Higher Incidence of Deteriorated Mental Health in Older People Being Mistakenly Labeled as Dementia: A Two-Year Consecutive Community-Dwelling Study in Shanghai, China

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Dementia has been increasingly paid attention by policymakers in China. However, the majority of the public has an indistinct concept of dementia and its diagnostic criteria. Therefore, many abnormal characteristics and actions of older people are labeled as having dementia while diagnosed without dementia. We examined a multi-stage cluster sample of 11,223 participants aged 60 years and above who have been clinically confirmed by general practitioners as not having dementia in 2013, and 7,861 participants were willing to participate the following study and were followed-up in 2014. To assess the differences of status of older people who were mistakenly labeled as having dementia or not, we asked main caregivers 'Do you think this older person suffers from dementia?', and found out that 244 participants had been mistakenly labeled as having dementia since 2013. Related effects were measured using international generic scales as well, and the results showed that participants with better physical status deteriorated more rapidly if they were mistakenly labeled as having dementia. Additionally, the mental health of these 244 participants also deteriorated more quickly. Older adults that were not labeled as having dementia were more willing to participate in social activities relative to their labeled counterparts. In conclusion, being mistakenly labeled as having dementia without a medical diagnosis impaired older adults' physical functioning and mental health. Moreover, the reduction of social activities of labeled older people leads to separation and social exclusion.

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Introduction

In China, the rise in dementia cases in recent years has attracted public and political attention (Chiu et al. 2010). Most non-professionals are unclear about the diagnostic criteria for dementia, and popular misuse of the terms 'dementia' and 'demented' is prevalent (Graham et al. 2003). Many individuals consider certain characteristics or actions of older individuals to be abnormal. To understand these abnormalities, individuals often attach the label of dementia to those who exhibit them, even without a formal medical diagnosis (Cheng et al. 2011). Therefore, in China, dementia is often a casual stigmatic label rather than a diagnostic term

Labeling theory posits that individuals' self-identity and behavior are determined or influenced by the terms

used to describe or classify them (Link et al. 1989). Labels are often associated with stigma (Green et al. 2005). Some studies have indicated that stigmatization exerts a considerably negative effect and causes labeled individuals to drastically alter their self-concepts, withdraw from society, and experience rejection (Link et al. 1989; Crisp et al. 2000; Lee et al. 2005; Blay and Toledo Pisa Peluso 2010). Stigma may lead to interpersonal isolation and social exclusion, rather than care, from the community (Corrigan 2004), as the 'Alzheimer's' label triggers terror in some individuals (Benbow and Reynolds 2000). Hostile neighborhoods affect self-concept and quality of life (Wright et al. 2000), and stigmatization is associated with distress and depression in patients and caregivers (Mak et al. 2007; Perlick et al. 2007). As with other illnesses, including mental health disorders, studies have shown that public stigma concerning

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dementia is widespread in international communities (Umegaki et al. 2009; Banerjee 2010; Blay and Toledo Pisa Peluso 2010; Chiu et al. 2010; Mukadam and Livingston 2012).

In Chinese, dementia is expressed as 'lao-nian chidai.' 'Lao-nian' means old age and 'chi-dai' means dull witted, mentally slow, or demented. In China, 'lao-nian chi-dai' is not only the name of disease, but also an insulting language, which highlight the stigma attached to dementia and the tendency to label some older people as having dementia even without a medical diagnosis of dementia (Liu et al. 2008). In Chinese culture, stigmatized people and their family members experience a 'diu lian' (loss of face) that is perceived individually as shame and guilt and socially as a loss of status and respect (Yang 2007).

This study focused on labeling of older people with dementia and examined their neighbors' and family members' subjective attitudes by asking the question, 'Do you think that this older person suffers from dementia?' in a community in Shanghai, China. Based on the information provided by gerontologists through deep interview, the older people who have been mistakenly labeled as having dementia must have showed some abnormal behaviors. such as failure of memory, slow response. Although the behaviors of older people do not match the diagnostic criteria of dementia diagnosis, they can not be understood by older people's family or neighbors either. Thus, these older people are easily mistakenly labeled as having dementia. The older people mistakenly labeled as having dementia might recognize their situation (being mistakenly labeled as having dementia) through interaction pattern between their family members and themselves. Older individuals in our study may have been labeled as having dementia by their neighbors or family members; however, these judgments were not a clinical diagnosis of dementia; therefore, they are described as a mistakenly labeled sample.

Methods

We hypothesized that neighbors and family members labeling older individuals with dementia would result in negative consequences for the older individual such as impairment in their social activities and in their physical, cognitive, and mental well-being.

Sample

This study used a continuing cohort survey that was conducted at city level in Shanghai in 2013 and 2014 by the Shanghai Health Development Research Center. The survey was conducted in eight districts in Shanghai, including three central and five suburban districts that were randomly selected. Questionnaires were sent to local neighborhood committees that were regarded as the basic administrative institutions of communities, nursing homes, and community health service centers.

In 2013, 11,223 individuals aged 60 years or older living in the selected districts were included. Of them, 7,861 were followed up with in 2014 (none of whom had been clinically diagnosed with dementia). We further divided them into different two groups: older people labeled as having dementia by their family members and neighbors despite the absence of a clinical diagnosis (244 people) and unlabeled by others as having dementia (7,617 people) (Fig. 1).

Measurement

The Shanghai Long-Term Care Needs Assessment Questionnaire is an official tool to verify older adult's qualification for public services. This questionnaire included demographic items such as age and sex, as well as information on activities of daily living (ADL, which means routine activities which people can do everyday without assistance, including eating, bathing, dressing, toileting, transferring and continence (Katz et al. 1970)), instrumental activities of daily living (IADL, which means six daily tasks, including light housework, preparing meals, taking medications, shopping, using the telephone and managing money (Lawton and Brody 1969)), mental health, cognitive status, physical status, and a clinical diagnosis provided by general practitioners. The questionnaire was adopted by the Shanghai

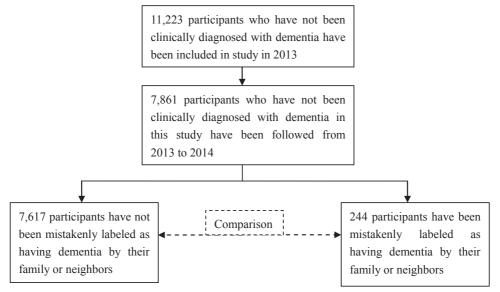


Fig. 1. The flow chart of participants who have been included in the study.

Municipal Government as the official tool for assessing demand for long-term care services for older individuals in Shanghai.

Physical health items: Health professionals assessed basic physical status, including vision, hearing, ADL, and IADL. Further, to eliminate the effects of initial ADL and IADL scores, differences were examined hierarchically. Participants were assigned to one of five groups based on their ADL score: independent, mildly dependent, moderately dependent, highly dependent, and fully dependent. IADL results were categorized into three groups: IADL 8, IADL 4-8, and IADL < 4. We also compared participant' choices with overlapping responses to the same question for both years and assigned them to one of two groups: deterioration and no deterioration. We measured the content validity of the ADL value by calculating the Pearson correlation coefficients between single items and the total ADL and IADL scores. The standard of Cronbach's coefficient alpha for the item scores of ADL and IADL were all above 0.9.

Cognitive status items: The cognitive items of the questionnaire included judgment, expressive ability, and comprehension.

Mental health items: The questionnaire included a series of items concerning mental status that were mainly taken from the Neuropsychiatric Inventory (Cummings et al. 1994). To make them easier for older people to understand, we revised some items as specific questions. Items concerning negative language and crying for no reason represented depression; items concerning persecutory delusion represented delusions; items concerning verbal abuse and damage to everyday items represented de-repression; items concerning resisting treatment and aggressive behavior represented agitation; and items concerning going outside alone and suicide represented aberrant motor behavior.

Statistical methods

Logistic models were considered when the response was a categorical variable. Assuming that Y is a binomial response and may be 0 or 1, for a logistic model with a single predictor where β_0 and β_1 are coefficients and X represents the predictor considered the equation is as follows:

$$\log \frac{P(Y=1)}{P(Y=0)} = \beta_0 + \beta_1 X.$$

After the model is fitted, if β_1 is a numeric value, the odds ratio is the following:

Odds Ratio = $e^{\beta 1}$.

We concluded that the predictor is significant when 1 belongs to the 95% Wald confidence interval (CI) for the odds ratio (OR) value.

We examined the effects of being mistakenly labeled as having dementia using a logistic regression model (i.e. being mistakenly labeled as having dementia was a predictor variable and deterioration, including that of cognitive and mental status, was a response variable).

When a response is a continuous variable, such as differences in ADL and IADL over two years, the Wilcoxon Rank Sum Test (or Mann-Whitney Test) was used to determine whether being mistakenly labeled as having dementia exerted a significant effect. As a non-parametric statistical hypothesis test, the Wilcoxon Rank Sum Test is a distribution-free method, which is superior to the t test. The null hypothesis was that the difference between the two groups would be

non-significant, and if a probability statistic greater than the significance level occurred, we would accept the null hypothesis; otherwise, we would reject it.

Quality control

The survey included three stages designed to control questionnaire quality. The interviewer completed the questionnaire to determine whether there were any blank spaces. A health professional then checked the questionnaire's logic and identified missing data; if any major issues were discovered, the related data were reconfirmed with the interviewees. The researcher then checked the questionnaires randomly and spoke to interviewees via telephone.

We hired a professional company to input the data and establish a database. We then performed final data checks and initiated the data analysis.

Ethics statement

The study achieved ethics approval from the Shanghai Health Development Research Center's ethics committee to study older individuals in Shanghai.

Results

Basic characteristics

Among 7,861 participants, 244 older adults were mistakenly labeled as having dementia. Companying with the increasing of age, older people have more possibility to be labeled as having dementia, and the majority of those people who were mistakenly labeled as having dementia were female. Furthermore, the older adults mistakenly labeled as having dementia had a worse health status than the group that was unlabeled, including worse ADL and IADL (Table 1).

Effects associated with being mistakenly labeled as having dementia

Effects on physical status: To determine the influence being mistaken labeling with dementia has on older adult's physical status, we examined differences in ADL and IADL scores, vision, and hearing for each overlap between the 2013 and 2014 samples. Those who were mistakenly labeled as having dementia experienced a significantly more rapid reduction in ADL scores relative to those that were unlabeled in the independent (p < 0.001) and mildly dependent groups (p = 0.002). This indicated that healthier older individuals' ADL performance declined more rapidly if they were mistakenly labeled as having dementia. This was also true of IADL performance in older people with higher IADL scores; therefore, the results for these two indices were consistent (Table 2).

The results also revealed that the likelihood of deterioration in vision (OR = 2.42, CI = 1.83-3.21, p < 0.001) and hearing (OR = 1.95, CI = 1.46-2.59, p < 0.001) were higher in participants mistakenly labeled as having dementia (Table 3).

Effects on cognitive status and mental health: We compared participants' cognitive status and mental health choices with overlapping responses to the same question for

Table 1. Demographics, ADL scores, and IADL scores of participants according to whether participants were labeled as having dementia while diagnosed without dementia in 2013 and 2014.

	2	013	2014		
Items	Labeled with dementia	Unlabeled with dementia	Labeled with dementia	Unlabeled with dementia	
Total	244	7,617	244	7,617	
Age (Mean \pm SD)	80.77 ± 9.02	73.00 ± 8.98	81.77 ± 9.02	74.00 ± 9.02	
Sex (n (%))					
Male	92 (37.70)	3,487 (45.78)	92 (37.70)	3,487 (45.78)	
Female	152 (62.30)	4,130 (54.22)	152 (62.30)	4,130 (54.22)	
Living Status (n (%))					
Living alone	32 (13.45)	1,444 (19.32)	26 (10.79)	1,214 (16.00)	
Living with spouse	38 (15.97)	3,005 (40.20)	37 (15.35)	3,474 (45.78)	
Living with spouse and others	18 (7.56)	1,151 (15.40)	11 (4.56)	1,097 (14.46)	
Living with children	76 (31.93)	1,563 (20.91)	67 (27.80)	1,445 (19.04)	
Living with relatives	3 (1.26)	139 (1.86)	4 (1.66)	105 (1.38)	
Living with non-relatives	71 (29.83)	174 (2.33)	96 (39.83)	254 (3.35)	
Main caregiver (n (%))	` '		· · · · · ·		
Spouse	35 (15.70)	2,951 (55.64)	35 (15.02)	3,792 (55.44)	
Children	109 (48.88)	1,940 (36.58)	95 (40.77)	2,497 (36.51)	
Relatives	6 (2.69)	192 (3.62)	9 (3.86)	179 (2.62)	
Non-relatives	73 (32.74)	221 (4.17)	94 (40.34)	372 (5.44)	
ADL score (Mean ± SD)	10.46 ± 7.60	19.11 ± 2.94	10.47 ± 7.72	18.67 ± 3.71	
IADL score (Mean \pm SD)	2.67 ± 3.07	7.25 ± 1.85	3.51 ± 2.64	7.08 ± 1.87	

SD, standard deviation; ADL, activities of daily living; IADL, instrumental ADL.

Table 2. Differences in ADL and IADL scores between 2013 and 2014 according to whether participants were labeled as having dementia while diagnosed without dementia.

	Unlabeled with dementia			Mistakenly labeled with dementia			Comparison	
Items	n	Difference of mean	Standard error	n	Difference of mean	Standard error	Difference between unlabeled and labeled	p-value***
ADL category*								
Independent [20]	6,314	-0.55	2.20	46	-1.31	2.98	0.76	< 0.001
Mildly dependent [15-20]	872	-0.58	4.14	51	-3.07	6.26	2.49	0.002
Moderately dependent [10-15]	190	1.62	5.56	33	0.32	6.46	1.30	0.344
Highly dependent [5-10]	140	0.79	5.45	32	1.19	5.85	-0.39	0.797
Fully dependent [0-5]	98	2.36	4.80	82	2.08	4.60	0.28	0.707
IADL category**								
IADL [8]	6,144	-0.38	1.14	40	-1.18	1.88	0.79	< 0.001
IADL [4-8]	921	0.29	2.06	43	0.05	2.14	0.24	0.337
IADL [0-4]	533	1.59	0.29	161	1.54	1.56	0.03	0.942

ADL, activities of daily living; IADL, instrumental ADL.

both years and assigned them to one of two groups: no deterioration and deterioration. The results of unlabeled and labeled participants in each group are shown in Table 4. Logistic regression models were produced with deterioration as the response variable, and participants labeled as having dementia as the predictor variable. The reference groups were the no deterioration and unlabeled groups.

According to the data, cognitive status deteriorated more rapidly in participants who had been mistakenly

labeled as having dementia relative to those who had not. This deterioration occurred for each item representing cognitive status including judgment (OR = 2.76, CI = 2.07-3.67, p < 0.001), expressive ability (OR = 3.89, CI = 2.86-5.29, p < 0.001) and comprehension (OR = 4.65, CI = 3.45-6.27, p < 0.001).

Moreover, results for most items concerning mental status were statistically significant, indicating that older individuals who were mistakenly labeled as having demen-

^{*}value range of ADL.

^{**}value range of IADL.

^{***}The p-values are calculated by Wilcoxon rank sum test.

Table 3. Differences in physical status between 2013 and 2014 according to whether participants were labeled as having dementia while diagnosed without dementia.

	No deterioration		Dete	rioration			
Items	Unlabeled with dementia	Labeled with dementia	Unlabeled with dementia	Labeled with dementia	OR	95% Wald CI	p-value
Vision	6,293	162	1,203	75	2.42	1.83-3.21	< 0.001
Hearing	6,184	166	1,339	70	1.95	1.46-2.59	< 0.001

OR, odds ratio; CI, confidence interval.

Table 4. Differences in cognitive status and mental health between 2013 and 2014 according to whether participants were labeled as having dementia while diagnosed without dementia.

	No deterio	No deterioration		ration			
Items	Unlabeled with	Labeled with	Unlabeled with	Labeled with	OR	95% Wald CI	p-value
	dementia	dementia	dementia	dementia			
Cognitive status							
Basic judgment	6,529	166	999	70	2.76	2.07-3.67	< 0.001
Expressive ability	6,934	178	581	58	3.89	2.86-5.29	< 0.001
Comprehension	6,939	171	567	65	4.65	3.45-6.27	< 0.001
Mental health							
Negative language	7,245	208	296	26	3.06	2.00-4.68	< 0.001
Crying for no reason	7,281	209	271	24	3.09	1.99-4.79	< 0.001
Persecutory delusion	7,358	217	193	17	2.99	1.79-4.99	< 0.001
Verbal abuse	7,341	217	209	19	3.08	1.89-5.01	< 0.001
Damage to everyday items	7,402	229	151	9	1.93	0.97-3.82	0.061
Resisting treatment	7,320	218	229	16	2.35	1.39-3.96	0.001
Aggressive behaviour	7,400	228	155	9	1.89	0.95-3.74	0.070
Going outside alone	6,807	228	713	9	0.38	0.19-0.74	0.004
Had contemplated suicide	7,512	237	42	1	0.76	0.10-5.51	0.782
Self-rated health status	3,243	127	4,360	112	0.66	0.51-0.85	0.001

OR, odds ratio; CI, confidence interval.

Table 5. Social activity level and frequency in 2014 according to whether participants were labeled as having dementia while diagnosed without dementia.

Items	Unlabeled with dementia	Labeled with Dementia	OR	95% Wald CI	p-value
Activity Level					< 0.001
Mostly lying in bed	247	85	1.00		
Mostly sitting	220	31	2.40	1.56-3.83	
Indoor mainly	991	57	5.98	4.16-8.60	
Inside community	1,236	24	17.72	11.04-28.45	
Outside community	4,880	47	35.73	24.47-52.17	
Social frequency					< 0.001
Never	2,259	150	1.00		
Once in a while	1,575	30	3.49	2.34-5.19	
Sometimes	1,408	35	2.67	1.84-3.88	
Often	1,056	10	7.01	3.68-13.36	
Always	1,285	17	5.02	3.03-8.33	

Cumulative logistic regression is conducted since the response levels are ordering. OR, odds ratio; CI, confidence interval.

tia were more likely to experience deterioration in all areas with the exception of going outside alone (OR = 0.38, CI = 0.19-0.74, p = 0.004) and suicide (OR = 0.76, CI = 0.10-

5.51, p = 0.782).

Effects on social activity: We studied whether being mistakenly labeled in 2013 affects older adults' social activ-

ity scope and frequency in 2014. Since the items concerning social activity involved more than two choices, we used multinomial response models. The results are shown in Table 5. Older individuals that were unlabeled by others were more likely to venture outside the community and participate in social activities relative to those who were mistakenly labeled as having dementia.

Discussion

The study was a two-year large-sample survey with 7,861 participants, conducted at city level in Shanghai. The results of our research showed that being mistakenly labeled as having dementia resulted in the impaired older individuals' physical function, cognitive status, and mental health, thereby leading to more abnormal behavior. Additionally, these individuals showed reduced levels of social activity that led to separation and social exclusion.

Negative effects of being mistakenly labeled as having dementia

As defined by the World Health Organization, health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. Psychological and social factors are important determinants of health. The results of our research showed that being mistakenly labeled as having dementia affected the elderly both personally and socially. Results of previous studies have revealed that the negative consequences of labeling arose via two socio-psychological processes (Link 1987; Link et al. 1989). First, when an individual is labeled as having dementia, ideas concerning the cultural stigmatization associated with dementia (e.g. being incompetent or dangerous) become personally relevant and foster negative emotions. Second, because of these personally relevant cultural meanings, the individual expects others to reject them and tends to reduce their engagement in social activities (Link 1987; Link et al. 1989).

Effects on personal physical and mental health

Being mistakenly labeled as having dementia affected older individuals' physical health, daily activity, and exacerbated their cognitive and mental distress. Relative to unlabeled participants, labeled participants showed greater deterioration of physical functions including reduced ADL and IADL performance; vision and hearing impairment; and an increase in negative cognitive, behavioral, emotional, and psychological symptoms.

Physical function deteriorated more rapidly in healthier participants within a year of being mistakenly labeled as having dementia. This indicated that the stigma associated with being mistakenly labeled as having dementia could increase risk factors for impaired physical and cognitive functioning and reduce self-confidence and independence. These results were congruent with previous findings that indicated that the responses and reactions of others, such as family members and neighbors, exerted a detrimental effect on older people (Pai 2008), and the behavioral and psychological symptoms of dementia often reflect the behavioral and psychological symptoms of the caregiver, and in particular the caregiver's attitude (Butler et al. 2012).

Effects on social activities, status, and exclusion

From a social perspective, being mistakenly labeled as having dementia was significantly associated with a decrease in older adults' social activity levels. Previous studies have noted that individuals showing signs of an inability to connect with others, refusal to leave their house, and avoidance of others might be socially isolated (Lowenthal 1964). This stigma is associated with many negative social consequences including stereotyping, separation, status loss, and discrimination (Link and Phelan 2001). In congruence with previous findings, older adults mistakenly labeled as having dementia engaged in fewer outdoor social activities relative to their unlabeled peers. One reason for this might be that impairment of judgment, expressive ability, and comprehension encouraged those labeled as having dementia to stay home, which led to a secluded life and reduced others' ability to reach them. Therefore, older adults tended to be socially excluded and the publicly discriminated against. Another possibility is older adults labeled as having dementia were embarrassed, which led to a tendency to isolate themselves and avoid social interaction because of the fear that they would be judged or stigmatized (Mukadam et al. 2013). Unfortunately, exclusion of older people labeled as having dementia prevents them from accessing social opportunities and maximizing their quality of life.

Furthermore, studies have revealed that loss of social-status and discrimination occurs when stigmatization interferes with older people's ability to participate in their communities (Graham et al. 2003; Green et al. 2005). In this study, the personal preferences of older people labeled as having dementia may have been ignored because of their reduced comprehension and expressive ability. These findings partly explain why older people labeled as having dementia were more likely to remain at home and reduce their social activity. Their social status may have been affected because they failed to maintain social connections in a reciprocal and culturally respected way. That might be viewed as them being personally responsible for their difficulties and suffering.

Implications for practice or policy

Overall, being mistakenly labeled as having dementia exerts a negative impact on older people's physical, mental, and social well-being. It is important to identify the factors associated with labeling and address them in future research. The educational approach posits that stigma is based on misunderstanding and that the publics' views can be revised when accurate information is provided (Link et al. 1999; Angermeyer and Matschinger 2003). The public requires basic information about dementia to recognize the

negative effects that labeling, stigmatization, and discrimination have on older adults and their families. Society should promote a culture of respect, care, and support for the older individuals to improve their health and well-being. Furthermore, promoting value-neutral and label-free language could improve older people's health and well-being.

In recent years, many prevention measures have been proposed for tackling dementia in Shanghai, including lifestyle changes, exercise, and medication. Lifestyle and behavioral interventions such as encouraging older people to participate in social activities may be useful. Educating and providing emotional support to caregivers is also of importance. Exercise programs may be beneficial with respect to ADL scores and potentially improve symptoms of dementia.

Study Limitations

Although examining older people mistakenly labeled as having dementia is meaningful, the target group was only part of the population and the size of the subgroup was too small for some findings to be statistically significant. Therefore, the list of observed effects might not be exhaustive. Moreover, the survey on social activity has been only carried out in 2014, so the related data is not enough to have comparative discussion. Further studies are required.

Conclusion

In this study, we examined the negative effects that being mistakenly labeled as having dementia had on the lives of older individuals. Older individuals are a disadvantaged group and are vulnerable to being mistakenly labeled as having dementia. It is important to confront this misunderstanding to reduce stigmatization. The characteristics associated with being older that lead to individuals being mistakenly labeled as having dementia might be modifiable by changing the social context. Promoting a culture of respect and educating the public may result in an altering of people's attitudes and behaviors. This would reduce the negative effects of being mistakenly labeled as having dementia and lead to older adults having a better quality of life.

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Conflict of Interest

The authors declare no conflict of interest.

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