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Understanding ageing: fear of chronic diseases later in life

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Abstract

Objectives: Ageing is often associated with deteriorating mental and physical health and the need for long-term care, creating a fear of ageing. We investigated what people fear most in terms of disabling chronic diseases and their concerns regarding having long-term illnesses.

Methods: Data were obtained from an online survey of 518 respondents aged 40 years and older residing in Malaysia, which was based on a convenience sample collected in May 2015 to January 2016. Data were analyzed using chi-squared tests and multinomial logistic regression.

Results: Of the most dreaded diseases, heart disease and cancer are life-threatening; however, dementia, diabetes, and hypertension persist and have a disabling effect for a long time. While there were variations in the diseases feared most across sex, ethnicity, and place of residence, the biggest worry for all respondents with regard to having a long-term illness was that they would become a burden to their family, a concern that superseded fear of dying.

Conclusions: We found our survey respondents had a fear of chronic diseases and placing a burden on others. Thus, there is a need to provide motivation for people to adopt a healthy lifestyle, to remain healthy.

Keywords

Ageing, fear, disabling diseases, burden to family, dying, multinomial logistic regression

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Introduction

As much as people wish to stay youthful and no matter to what lengths they will go to remain young, some degree of depressing thoughts about ageing linger in the minds of most people. Mental and physical decline, losing loved ones, not being able to financially support oneself or loved ones, and becoming a burden or dependent on family members and friends are some of the reasons

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people fear getting old. The perceptions, experiences, and interpretations of an individual's own ageing process contribute to the development of a fear of ageing.[1] The ageing self as a concept of an individual's ageing process can be explained in relation to their social cultural background, social experiences, and socioeconomic conditions.[2–3] Ageing is a process that is related to but distinct from each individual's concept of physical self, social self, personal identity,[1] personal experience, attitude towards ageing, and age stereotypes.[4–6] The experience of the passing of time is fundamental to the human condition, and how one perceives living well throughout old age is highly subjective.[7,8]

Ageing is often associated with poor health and particularly the onset and progression of chronic illness such as cancer, Alzheimer's disease, diabetes, arthritis, and heart disease. Ageing can entail multiple losses, including the loss of work (through retirement) and physical functioning.[9] There have been considerable studies on psychosocial gerontology examining how individuals retain and reshape their self concept as they age. However, the concepts of the ageing self and one's personal sense of ageing as well as how much importance one places on the signs of ageing, its attributes, and the inevitability of physical decline that comes with ageing are relatively new.[10–13]

According to a 2015 World Health Organization (WHO)[14] fact sheet, cancer is the disease feared most by the majority of people. There were approximately 14 million new cases of cancer and 8.2 million cancer-related deaths in 2012. Cognitive impairment and dementia is another health concern expressed by older individuals. Attitudes towards this illness, such as fears of memory loss, losing independence, and burdening family members and society are deeply embedded in people's cultural biographies and life experiences.[15–17] Alzheimer's disease, the most prevalent type of dementia,[18] is known not only for its negative effect on the quality of life of patients and caregivers but also for the stigma surrounding it, which is attributable to a lack of understanding of the disease.[19–23] The World Alzheimer Report (2015) estimates that 46.8 million people currently live with dementia worldwide. More than 9.9 million new cases are recorded annually and these numbers are projected to increase to 74.7 million by 2030 and 131.5 million by 2050; people living in Asia will account for nearly half of these cases.

The 2015 WHO fact sheet[14] also reported that cardiovascular disease (CVD) remains the leading cause of death globally. An estimated 17.5 million people died from CVDs in 2012, which represents 31% of deaths globally. At the same time, the number of people with diabetes rose from 108 million in 1980 to 422 million in 2014. Approximately 1.5 million deaths in 2012 were directly associated with diabetic conditions. Older people with diabetes have considerable functional impairments that lead to reduced health status and reduced health-related mental and physical quality of life.[24,25]. There is also a general perception that musculoskeletal conditions such as low back pain and osteoarthritis are "old person's diseases" and that the burden of disease is an inevitable consequence of ageing that entails physical impairment and having to live with pain.[26–29]

Aside from being life-threatening, chronic illnesses tend to persist and have disabling effects that require long-term care, the consequences of which may include of relatives and friends, causing burnout among caregivers, financial distress, and job modifications.[30–33]

Negative attitudes towards older adults are predicted by personal anxieties about ageing and death, as reported by Depaola *et al.* (2003).[34] Death anxiety can form a basic fear underlying certain psychological

conditions and is a uniquely human dilemma that can consciously or unconsciously impact a person's everyday life domains and functioning.[35] Anxiety about death can be influenced by how individuals are able to see themselves from a true perspective; this in turn affects one's ability to see dying in a positive or negative light.[36] Studies show that fear of death is positively related to low self-esteem, feeling that one has little purpose in life, and poor mental well-being; a fear of death is negatively related to happiness.[37–39] Young people generally have negative perceptions of elderly adults and tend to view ageing as a negative process that involves depression, stress, regrets, weight gain, becoming less active, and mid-life crisis.[40,41] In contrast, older people have either a positive or a negative view of ageing. Generally older adults view ageing as being accompanied by both losses (physical and social) and by gains, such as more freedom and time for new interests and social activities.[42–44]

This research aimed to investigate how Malaysians generally view ageing and the fears and attitudes relating to disease and long-term illness that are perceived as being part of the ageing process. In particular, we were interested to find what are the most feared disabling diseases and long-term illnesses. Alongside people's fears lie their expectations and their needs for support, which give rise to social and policy implications.

Materials and methods

This paper is based on data collected from a convenience sample of 518 respondents aged 40 years and above, using an online self-administered survey conducted in Malaysia (excluding non-Malaysians) in May 2015 to January 2016. Convenience sampling was used owing to the lack of a sampling frame. However, efforts were made to include different segments of the population so as to have a good representation of the population in the country. Under simple random sampling, a sample size of around 500 respondents would produce a margin of error of around 4.5% for estimating proportion (assuming $P = 0.5$). Together with obtaining information on sociodemographic background, respondents were asked about their most feared disabling diseases in later life, their fears regarding having long-term illness, and their opinions on various dimensions of ageing. Close-ended questions were used that contained a list of possible responses. Descriptive statistics were generated to explore the distribution of respondents across the variables of interest. Chi-squared tests and multinomial logistic regression were performed to test for significant associations between the dependent and independent variables.

Results

Respondents' demographic and employment profiles

Table 1 shows the basic demographic characteristics of respondents. The sex ratio was 45:55. A high proportion of respondents were younger than 60 (84.5%) years of age, of which 47% were aged 40–49 years. In terms of ethnicity, about 66% of respondents were Malay, 21% were Chinese, and 5.6% were Indians. The ethnic composition of the sample corresponds closely to that of the total population of Malaysia. For purposes of analysis, Indian and other ethnic groups were combined into one group. A little more than 70% of respondents were from urban areas.

Most respondents had ever worked, with about 44% currently working in the public sector, 25% in the private sector, and about 12% were self-employed. Nearly 6% of respondents were fully retired whereas 5% were retired but continued to work. The data suggest that about 61% of respondents

Table 1. Respondents' demographic profile.

Demographics	Frequency	Percent
Total	518	100.0
Sex		
Male	233	45.0
Female	285	55.0
Age (years)		
40–49	243	47.1
50–59	193	37.4
60–69	80	15.5
Ethnicity		
Malay	340	65.6
Chinese	108	20.9
Indian & Other	70	13.5
Locality		
Urban	367	71.0
Rural	150	29.0

Table 2. Respondents' employment status.

Employment	Frequency	Percent
Total	518	100.0
Ever Worked		
Yes	494	95.4
No	24	4.6
Employment status		
Working in public sector	226	43.6
Working in private sector	130	25.1
Self-employed	61	11.8
Retired from public or private sector	29	5.6
Retired and continues to work	25	4.8
Not working	47	9.1
Employment Category		
Professional or management	312	60.5
Other	206	39.5

were in professional or management positions (Table 2).

Fears of deteriorating health and contracting diseases

In this survey, respondents were asked to state the one disease they feared most. The three most feared disabling diseases were cancer (37.3%), Alzheimer's disease (22.5%), and heart attack or heart disease (19.2%) (Table 3). A sizable proportion identified diabetes (10.6%) as their most dreaded disease followed by arthritis (3.7%), stroke (1.7%), and hypertension (0.9%). The remaining 4% responded with the category of "Other"; however, these respondents did not specify the disease. Owing to the small number of responses for arthritis, stroke, hypertension, and other diseases, these were combined for the analysis.

The proportion of respondents who reported fearing cancer and Alzheimer disease was significantly higher among women than men whereas the opposite was true for a fear of heart attack or heart disease and diabetes (Table 4). Significant differences in the fear of disabling diseases were also observed across ethnic groups and locality. The number of respondents who reported fearing cancer and heart disease was highest among Malays, followed by Indian and Chinese respondents. However, the number of Chinese respondents who expressed fear of contracting Alzheimer's disease was nearly double that of Malays. A higher proportion of rural respondents said they feared cancer, heart disease, and diabetes compared with urban respondents, but the opposite was true for fear of Alzheimer's

Table 3. Most feared disabling disease later in life.

Disease	Frequency	Percent
Cancer	193	37.3
Alzheimer's disease	117	22.5
Heart attack/disease	99	19.2
Diabetes	55	10.6
Arthritis	19	3.7
Stroke	9	1.7
Hypertension	5	0.9
Other	21	4.1
Total	518	100.0

Table 4. Associations between most feared disabling disease and selected variables.

Variable	Cancer	Alzheimer disease	Heart attack/ disease	Diabetes	Arthritis/ other	*P*-value
Sex						
Male	79 (33.9)	45 (19.3)	59 (25.3)	28 (12.0)	22 (9.4)	0.01
Female	114 (40.0)	72 (25.3)	40 (14.0)	27 (9.5)	32 (11.2)	
Age group						
40–49 years	91 (37.4)	52 (21.4)	51 (21.0)	27 (11.1)	22 (9.1)	0.31
50–59 years	69 (35.8)	49 (25.4)	32 (16.6)	16 (8.3)	27 (14.0)	
60+ years	32 (40.0)	15 (18.8)	16 (20.0)	12 (15.0)	5 (6.2)	
Ethnicity						
Malay	131 (38.5)	64 (18.8)	80 (23.5)	35 (10.3)	30 (8.8)	0.00
Chinese	37 (34.3)	38 (35.2)	10 (9.3)	7 (6.5)	16 (14.8)	
Indian/Other	25 (35.7)	15 (21.4)	9 (12.9)	13 (18.6)	8 (11.4)	
Locality						
Urban	130 (35.4)	100 (27.2)	67 (18.3)	30 (8.2)	40 (10.9)	0.00
Rural	62 (41.3)	17 (11.3)	32 (21.3)	25 (16.7)	14 (9.3)	
Employment status						
Employed	142 (37.3)	88 (23.1)	73 (19.2)	38 (10.0)	40 (10.5)	0.09
Self-employed	20 (32.8)	12 (19.7)	13 (21.3)	8 (13.1)	8 (13.1)	
Not employed	31 (40.8)	17 (22.4)	13 (17.1)	9 (11.8)	6 (7.9)	
Employment category						
Professional/management	124 (39.7)	76 (24.4)	53 (17.0)	26 (8.3)	33 (10.6)	0.95
Other	69 (33.5)	41 (19.9)	46 (22.3)	29 (14.1)	21 (10.2)	

Note: Reported as frequency (percent).

disease. The most feared disabling diseases later in life were not significantly associated with age and employment status or category (Table 4). It should be noted that for employment status, working in the public or private sector were combined and categorized as employed; retired or not working were categorized as not employed.

Multinomial logistic regression was performed for the most feared diseases. Results of the significant odds ratios are shown in Table 5. Compared with women, men were significantly more likely to fear heart attack/disease over arthritis (adjusted odds ratio (AOR) 2.422, 95% confidence interval (CI) 1.195–4.909), cancer (AOR 2.360, 95% CI 1.403–3.970), and Alzheimer disease (AOR 2.950, 95% CI 1.637–5.314). Malays were significantly more likely than Indians or other ethnic groups to fear heart attack/disease compared with arthritis/other diseases (AOR 3.174, 95% CI 1.084–9.297), Alzheimer's disease (AOR 2.803, 95% CI 1.106–7.104), and diabetes (AOR 3.301, 95% CI 1.250-8.716). Urban respondents were significantly more likely than their rural counterparts to fear Alzheimer's disease over cancer, heart attack/disease, and diabetes whereas respondents with professional jobs were significantly less likely to fear heart attack/disease compared with cancer.

Fears regarding having long-term illness

Respondents were asked what they feared most in relation to having a long-term illness. About 66% of respondents feared being a burden to their family, followed by a fear of exhausting their savings (13.7%), dying (9.5%), and ending up in a nursing

Table 5. Multinomial logistic regression of most feared disabling diseases.

	Variable	AOR	95% CI	*P*-value
Heart attack/disease	Sex			
vs. arthritis/others	Male	2.422	1.195–4.909	0.014
	Female	(reference)		
	Ethnicity			
	Malay	3.174	1.084–9.297	0.035
	Chinese	0.749	0.206–2.731	0.662
	Indian/Other	(reference)		
Alzheimer's disease	Locality			
vs. cancer	Urban	3.244	1.627–6.467	0.001
	Rural	(reference)		
Heart attack/disease	Sex			
vs. cancer	Male	2.360	1.403–3.970	0.001
	Female	(reference)		
	Current Employment			
	Professional	0.466	0.258–0.843	0.012
	Other	(reference)		
Heart attack/disease vs.	Sex			
Alzheimer's disease	Male	2.950	1.637–5.314	0.000
	Female	(reference)		
	Locality			
	Urban	0.403	0.185–0.876	0.022
	Rural	(reference)		
	Ethnicity			
	Malay	2.803	1.106–7.104	0.030
	Chinese	0.691	0.223–2.144	0.522
	Indian/Other	(reference)		
Diabetes vs.	Locality			
Alzheimer's disease	Urban	0.232	0.097–0.555	0.001
	Rural	(reference)		
Heart attack/disease	Ethnicity			
vs. diabetes	Malay	3.301	1.250–8.716	0.016
	Chinese	1.754	0.461–6.677	0.410
	Indian/Other	(reference)		

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.

home (6.0%). The category of "Other" included fear of medical treatment cost, losing independence, and not being able to live a meaningful and dignified life (Table 6).

The fear of having a long-term illness was examined across the various sociodemographic variables (Table 7). The proportion of respondents who feared being a burden to their family was higher among women than men, higher among Chinese respondents than Malays or Indians, and higher among

Table 6. Fears regarding having a long-term illness.

Type of Fear	Frequency	Percent
Being a burden to family	340	65.6
Using up savings	71	13.7
Dying	49	9.5
Ending up in a nursing home	31	6.0
Other	27	5.2
Total	518	100.0

Table 7. Fear of having a long-term illness, by socioeconomic variable.

Variable	Being a burden to family*	Using up savings*	Dying*	Ending up in a nursing home/Other*	*P*-value
Sex					
Male	146 (62.7)	32 (13.7)	24 (10.3)	31 (13.3)	0.46
Female	194 (68.1)	39 (13.7)	25 (8.8)	27 (9.5)	
Age group					
40–49 years	164 (67.5)	32 (13.2)	23 (9.5)	24 (9.9)	0.96
50–59 years	124 (64.2)	28 (14.5)	17 (8.8)	24 (12.4)	
60+ years	50 (62.5)	11 (13.8)	9 (11.2)	10 (12.5)	
Ethnicity					
Malay	222 (65.3)	44 (12.9)	37 (10.9)	37 (10.9)	0.67
Chinese	73 (67.6)	14 (13.0)	7 (6.5)	14 (13.0)	
Indian/Other	45 (64.3)	13 (18.6)	5 (7.1)	7 (10.0)	
Area					
Urban	254 (69.2)	47 (12.8)	28 (7.6)	38 (10.4)	0.03
Rural	85 (56.7)	24 (16.0)	21 (14.0)	20 (13.3)	
Employment category (current/previous)					
Professional	215 (68.9)	40 (12.8)	27 (8.7)	30 (9.6)	0.26
Others	125 (60.7)	31 (15.0)	22 (10.7)	28 (13.6)	
Current employment status					
Employed	259 (68.0)	55 (14.4)	31 (8.1)	36 (9.4)	0.13
Self-employed	35 (57.4)	6 (9.8)	10 (16.4)	10 (16.4)	
Not employed	46 (60.5)	10 (13.2)	8 (10.5)	12 (15.8)	

Note: Reported as frequency (percent).

urban respondents than rural ones; this fear decreased with increasing age. However, none of these associations were statistically significant. There was little difference in fears regarding long-term illness across age groups and employment status.

Discussion

The population of Malaysia is ageing rapidly, and the country will be a super-aged nation around 2035 when the proportion of people aged 60 years and over exceeds 15% of the total population. Population ageing poses great challenges to existing models of caregiving and social support. Ageing is inevitably associated with a deterioration in health and the increased need for physical, financial, and emotional support, which affect the well-being of the individuals themselves and that of their families. In this study, we focused on the perceptions of people towards ageing, in terms of their fears of contracting a disabling chronic disease requiring long-term care. Among our findings, we found that the fear of burdening family even superseded the fear of dying.

A study using data of the 2004 Malaysian Population and Family Survey[45] showed that arthritis is the most common noncommunicable disease among older Malaysians (45.3%), followed by high blood pressure or hypertension (35.8%), diabetes (14.1%), asthma (13.2%), and coronary heart disease (8.0%). However, in this study, arthritis was only ranked fifth in terms of the most feared disease, and hypertension was hardly

mentioned as a dreaded illness. Instead, the most feared disabling diseases reported were cancer, followed by Alzheimer's disease, heart attack or heart disease, and diabetes. Cancer and heart disease are feared because of the severe pain that is usually involved and the fact that patients tend to die within a relatively short period. By contrast, Alzheimer disease and diabetes tend to persist, with accompanying disability, for a much longer time. WHO reports and previous studies show that these are common illnesses associated with people going through the ageing process, especially Alzheimer's disease and arthritis.[15,24,26,27]

Significant differences were found with respect to the fear of contracting these diseases according to sex, place of residence, and ethnicity. These differences could be attributable to personal life experiences and exposure within respondents' own social circles. Men and Malays were more likely to fear heart attack or disease over diseases. Urban respondents were more likely to fear heart attack or disease over Alzheimer's disease compared with cancer or diabetes. With regard to coping with a long-term illness, respondents expressed more concern and fear over becoming a burden to family, followed by the fear of exhausting their savings and fear of dying. This finding is consistent with those of Lynn and Adamson (2002), Chappell and Reid (2002), and Almberg *et al.* (1997).[28,30,31] These fears arise from the fact that having a chronic disease or long-term illness requires long-term care, which leads to the need for caregiving and adds a financial burden. The fear of chronic disease and the realization that the debilitating effects of these diseases can place a heavy burden on families and caregivers should provide sufficient motivation for people to adopt a healthy lifestyle and to remain healthy. In addition, health education and awareness campaigns should be regularly carried out to promote healthy living, especially with respect to food consumption, stress management, and physical activity. There is also a need to dispel the myths of some traditional beliefs with regard to health and health care later in life.

Conclusions

Much as people wish to stay youthful and healthy, there is always lingering fear about old age and especially of diseases that may come with age. The fear of chronic diseases is often accompanied by the knowledge that the debilitating effects of these diseases can be psychologically distressing and can place a heavy burden on families and caregivers. These fears, as well as greater awareness of the causes and consequences of chronic diseases, could motivate people to adopt a healthy lifestyle and to remain healthy. Health education should be stepped up and be accorded top priority in education and health care systems.

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The authors declare that there is no conflict of interest.

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