Social Workers' and Nurses' Illness Representations About Alzheimer Disease

An Exploratory Study

Shiri Shinan-Altman, PhD,* Perla Werner, PhD,† and Miri Cohen, PhD†

Abstract: Professionals' perceptions of patients' diseases (illness representations) are a major factor influencing the quality of treatment they provide. The aim of the study was to examine and compare Alzheimer disease (AD) illness representations among 2 main professional groups involved in the care of Alzheimer patients. A total of 327 nurses and social workers in Israel were asked to report their cognitive representations (dimensions of identity, cause, timeline, consequences, control, coherence, timeline cycle) and emotional representations. Knowledge about AD, demographic, and occupational characteristics were also obtained. Participants perceived AD as a chronic disease associated with severe consequences. Statistically significant differences were found between the groups, as nurses attributed psychological reasons to AD more than the social workers. Nevertheless, social workers perceived AD as more chronic with severe consequences compared with the nurses. Despite some resemblance, there were differences between the social workers and nurses regarding AD illness representations. Therefore, continuing to distribute materials to professionals regarding AD is recommended, with attention to the unique characteristics of each professional group. Furthermore, the findings encourage the development of training and support programs that will not only deal with the organizational and instrumental levels of treating AD patients but also with the assessment and consequences of professionals' illness representations.

Key Words: illness representations, social workers, nurses

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Alzheimer disease (AD) is a devastating neurological disorder characterized clinically by a decrease in memory and cognitive function.[1] Epidemiological forecasts predict an increase in the prevalence of AD over the next few years, necessitating professional treatment for a growing population of patients and their families.[2] AD presents significant management challenges for health-care professionals, as almost all patients are affected by complicated problems at some time during their illness.[3] Therefore, the care of persons with AD and their families requires a multiprofessional approach. Furthermore, AD is especially frustrating and burdensome to professional caregivers as there is no known effective medical or pharmacological cure or treatment.[4,5]

Social workers and nurses are 2 main professional groups providing care and treatment for the AD patients. Although both groups are required to cope with the inherent burden of care associated with AD patients,[6,7] each group has unique roles and responsibilities. In Israel, like in some other countries, the social workers' main role and training consist of providing support to the AD patients and their relatives, including individual and group clinical interventions, emotional support, case management, and discharge planning.[5,8]

Therefore, as part of their role, social workers deal with the consequences of the illness on the emotional state and coping abilities of the patients and their families.[5,9] Nurses have the main responsibility for the practical and informational support of the patients,[10] focusing their care primarily on the clinical changes of the disease.[11] From a medical perspective, nurses are generally guided in their professional actions by evidence-based guidelines that enable them to recognize the characteristics of their patients' diseases.[12]

As studies have shown that the professionals' beliefs affect the care they provide,[13,14] it is important to assess the social workers' and nurses' beliefs about their patients' diseases. However, to the best of our knowledge, no study to date has assessed these professionals' perceptions regarding AD and its consequences. Therefore, the aim of the present study was to assess and compare perceptions regarding AD among social workers and nurses.

A variety of psychological models such as the theory of planned behavior,[15] the locus of the control model,[16] and the theory of self-efficacy[17] have offered a wide range of beliefs and attributions that may affect health-related behavior. However, these models do not apply to cognitive processes that may be predictors of health and illness behaviors.

The study was based on the Self-Regulatory Model (SRM), which provides an integrated and empirically validated model for dealing with beliefs and coping related to illness. According to the model, illness representations comprise individuals' subjective appraisals of illness, influencing the ways in which they attempt to cope with it. The core of the SRM is that people use common sense in constructing their representations, based on their prior knowledge generated according to the principles of logic and rationality.[18] During the appraisal stage, illness representations are processed and interpreted in parallel by 2 qualitatively differing modes of representations: cognitive and emotional.[19–21]

The major attributes of cognitive illness representation are oriented around a number of dimensions of experience: (i) beliefs about symptoms (illness identity), (ii) chronicity

or recurrence of the condition (timeline and cyclical timeline), (iii) consequences, (iv) personal control, (v) treatment control, (vi) illness coherence, and (vii) causes of the condition. The emotional illness representation includes affective reactions to the perceived threat of the illness, such as fear or anger.[21]

Studies examining illness representations have been focused mainly on assessing the perceptions of persons with a specific disease,[22–24] of family members,[25,26] and of lay people.[27,28] Although only a few studies have assessed professionals' illness representations about different diseases (eg, chronic obstructive pulmonary disease, asthma, diabetes, and osteoarthritis), the results have consistently shown that these perceptions are an important factor affecting the quality of treatment that health-care professionals[29,30] provide and the level of their own well-being.[31]

METHODS

Participants

A convenience sample of 327 professionals participated in the study. As there were relatively more nurses than social workers in the health-care settings, we sampled 122 social workers and 205 nurses from 5 medical centers and 30 nursing homes in the central and northern areas of Israel. In the medical centers, only general wards with AD patients were sampled. The medical centers and nursing homes in the current study represent all the medical centers and nursing homes in Israel, which implement the same laws and procedures.

The sociodemographic characteristics of the participants are shown in Table 1. The participants' mean age in both groups was about 41 years, with more than half of them married with an average of 2 children. More than 3-quarters of the participants were Jewish, and the rest were Muslim and Christian. About half of the social workers and nurses worked in medical centers, and the other half worked in nursing homes.

Compared with the social workers, a higher percentage of the nurses were female, without an academic degree and with less years of education, but with higher seniority in their profession. Compared with the nurses, a higher percentage of the social workers were Jewish, born in Israel, and reported that their gross household income was below average in Israel.

Measures

Illness representations were measured using the Revised Illness Perception Questionnaire (IPQ-R).[21] The questionnaire was developed to assess ill persons' representations and in the present study was adapted to professional caregivers and to AD by changing the words "my illness" to "Alzheimer disease."

Indeed, studies have already shown that the IPQ-R can be used to assess illness representations among other population, rather than ill people, such as family caregivers who treat AD patients[32] and illness representations among the lay public.[33] These studies improved that the IPQ-R can serve as a qualified tool to assess illness representations among these populations.

Twenty-nine items were assessed tapping 8 dimensions: illness identity, perceptions of symptoms; causes, perceived causes of symptoms; timeline, beliefs about the acute/chronic course of the illness; consequences, perceived

TABLE 1. Participants' Demographic Characteristics

Characteristics	Nurses (n = 205)	Social Workers (n = 122)	P
Sex [N (%)]			
Male	24 (12.5)	7 (5.7)	$\chi^2_1 = 3.83$*
Female	168 (87.5)	115 (94.3)	
Mean age (SD)	40.54 (10.15)	41.33 (11.53)	NS
Place of birth [N (%)]			
Israel	100 (49.5)	94 (79.7)	$\chi^2_3 = 39.1$**
Soviet Union	87 (43.1)	12 (10.2)	
Europe-America	6 (3.0)	8 (6.8)	
Asia-Africa	9 (4.5)	4 (3.4)	
Marital status [N (%)]			
Single	24 (11.9)	26 (21.3)	NS
Married	151 (75.1)	79 (64.8)	
Divorced/separated	26 (13.0)	16 (13.1)	
Mean no. children (SD)	2.23 (1.13)	2.42 (1.01)	NS
Religion [N (%)]			
Jewish	151 (75.9)	115 (96.6)	$\chi^2_3 = 25.42$**
Muslim	29 (14.6)	0 (0)	
Christian	13 (6.5)	2 (1.7)	
Others	6 (3.0)	2 (1.7)	
Mean years of education	15.51 (2.25)	16.65 (1.69)	$t_{306} = 4.70$**
Academic degree [N (%)]			
No degree	58 (33.0)	0 (0)	$\chi^2_3 = 60.13$**
First degree	95 (54.0)	75 (62.0)	
Second degree	22 (12.5)	45 (37.2)	
Third degree	1 (0.6)	1 (0.9)	
Mean years of seniority in profession (SD)	16.08 (10.85)	13.13 (10.80)	$t_{200} = 2.33$**
Income [N (%)]			
Above average	53 (27.3)	25 (22.9)	$\chi^2_4 = 19.06$**
Average	46 (23.7)	15 (13.8)	
Below average	95 (48.9)	69 (63.3)	
Place of work [N (%)]			
Nursing home	105 (63.6)	60 (36.4)	$\chi^2_1 = 13.00$
Medical center	100 (61.7)	62 (38.3)	

**$P < 0.01$.
*$P < 0.05$.
NS indicates not significant.

impact of the illness; control, perceived ability to control the illness; illness coherence, extent to which patients perceive that they understand the illness and its implications; cyclical timeline, beliefs about the temporal changeability of the illness; and emotional illness representations, emotional responses to the illness. The questionnaire was translated to Hebrew by Benyamini et al[34] and was published on the website of the SRM.[34] In the dimension of illness identity, participants were asked whether they perceived a list of 13 symptoms as being related to AD. An overall index was calculated by summing the number of symptoms rated as being related to AD. Total scores ranged from 0 to 13, with higher scores indicating a stronger illness identity.

On the other dimensions, participants were asked to indicate their degree of agreement or disagreement on a 5-point scale (ranging from 1 = strongly disagree to 5 = strongly agree) with statements concerning the chronicity of AD (5 items); cyclical timeline (4 items); consequences of AD (6 items); personal control (6 items);

treatment control (5 items); illness coherence (5 items); and emotional representations (6 items). The causal domain consisted of 18 attribution items, which were divided into 4 subdimensions: psychological attributions, such as personality, stress, or worry (6 items); risk factors, such as heredity and smoking (7 items); immunity-related germs or viruses (3 items); and accident or chance (2 items). Overall, indices for all dimensions were calculated as the mean of the items per scale, with a higher score indicating a greater perception that AD is chronic and cyclical, associated with less perceived control and greater consequences, as well as greater attribution to psychological factors, risk factors, immunity and accidental causes, greater negative emotions, and perceived poorer coherence of AD. The internal consistency of these subscales was modest to excellent (Cronbach α ranged from 0.68 to 0.90).

Knowledge about AD was measured using a 30-item true/false AD knowledge test assessing the nature, symptoms, course, etiology, diagnosis, and treatment of AD.[35] An overall index of knowledge was calculated by summing the correct answers. Total scores ranged from 0 to 30, with a higher score indicating a greater knowledge of AD. The questionnaire was translated from English into Hebrew and then retranslated into English. The original and the translated versions were compared with ensure accuracy of content (Cronbach α = 0.60).

Sociodemographic and professional characteristics included sex (female/male), age, marital status (single/married/widowed/divorced/separated), number of children; years of education, place of birth (Israel, Asia/Africa, Europe/America, others), place of work (medical center, nursing home), profession (social worker, nurse), years of seniority in profession, and income (above average, average, or below the average income in Israel, as published by the Israeli Central Bureau of Statistics).

Procedure

A pretest was conducted with 10 social workers and 10 nurses to test the clarity of the items and to identify difficulties in understanding them. Comments from participants in the pretest contributed to the construction of the final questionnaire, with the wording changed where necessary. For example, the word "puzzling" was changed to "mystery." Next, the managers of 5 large medical centers

and 35 managers of nursing homes were asked for permission to include their social workers and nurses in the study. Five nursing home managers refused to participate, claiming that the questionnaire was too long. Overall, 360 social workers and nurses were asked to participate in the study, of which 327 consented (205 nurses and 122 social workers), representing a response rate of 90.8%. Reasons for nonparticipation included lack of interest and time constraints.

The study was approved by the Helsinki Committee in the 5 medical centers and by the University of Haifa's Ethics Committee for the nursing homes. Subjects were included in the study after signing a consent form. The interviews were coded anonymously to a password-protected file to protect the participants' privacy.

Statistical Analyses

All data were coded and analyzed using SPSS-12 software.[36,37] The statistical analysis included descriptive statistics (means, SD, percentages) to describe the sample and the main study variables (cognitive and emotional representations and background data). To assess professional differences, t and χ^2 tests were conducted according to the type of variable. Analysis of covariance was implemented, with education entered as a covariate. Multiple regressions were applied to further assess the contribution of the study variables to the explained variance of AD illness representations.

RESULTS

Cognitive and Emotional Illness Representations

As can be observed in Table 2, most symptoms of AD were recognized by the participants. The most frequently recognized symptoms were "memory decline," "confusion with time and place," and "judgment problems." Language difficulties and delusions were the only symptoms recognized by < 60% of the participants as AD symptoms. Thus, higher percentages of cognitive symptoms were perceived as being related to AD than other symptoms. Regarding the other illness representation dimensions, as can be seen in Table 3, AD was perceived as a chronic disease caused mainly by the risk factors presented (eg, heredity, smoking, alcohol), with serious consequences and a low sense of

TABLE 2. Identity Dimension—Percentage of Responses that the Symptom is Related to Alzheimer Disease (n = 327)

Identity Dimensions	Total Sample (n = 327)	Social Workers (n = 122)	Nurses (n = 205)	t (df = 2)
Memory decline	89.6	96.7	85.3	10.67**
Confusion with time	88.4	94.3	84.9	6.59*
Confusion with place	88.4	94.3	84.9	6.97*
Language difficulties	56.0	60.7	53.2	NS
Judgment problems	87.2	95.1	82.4	11.06**
Apathy	67.8	61.9	71.4	NS
Grumpiness	72.5	73.3	72.0	NS
Concentration difficulties	81.3	80.7	81.7	NS
Learning difficulties	82.5	86.1	80.3	NS
Confusion	84.7	91.8	80.4	7.71*
Delusions	56.3	67.2	49.8	11.18**
Sadness/depression	70.6	66.4	73.2	NS
Restlessness	73.1	69.7	75.1	NS

*P < 0.01.
**P < 001.
NS indicates not significant.

TABLE 3. Means (SD) and Differences of Indices of Alzheimer Disease (AD) Representations Between Social Workers and Nurses

AD Representations	Total Sample (n = 327) [*M* (SD)]	Social Workers (n = 122) [*M* (SD)]	Nurses (n = 205) [*M* (SD)]	*t** (*df* = 2)	Range
Causes					
Psychological attributions	2.16 (0.73)	2.00 (0.76)	2.25 (0.70)	2.94 (324)**	1-4
Risk factors	2.92 (0.64)	2.94 (0.61)	2.91 (0.66)	−0.47 (325)	1-5
Immunity	1.87 (0.73)	1.81 (0.68)	1.91 (0.76)	1.24 (324)	1-4
Accident or chance	1.99 (0.66)	1.96 (0.70)	2.00 (0.64)	0.61 (325)	1-5
Timeline	4.25 (0.67)	4.46 (0.59)	4.13 (0.69)	−4.51 (287)**	1-5
Consequences	3.62 (0.61)	4.33 (0.58)	4.04 (0.68)	−3.92 (325)**	1-5
Control	2.83 (0.31)	2.83 (0.32)	2.83 (0.30)	−0.16 (325)	1-5
Cyclical timeline	2.56 (0.51)	2.54 (0.49)	2.58 (0.51)	0.67 (325)	1-5
Illness coherence	2.26 (0.59)	2.28 (0.65)	2.28 (0.57)	−0.09 (230)	1-5
Emotional representation	2.54 (0.54)	2.53 (0.65)	2.49 (0.71)	1.49 (325)	1-5

*Differences between social workers and nurses only; possible scale range: 1-5.
**P < 001.

control. In addition, moderate negative emotional representations were expressed.

As can be observed in Tables 2 and 3, overall, a higher percentage of the social workers than the nurses endorsed each one of the identity items. This difference was statistically significant for memory decline, confusion with time and place, judgment problems, and delusions. As the social workers recognized more symptoms of AD than the nurses, we analyzed differences in identity while controlling for education, using analysis of covariance. Results showed that the differences between the social workers and the nurses ceased to be significant ($F_{1,307} = 16.99$, $P < 0.01$). Therefore, the differences between groups in recognizing symptoms of AD may be attributed to more years of education in the social workers' group.

The differences between the 2 professional groups in all other AD representations were more marked, with the social workers expressing more pessimistic beliefs than the nurses about the disease's timeline and consequences. However, relative to the social workers, the nurses attributed more psychological causes to AD. No statistically significant differences were found between the social workers and the nurses regarding the other causes of AD (risk factors, immunity, accident, or chance), control, cyclical timeline, illness coherence, or emotional illness representations.

Associations Between Knowledge About AD and AD Representations

To examine the associations between knowledge about AD and AD representations, Pearson correlations were calculated. Participants who had more knowledge about AD identified more symptoms ($r = 0.31$, $P < 0.01$), reported on greater risk factors ($r = 0.20$, $P < 0.001$), tended to believe that AD was chronic ($r = 0.29$, $P < 0.01$) and had severe consequences ($r = 0.34$, $P < 0.01$), and believed that they understood AD (illness coherence; $r = 0.16$, $P < 0.05$). No statistically significant correlations were found between knowledge about AD and any other AD representations, including the emotional ones.

Associations Between Sociodemographic Variables and Knowledge About AD and AD Representations

Higher age was significantly associated with lower perceptions of AD as being caused by psychological attributes ($r = -0.13$, $P < 0.05$). In addition, higher age and more years in the profession were significantly associated with fewer perceptions that AD is caused by risk factors ($r = -0.19$, $P < 0.05$ and $r = -0.18$, $P < 0.05$, respectively) and with perceptions that the disease is less controllable ($r = -0.13$, $P < 0.05$ and $r = -0.15$, $P < 0.05$, respectively). However, no statistically significant correlations were found between age and years in the profession and knowledge about AD.

Multiple Regression Analyses for Identifying Predictors of AD Representations

After the bivariate analysis, a multivariate regression analysis was performed. Only background variables found to be significantly associated with at least one of the AD illness representations were included in the equation. Thus, the independent variables included in the equation were: sex, age, place of birth, years in the profession, place of work, profession, and knowledge about AD. After controlling for the background variables, knowledge about AD and profession emerged as significant predictors of the perceptions of timeline ($F_{7,292} = 4.79$, $P < 0.01$; β = 0.14 and 0.24, $P < 0.05$, respectively) and the perceptions of consequences ($F_{7,292} = 6.02$, $P < 0.01$; β = 0.14 and 0.27, $P < 0.05$, respectively). These 2 variables were found to explain 10.9% of the variance in the perceptions of timeline and 12.9% of the variance in the perceptions of consequences. Knowledge about AD emerged as a significant predictor of the perceptions of illness coherence ($F_{7,291} = 2.29$, $P < 0.01$; β = 0.19, $P < 0.05$), the perceptions of identity ($F_{7,292} = 4.72$, $P < 0.01$; β = 0.32, $P < 0.01$), and the perceptions of risk factors ($F_{7,292} = 3.53$, $P < 0.01$; β = 0.21, $P < 0.01$). This variable explained 5.2% of the variance in the perceptions of illness coherence, 10.1% of the variance in the perceptions of identity, and 8.2% of the variance in the perceptions of risk factors.

DISCUSSION

This study assessed for the first time the social workers' and nurses' perceptions regarding AD, using the SRM as the theoretical background. We found that nurses and social workers characterized AD as a chronic disease, with more cognitive symptoms than other symptoms. In addition, they perceived AD as being caused mainly by risk factors, with serious consequences for both the patients and their families,

as well as a low sense of control. Moreover, they expressed moderate negative emotional representations.

Overall, these findings are congruent with the clinical characteristics of AD. However, a notable minority of the participants reported misconceptions that could lead to providing erroneous treatment. For example, more than half of the participants assumed that language difficulties and delusions are not related to AD. Such misguided assumptions might make professionals angry or even accusatory toward AD patients for their inappropriate behavior. Thus, even if professionals who are familiar with AD are not fully informed about the disease, then efforts to increase their knowledge and awareness are clearly warranted.[32]

The nurses and social workers in our study expressed moderate negative emotional representations, such as depression and anger. This finding is in line with those of other studies examining emotional responses to AD patients among the lay public. According to these studies, participants expressed more positive than negative emotions to AD patients,[38–40] possibly owing to the belief that the patients are not responsible for their disease[40] and are not dangerous to their surroundings.[41]

Surprisingly, we found that in comparison with the nurses, the social workers recognized more symptoms of AD and perceived AD as being more chronic and having more severe consequences. These findings are in contrast to previous reports showing that nurses are the ones to recognize more signs and symptoms of AD while focusing their care mainly on the clinical changes of the disease.[10,12] An explanation for this finding may be that the social workers in the present study had higher education than the nurses, which may mean that they had more opportunities to be exposed to courses and continuing education programs on AD. This finding is in line with another study demonstrating that higher levels of knowledge about AD among caregivers were associated with higher education.[42]

Our findings on the positive associations between knowledge about AD and illness representations support the SRM's assumptions.[18] Even after controlling for background variables, we found that higher knowledge about AD was associated with the recognition of an increased number of symptoms in the identity dimension and with higher perceptions that AD is chronic, has severe consequences, and is caused by risk factors. Professionals' knowledge about AD is vitally important given the nature of their role, which includes both patient care and maintaining relationships with the patients' families. In addition, professionals are involved in the process of providing information to patients and their families and in some cases even in the diagnosis of the disease.[43,44]

Four main limitations regarding our study should be noted. First, the use of a convenience sample does not allow us to generalize the results nor does it provide an accurate representation of all social workers and nurses in Israel. Second, not all participants were currently taking care of AD patients. It can be assumed that some answers were given in light of their past experience, closeness to ill family members, or general knowledge about AD. All of these may influence cognitive and emotional illness representations. Third, there might be a difference in illness representations between participants in medical centers and participants in nursing homes, which should be considered. Finally, our study examined professionals' attitudes and perceptions and did not examine their impact on professional behavior

and treatment patterns. Therefore, any explanation on these relationships is left on hypothetical basis. Future studies should examine these associations.

Despite these limitations, the current study has significant theoretical and practical implications. Our findings expand the limited theoretical knowledge available regarding health professionals' illness representations. For the first time, the SRM was implemented to compare the illness representations between the 2 professional groups. Practically, differences in the illness representations can lead to establishing different priorities or goals for daily functioning and treatment expectations, which in turn can influence the quality of treatment received by AD patients. Furthermore, different interpretations of illness can point to differences in the underlying knowledge base, which can be a source of difficulties in communication between health professionals. Managers and team leaders may believe that nurses have enough knowledge about AD and therefore provide them with less training regarding treatment for AD patients.

However, our findings demonstrate that knowledge about AD should not be assumed and that efforts should be made to examine the professionals' knowledge about AD, with special attention paid to the unique and specific characteristics of each professional group. This might enable the adaptation of illness representations to reduce the incorrect or inaccurate perceptions about the disease. It is also recommended that the contents of professional education programs be assessed and expanded where needed. Finally, the negative emotional representations reported by the participants stress the need for broadening the support provided to health professionals.

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