

Lay Interpretation of Dementia

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ABSTRACT. Dementia is a relatively "new" disease in the medical field. Over the past few decades, neurologists, geriatricians, psychologists, and sociologists were keen to determine the causes of dementia. The prevalent picture of the scientific and theoretical causation of dementia, however, overshadows the lay perspective of dementia. To get a better understanding of the latter aspect, this study examined family carers' knowledge of dementia and how they made sense of the disease. Individual interviews were completed with 18 family carers. The interview data were analyzed based on grounded theory, which is characterized by a constant comparative method of analysis (Glaser & Strauss, 1967). This method of analysis is inductive in nature and allows the construction of a theory of the lay interpretation of dementia. The study revealed family carers' limited knowledge of dementia might be related to medical professionals' inadequate explanations of the multifaceted dimensions of dementia. Hence, the family carers tended to use external events and personal experiences to explain the occurrence of dementia. Findings suggested that the development of a lay understanding of dementia was a means for family carers to gain control of this abstruse disease and served as an adaptive strategy to cope with the loss experienced during the caring process. The study indicates a definite need for health care professionals to form partnerships with family carers in order to develop good dementia care.

LITERATURE REVIEW

After the initial discovery of Alzheimer's disease in 1907, professionals in medicine and related fields actively examined the underlying causes of the dementia syndrome. Some latest neuropathological explanations are a deposition of neurofibrillary tangles and

neuritic plaques in the brain and granulovacuolar degeneration of neurons (Chui et al., 1993; Mirra, 1997), and familial acquisition and genetic transmission via cerebral deposition of amyloid beta protein and apolipoprotein E gene (Citron et al., 1995). Clinical psychologists and sociologists, however, challenge the predominant pathophysiological explanation of dementia. They strongly advocate the consideration of social and psychological factors when examining the symptom formation and the course of dementia (Harding & Palfrey, 1997; Kitwood, 1990).

Dementia, dated back to the 1960s, was perceived as a kind of senescent defense against an inevitable death

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(Meacher, 1972; Morgan, 1965). Maisondieu (cited in Crisp, 1999) further stated that dementia was triggered by a pathological fear of death. Additionally, the label of "dementia" shapes an individual into a condition that is similar to the clinical presentations of dementia (Innes, 1998). More recently, dementia is thought to be an outcome arising from a complex interaction of neurological impairments, physical health, personality, critical life events, and the social psychology surrounding the person (Kitwood, 1997; Kitwood & Bredin, 1992). In short, dementia is not only a neurological disease, but also represents the psychosocial dysfunction of an individual.

Compared to the predominant biomedical research and upcoming psychosocial research on the understanding of dementia, very little is known about lay people's perception and interpretation of dementia (Noelker, 1992). The lay sector, one of the three interconnecting sectors of health care, consists of families and their related networks (Kleinman, 1988). This sector is significant in the formation of lay knowledge and beliefs of health and illness, and the type of help-seeking behaviors initiated by lay people. Unlike professional knowledge, which is established on a scientific and theoretical basis, lay knowledge has its roots in the experience of an illness (Helman, 1994; Williams & Popay, 1994). The lay understanding of a disease condition is not only limited to diagnosis and clinical presentations, but also represents personal attitudes, beliefs, and observation (Aronowitz, 1998).

In a study examining family carers' perception of dementia, carers were noted to have a diverse understanding of dementia (Askham, 1995). Some reasons accounting for the variety in understanding were carers'

difficulty in comprehending the sophisticated medical explanations of dementia, and carers' need of choosing a definition that best described the carer-patient relationship. Likewise, Braun and colleagues (1996) identified Vietnamese carers' preference for using their words and phrases to describe and make sense of dementia. These two studies elicit a message that the construction of an understanding of dementia is both personal and culturally related.

The present health care system encourages a "client-centered" approach to care, so the failure to acknowledge lay people's understanding of dementia is an important oversight. Family carers are gatekeepers of health services (Gitlin et al., 1995) and lay practitioners for interventions (Chung, 1997). Their viewpoints of dementia are significant for the formulation of meaningful interventions. Moreover, the implications of the relationship of the lay understanding of dementia to professional-client interaction, service utilization, quality of care, and caregiving stress are evident (Kitwood, 1997; Nolan & Keady, 1995; Silver et al., 1998). It is believed that, with a proper understanding of the lay perspective of dementia, health care professionals can formulate realistic interventions both for individuals with dementia and for their carers, and in turn promote their well-being. In view of the above implications, this study was designed to examine the knowledge and subjective understanding of dementia in 18 family carers in Hong Kong.

METHOD

Because this study aimed at exploring how family carers made sense of dementia, a grounded theory approach was

adopted because of its usefulness in discovering concepts and explanations (Glaser & Strauss, 1967; Seale, 1999). As such, family carers' knowledge and interpretation of dementia could be systematically explored and examined for the underlying reasons.

Subjects

This study was part of a 2-year longitudinal study on family caregiving of people with dementia in Hong Kong. Eighteen family caregivers, 11 from a local Alzheimer's disease association and 7 from two community-based centers, were invited to participate in the study. Inclusion criteria were based on the levels of caregiving experience and the carers' willingness to contribute relevant information on their knowledge and understanding of dementia. Among the interviewees, 6 were male and 12 were female. All male interviewees were spouses, whereas the female interviewees consisted of six spouses, five daughters, and one daughter-in-law. The mean age of spouse interviewees was 72.8 ($SD = 1.9$), whereas that of children interviewees was 41.2 ($SD = 2.4$). The duration of caring ranged from 26 months to 6 years, with an average of 3 years and 8 months. Apart from three children interviewees who were engaged in full-time jobs, all other interviewees were full-time carers at the time of the study. All interviewees gave informed consent to the study and were interviewed individually.

Data Collection

Subjective understanding of a disease condition is largely based on values, belief, culture, and experiences (Hasselkus,

1988). Intensive interviewing was adopted as the primary data collection strategy because of its ability to examine subjective meanings and personal viewpoints (Banister et al., 1994; Hammersley & Atkinson, 1995). During the interviews, interviewees were encouraged to express viewpoints in their own words by drawing upon their personal experiences. The major questions covered in the interviews were as follows:

1. How do you comment on your level of understanding of dementia? What makes you understand more about dementia, and what hinders you from understanding more?
2. Do you have your own set of understandings of dementia? If yes, what are they?
3. On what basis do you develop your own interpretation of dementia?
4. How much is your personal understanding of dementia matched with the explanations given by health care professionals?

These questions served only as interview guidelines, and interviewees were encouraged to express any issues they thought were relevant and pertinent to the study matter. Also, the researcher clarified and followed up significant issues during the interview. The average interview length was about an hour.

Data Analysis

All interviews were tape recorded, transcribed, and translated for detailed analysis. QSR NUD*IST (Qualitative Solutions and Research, 1997) was employed as the tool for data management and analysis. The analysis was based on a constant comparative method of grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The constant comparative method

of analysis is inductive in nature and allows the development of a grounded theory of the lay interpretation of dementia.

The analytic process consisted of two major stages. During Stage 1 (open coding), units of information that described informants' thoughts and experiences regarding the understanding of dementia were coded. These codes were then grouped into different categories according to their phenomena of data. For example, the codes "normal aging process," "brain-related disease," and "incurable disease" were grouped together under the category of "medical explanation of dementia."

In the second stage (axial coding), the relationship of categories and subcategories was examined with regard to a paradigm model, in which causal conditions, phenomena, context, intervening conditions, action/strategies, and consequences were explored (Strauss & Corbin, 1990). Also, the relationships of categories and subcategories were constantly proposed and checked against the data sets. Eventually, two central categories were identified: (a) lay interpretation of dementia is associated with family carers' limited understanding of dementia, (b) a process of searching for a subjective understanding of dementia is a means of gaining control of dementia.

RESULTS

Two broad categories that emerged from the data sets illustrated the lay interpretation of dementia among the 18 family carers:

- Lay interpretation of dementia is associated with family carers' limited understanding of dementia.

- The process of searching for a subjective understanding of dementia illustrates family carers' intention of gaining control of the disease process of dementia.

Inadequate Understanding of Dementia

Fourteen interviewees (78%) revealed their limited knowledge of dementia. Although they vaguely knew that dementia is related to brain degeneration, they understood very little about its course, prognosis, and management. Interviewees tended to perceive forgetfulness to be a normal presentation of old age. The following two quotations illustrate carers' typical explanations for this perception:

We thought it was natural for Mum, at her age, to be poor in memory. She was about 74 years old when we noted her deteriorated memory capacity. We took it for granted because we presumed that memory problems are common in older people. Honestly speaking, we could hardly relate her memory impairments to such a terrible disease. . . . Moreover, the doctors with whom our mother consulted knew very little about dementia. They simply told us that her presentations were a form of senility.

I took her (wife) to three doctors, but each of them gave a different explanation for her memory problem and problematic behaviors. One said that her cognitive impairments were common in her age, another one thought that the impairments were caused by some degrees of brain degeneration, while the third one simply said that her illness was incurable. I was totally confused upon receiving three different explanations, and did not know which one was reliable.

Evidently, interviewees' level of understanding of dementia was much influenced by the clarity and consistency of information they received from health care professionals. The diagnoses the individuals with dementia received varied greatly from "a normal aging presentation" to "a kind of brain degeneration" to "an incurable disease." Four interviewees were particularly angry about the unclear and incomplete diagnosis their relatives received. One interviewee explained his anger:

. . . My heart was trembling when I heard the word "incurable." When we asked the doctor to tell us more about Mum's condition, he simply said that there was no cure for it. I wondered if he knew anything about dementia. . . . As we received such little information about Mum's condition, we had no idea of what dementia would be like. I could never imagine that Mum could become so poor in cognitive and functional performance. If I knew Mum was suffering from such a deteriorating disease, I would have spent more time with her. I regret that I did not treat her with all my best. . . . Also, I am very much dissatisfied with the doctors' limited knowledge of dementia.

Subjective Understanding of Dementia

Because most interviewees (78%) had insufficient information about dementia, many questions were left unanswered. A common question puzzling them was why dementia occurred in their relatives. Although the interviewees generally knew that dementia is a form of brain degeneration, they were not at all satisfied with this biomedical explanation, particularly when noticing their

relatives' inconsistent behaviors and functional levels. More than half of the interviewees therefore chose to use external events and personal experiences to explain the occurrence of dementia.

First of all, interviewees tended to relate the development of dementia with the *past medical history* of the individual with dementia. One interviewee questioned why his wife had a more rapid rate of brain degeneration than other older adults did. He postulated that her dementing condition might be due to the side effects of anesthesia applied in the 10 surgeries that she received over the past 20 years. Another interviewee gave a similar comment:

I tend to think that his (husband) illness has something to do with painkillers. He took loads of painkillers in the past and never skipped one day of intake. . . . Perhaps these painkillers made his brain dumb.

Second, *critical life events* were thought to be provoking factors for the occurrence of dementia. A daughter interviewee wondered if the death of her brother (who had been in a coma and later deceased) was a great shock to her mother and led to the development of dementia. After that sorrowful incident, she found her mother rigid and stubborn. Gradually, her memory ability deteriorated. Likewise, a lack of stimulation was thought to contribute to a decline in cognitive functions. Another daughter interviewee noted that her mother became dull when another family member took over the household responsibility:

When my sister-in-law offered to manage the household chores herself, Mum had nothing to do but to stay at home. She is always a quiet person and seldom takes

the initiative to go for gathering. Thus, when she was not required to prepare meals, she did not go to markets where she met friends but simply stayed at home for the whole day. . . . To my understanding, "family" has always been her focus of life and "housewife" her lifelong role. When she experienced a loss of her long-standing life role and living patterns, she lost herself as well as her life direction. . . . She began to talk irrelevantly and immersed herself in aimless thoughts.

The last way to explain dementia was *supernatural belief*. As identified from the data sets, when something such as confusing behaviors and delusions could not be explained by observable events, six interviewees (33%) used supernatural concepts to interpret them. An interviewee pointed out that her home's "feng shui" was not good, and therefore all her family had bad luck. Her husband had dementia, her sons left home, and the interviewee herself was nearly driven mad by the demanding caring duty. The interviewee was advised by a general practitioner to consult a psychiatrist when she told him her stressful and anxious presentations; but she declined the offer because she was afraid of the side effects of psychotropic drugs. Similarly, another interviewee related her husband's odd behaviors to evil things:

In the old days, people who behaved like him were believed to be manipulated by evil spirits. I had thought of taking him to temples and asked monks to rid him of the evil spirits, but my children stopped me from doing so and volunteered to take him for medical consultation. Although he received a diagnosis, I still think his illness has something to do with evil spirits.

DISCUSSION

It is not surprising to find that family carers develop their own ways of understanding dementia. The way they construct the subjective understanding is largely based on personal experiences, observations, and belief. This subjective understanding of a disease is indeed an illness story that gives meaning to the experience of ill health. The illness story places ill health in the context of the individual and his or her life history, and relates it to the wider themes of the society and culture in which the individual lives (Blaxter, 1993; Brody, 1987). Hence, an illness has more meaning in the context of the carers' life, rather than as a disease full of scientific and medical jargon. Family carers, when equipped with limited medical knowledge, tend to lose their way in the forest of jargon and uncertainties. To gain control of the disease process and the caring experiences, family carers' inclination to develop their own interpretation of dementia is valid and understandable (Askham, 1995).

The findings of this study also illustrate family carers' preference for using external events to explain the occurrence of dementia. The use of "external belief systems" to explain illness causation is common to lay people of both Eastern and Western cultures (Helman, 1994), but the former group is more likely to use external control and external responsibility to fill gaps of an illness experience (Meredith & Abbot, 1995). Hornik (1993) commented that many Chinese people had a keen interest in feng shui, and applied its principles at both home and workplace with the hope of attracting good fortune. They put the responsibility on feng shui and try influencing it

to change the luck when back luck comes. Also, family carers' use of particular life events, such as the loss of a loved one and a meaningful life role, to explain the onset of dementia is evident in the study. This finding supports the argument that dementia may be an adaptive response to psychological crisis occurring in late life (Kitwood, 1990; Meacher, 1972). The lay interpretation of dementia, therefore, not only reflects carers' cultural values and beliefs, but also substantiates the psychosocial causation of dementia.

Family carers' readiness to explore the causation of dementia reveals two issues that are often overlooked in the biomedical realm. First, it unveils the carers' need of gaining control of a disease with which they are not familiar. By creating an illness story, carers are able to bring the disease into a more acceptable perspective. In addition, an illness story reflects the needs of both the carer and the individual with dementia. Failing to get into the world of illness, health care professionals can hardly formulate a treatment regime that meets the physical, psychological, social, and emotional needs of clients (MacLeod, 1993). The therapeutic relationship between professionals and clients can be enhanced only if the former group respects the latter's culture and life experiences.

Second, the search for explanations of dementia is a means for family carers to ease their feeling of desperation when coming to terms with a tragic loss of a loved one. Externalizing the illness causation therefore serves the purposes of shifting the burden from the self to some uncontrollable outside forces of power. Also, the making of an illness story is a coping strategy for carers to handle the gradual distancing of a loved one and

stressful caring experiences (Chung, 1999; Kitwood, 1990; Lazarus & Folkman, 1984).

In spite of a limited size, the present study had the merit of examining an underresearched area of "lay understanding of dementia." Lay concepts of health and illness differ from the biomedical concepts, but they influence each other interactively (Helman, 1994). However, Helman's argument is valid for those disease conditions that are well established and receive a lot of discussions in the lay sector, such as the common cold. Dementia is such a relatively new disease that many health care professionals are still studying its causation, and there are limited lay voices and discussion of dementia. Thus, the interactive influence of the lay perspective of dementia on the predominant biomedical model is not evident. As illustrated in this study, the differences between lay interpretation and professional explanations of dementia are apparent.

The differences in understanding reflect different needs, expectations, and belief among professional carers, lay carers, and even the individuals with dementia. For family care of individuals with dementia to be effective, health care professionals must listen to and accept carers' subjective understanding of dementia, rather than insisting that they accept the biomedical explanations as the only causation of dementia. Having said that, family carers may better cope with their relatives' dementing conditions and the caring duties if they are equipped with basic biomedical knowledge and a psychosocial understanding of dementia. Additionally, health care professionals are advised to develop a partnership with family carers in dementia

practices, so that the voices of all parties are heard and respected (Powell-Cope, 1994). In conclusion, good dementia care can only be delivered when carers of both the professional and lay sectors mutually respect and acknowledge each other's understanding of the disease and agenda of care.

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Acknowledgments. This research was supported in part by a Departmental Research Grant from the Hong Kong Polytechnic University. Portions of this research were presented at the 12th International Congress of the World Federation of Occupational Therapists, Montreal, Canada, 1998. The author gratefully acknowledges Kit Sinclair and Pat Chung, assistant professors of the Hong Kong Polytechnic University, for their review of this manuscript. Last but not the least, interviewees' valuable contributions are highly appreciated.