that relational aspects of care were very important to the older persons. This finding is supported by a previous study indicating that in order for older persons to experience their care as positive, they must feel appreciated and acknowledged for who they are, contribute to decision-making and maintain their relationships (Bridges, Flatley, & Meyer, 2010).

Research on younger persons with mental disorders showed that they had the knowledge but lacked the initiative to improve their lives (Erdner, Nyström, Severinsson, & Lützen, 2002); in contrast, the older persons tried to shield their sanity and find their sanctuary. In their desire to be respected as individuals, older persons with mental disorders developed strategies to cope with daily life, maintain their sanity and exist as equal human beings. However, the subjective deterioration facing the older persons gave rise to a fatalistic view of life. The lack of autonomy over the own life entailed loss of dignity of identity and older persons often were dejected and experienced a meaninglessness and powerlessness that could impair the will to live. This finding is in accordance to a previous study showing that loss of dignity is connected to feeling ashamed or degraded, and subsequently decreases the will to live (Chochinov et al., 2002). Importantly, the actions of caregivers and relatives can result in a diminished self-image and self-respect among older persons. A previous study demonstrated that older persons depend on the behavior of caregivers to feel healthy (From, Johansson, & Athlin, 2007); there is no evidence to indicate that this differs for older persons with mental disorders. Consequently, to facilitate the maintenance of dignity of identity and thereby increase the will to live, the older persons need to be acknowledged and respected.

In addition to suffering from mental disorders, the older persons faced the natural degenerative processes of aging. In his philosophy, Ricoeur described the personal identity as dynamic and changing with the inner dialectic of the personality (Ricoeur, 1992). The combination of mental disorders and aging may increase the experience of

a changing identity, thus rendering dignity of identity more fragile and easily shattered. Wainwright and Gallagher (2008) argued that if the notion of dignity of identity is affected by changes in identity, induced either by the actions of others or one's own self-image, all persons will eventually lose their dignity as a consequence of the natural process of aging. This study, however, implicitly suggests that dignity of identity among older persons with mental disorders can be retained provided that they are recognized as equal human beings, as opposed to labeled with their diagnoses, and that their identity, integrity and wisdom are respected.

#### *Methodological considerations*

To reach as many older persons as possible, several different organizations in municipal home help services and psychiatry were contacted. Gatekeeping, defined as caregivers preventing access to eligible patients (Sharkey, Savulescu, Aranda, & Schofield, 2010), was a major hurdle during the recruitment phase of this study; consequently only seven older men and women participated. Gatekeeping occurred at different levels within these organizations, most notably by the older persons' closest caregivers. Whether the caregivers' primary objective was to protect the older persons or rather themselves remains unclear and calls for further studies. In line with the lifeworld perspective in which the quality of the sample depend more on variation and richness than exact numbers of participants (Dahlberg et al., 2008), it was concluded that the participants' narratives in this study offered enough depth to be included in the analysis. As the older persons narrated different situations, positive as well as negative, were both men and women and lived in different municipalities, the phenomenon has been allowed to vary to the extent possible and thus the generalizability increases. However, with the specificity of the phenomenon, generalizations to others than older persons with mental disorders must be made with consideration.

This study provides one interpretation of the text; other interpretations are also possible (Ricoeur, 1976). A philosophy on dignity of identity was determined to be appropriate for deepening the understanding of the text, following the evaluation of various philosophies and theories. The chosen philosophy was fruitful for the study and congruent with the aim and theory of science behind the method and design. The new, deeper understanding that emerged from this study contributes to the ongoing discourse concerning older persons with mental disorders, by highlighting the importance of acknowledging the older persons and



their existence. Although pre-understanding constitutes an important aspect of the analysis bracketing pre-understanding is never fully feasible. However, the authors discussed various aspects of pre-understanding and minimized the impact of prejudice and assumptions. Objectivity was maintained during the entire research process by being open for the phenomenon. Objectivity implies allowing the phenomenon to appear through the assumptions and thoughts held in relation to it (Dahlberg et al., 2008). The first author has been responsible for data collection, analysis and manuscript preparation. However, all four authors have been involved in the entire research process and the findings were thoroughly scrutinized and discussed amongst all authors until consensus was reached. The authors' different experience and knowledge background contributed to trustworthiness.

### Implications

The findings suggest that caregivers, both formal and informal, must acknowledge the lifeworld of older persons and help preserve their dignity of identity. By intruding on integrity and autonomy, regardless of the original intention, caregivers can alter the identity of older persons and leave them feeling alienated and less worthy. The loss of dignity of identity among older persons with mental disorders results in an increased need to be cared for as an equal human being in need of assistance.

Research on younger persons with mental disorders suggested that caregivers must foster a sense of belonging in the community (Granerud & Severinsson, 2006); the present study on older persons supports this conclusion. At present, daily activity centers and other organizations for persons with mental disorders are generally open to persons under the age of 65. Such discrimination, whether intentional or not, prohibits older persons from belonging to the community and consequently places more responsibility on caregivers to reinforce a sense of existential belonging. Such reinforcement requires that caregivers focus on the awareness of older persons and appreciate their experience and worth in order to facilitate their active participation in the relationship (Barker, 2000). Such proactive measures on the part of caregivers help to rebuild dignity of identity.

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