

Emotional and Spiritual Pain and Suffering of Older People with End-of-Life Dementia from the Perspective of Nurses and Care Workers: A Qualitative Study

Yoshihisa Hirakawa*

Center for Postgraduate Clinical Training and Career Development, Nagoya University Hospital, Japan.

*Corresponding author: Yoshihisa Hirakawa, Center for Postgraduate Clinical Training and Career Development, Nagoya University Hospital, 65 Tsuruma-cho, Showa-ku, Nagoya, Aichi, 466-8560, Japan, Tel: +81-52-744-2644; Fax: +81-52-744-2999; E-mail: y.hirakawa@med.nagoya-u.ac.jp

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Abstract

Although a number of studies have dealt with the emotional pain and suffering of older people with dementia, most of the research done so far has approached the topic from the standpoint of Behavioral and Psychological Symptoms of Dementia (BPSD) treatment. To acquire comprehensive insight into the emotional and spiritual pain and suffering of older people with end-of-life dementia beyond the scope of BPSD, we explored the emotional and spiritual pain and suffering of older people with end-of-life dementia as observed by nurses and care workers. As the results, we extracted eight dimensions of emotional and spiritual pain such as “they do not let me do the things I want to do” or “I am given medical treatment against my will”. We conclude that our results help enhance the quality of end-of-life care provided to older people with dementia who are often unable to voice their pain and suffering.

Keywords: Dementia; Spiritual pain; End-of-Life

Introduction

In Japan, the number of older people with dementia is steadily increasing [1]. Dementia, which is caused by a number of disorders that affect the brain, is a descriptive term for various symptoms of cognitive decline such as forgetfulness. There are various types of dementia like Alzheimer’s disease (AD), vascular dementia (VD), Lewy body dementia, and other rare hereditary dementias, each associated with particular symptoms [1]. However, older people with dementia generally lose their ability to solve problems and maintain emotional control, and they may experience personality changes as well as behavioral problems such as agitation, delusions, and hallucinations [1,2]. Moreover, some types of dementia, such as AD, lead to a progressive loss of physical and mental capacity and eventually to death [3]. Therefore, we believe that carefully assessing the pain and suffering of older people with advanced dementia can help us define the most suitable end-of-life care and support for them.

While advanced cancer patients and advanced dementia patients display similar distress symptoms and require comparable care [4], these two groups nevertheless exhibit important differences. For example, people with dementia need help with pain assessment because they have difficulty conveying their aches [5,6]. Moreover, people with dementia have trouble understanding abstract concepts [7], and it is thus difficult for care providers to properly assess their emotional and spiritual pain [2]. Although several behavioral observation tools offer a promising strategy to improve pain assessment in older people who are not able to communicate their pain verbally [8,9], some concerns exist related to the interpretation of these observation methods for decision making related to pain management. We need to provide a self-expression tool for pain assessment in people with difficulty in verbal communication, such as people with dementia. Therefore, as a new attempt, I previously developed a communication and symptom assessment tool called the “Nagoya Graphical Symptom Scale for the Elderly” (NGSSE) [10-12].

The rating scale, which features symptoms frequently observed among the older people who require care, was drawn using “manga (cartoons) rather than text or illustrations.

The aim of the present study was to collecting data to develop a promising communication and spiritual pain assessment tool for end-of-life dementia. We can benefit from exploring the emotional and spiritual pain and suffering of older people with end-of-life dementia as observed by nurses and care workers, who always stay close to them.

Materials and Methods

We collected qualitative data through focus group discussions among multidisciplinary professionals concerning dementia care in 2014. Study participants were randomly recruited from a list of 84 long-term care leaders related to Nagoya University Hospital by letter, considering adverse range of characteristics such as age, sex, workplace among the participants (Table 1). We did not include long-term care leaders who reported that they have little experience in end-of-life care for older people with dementia. We eventually stopped recruiting participants at 20 because we felt that the participants would cover the widest possible range of opinions and information. The twenty participants were divided into 3 smaller groups of 6 to 7 people. Each group elected a facilitator, who stimulates idea generation and wraps up the debate. First, the participants had an unstructured discussion of the “emotional, social and spiritual pain and suffering of older people with all types of end-of-life dementia” for ninety minutes, writing down all of the ideas and thoughts formulated during the exchange. In the discussion, end-of-life dementia was a synonym of advanced dementia. Prior to the discussion, the participants referred to NGSSE to understand the concept of emotional and spiritual pain. Because we did not seem to be getting close to a conclusion, one month later, a second focus group unstructured discussion was held with the same participants using the same format in order to gather further thoughts and ideas that may have been left unexpressed. Based upon these written notes, the author and his research assistant then drew up a complete list of all the ideas and thoughts generated during the two

discussions. Four nursing staff working at a psychiatric hospital supervised the discussion results. We then transferred all of the participants' ideas and thoughts onto individual labels for analysis.

We obtained an informed consent document from the participants according to procedures approved by the institutional review board of the Nagoya University Graduate School of Medicine.

We used a number of techniques of the KJ method as data interpretation tools. The concept and background of this method were explained elsewhere [8,9,13,14]. The KJ method allows selecting the number of labels carefully while saving time and labor. This procedure is called the multi-stage pick-up procedure. First, the author and his assistant selected 21 of the 121 labels using the procedure which works as follows: 1) Decide on a target number of labels, 2) Ask the participants to read the labels silently and memorize them to gain an overall impression, 3) Get the participants to mark the labels they wish to keep 4) In a second round of pick-up, get the participants to mark the labels they wish to keep among the previously selected labels, 5) Repeat this process until the resulting number of labels is close to the target number, 6) Be extremely careful when making a final pick-up. The target number of the multi-stage pick-up procedure is required to be more than twenty or one-fifth of all labels to assure the quality of study using the KJ method. They then organized these 21 labels into groups using the following KJ method procedure: 1) read the labels silently to grasp the entire concept, 2) combine labels that share a strong similarity in substance, 3) set aside any label that stands apart ('loner'), 4) make a name plate for each group of labels.

20	Home helper	Male	37	2
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Table1: Participants' characteristics.

Results and Discussion

Because the KJ method treats loner labels as separate groups, we ended up with eight groups (including a loner label) following group organization (Figure 1). Although a number of studies have dealt with the emotional pain and suffering of older people with dementia, most of the research done so far has approached the topic from the standpoint of Behavioral and Psychological Symptoms of Dementia (BPSD) treatment [2,15,16]. I believe that dementia care providers should acquire comprehensive insight into the emotional and spiritual pain and suffering of older people with end-of-life dementia beyond the scope of BPSD. This will help enhance the quality of end-of-life care provided to older people with dementia who are often unable to voice their pain and suffering. Our study results also contribute to understanding why people with dementia present with BPSD. For example, resistance to care is one of the BPSD that dementia care providers often face. Using our results as reference, we gather that such resistance stems from feelings of annoyance; the patient might think: "they do not let me do the things I want to do" or "I am given medical treatment against my will". In addition, our results help promote a better communication between caregivers and older people with end-of-life dementia who are unable to voice their pain [5,6]. Because older people with dementia are likely to have difficulty communicating their symptoms due to poor hearing or cognitive function, under-treatment is a critical issue of end-of-life care for people with dementia [17].

Participant	License	Sex	Age	Experience of dementia care (years)
1	Hospital nurse	Female	36	15
2	Facility care manager	Male	52	9
3	Facility care staff	Male	46	21
4	Facility care staff	Male	42	9
5	Facility care staff	Female	35	16
6	Facility care staff	Male	32	8
7	Facility care staff	Female	32	10
8	Group home nurse	Female	55	11
9	Group home nurse	Female	48	4
10	Group home care staff	Female	50	8
11	Group home care staff	Male	38	5
12	Group home care staff	Male	35	2
13	Group home care staff	Female	32	7
14	Community social worker	Female	49	7
15	Community social worker	Male	28	1
16	Visiting nurse	Female	35	4
17	Visiting nurse	Female	33	10
18	Home care manager	Female	50	9
19	Home helper	Female	47	11

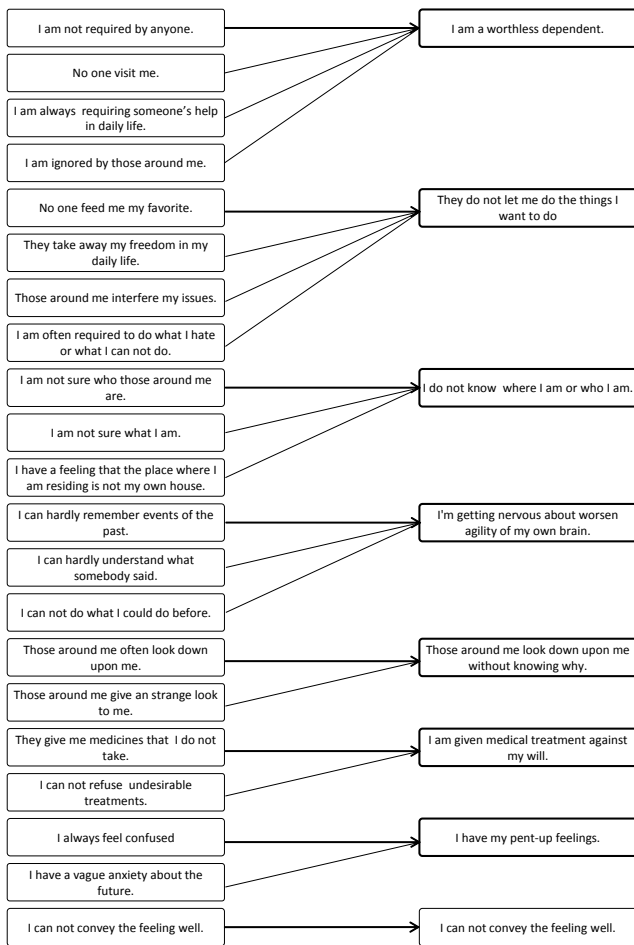


Figure1: Result of group organization.

There are several study limitations. First, the study participants were from a very limited area in and around Nagoya City. Because the way people think varies according to where they live, we believe that additional studies are needed to determine whether our results also apply to other areas. We also think that the view or thought of the older adults and their families and physicians are valuable to us for understanding end-of-life dementia. We should conduct the studies analyzing such samples. Lastly, data on the characteristics of the participants was limited. In qualitative methods including the KJ method, participants' experiences have an impact on data collection. We may not have collected enough qualitative data from the participants in this study. Additional qualitative studies should be conducted, and our results should be generalized with caution.

In conclusion, we explored the emotional and spiritual pain and suffering of older people with end-of-life dementia as observed by nurses and care workers. As the results, we extracted eight dimensions of such pain. We conclude that our results help enhance the quality of

end-of-life care provided to older people with dementia who are often unable to voice their pain and suffering.

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