

Quality of life and palliative care needs of patients with Niigata Minamata disease: A complete survey after 50 years since the disaster

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Abstract

Background: Minamata disease (MD) is caused by the ingestion of a large amount of fish or shellfish contaminated with MeHg included in industrial wastewater. In 1965, a number of cases were found along the Agano River in Niigata Prefecture in northern central Japan, which were collectively designated as “Niigata Minamata disease.” Patients with MD suffer from a set of complicated pains accompanied by various signs and symptoms. They also have mental and social pains, including loss of identity, stigmatization that leads to the refusal of friendship and marriage, and isolation in the local community. However, few studies have investigated the care and prevention measures required to relieve the symptoms of patients with MD.

Aim: The objective of this survey was to investigate the symptoms, pain, and suffering experienced by patients with Niigata Minamata disease as well as their QOL and coping strategies.

Design and setting: The survey was designed as a complete study of patients with MD accessible to the local government of Niigata Prefecture and that of Niigata City.

Results: The average score of the study subjects in the World Health Organization Quality of Life 26 (WHO/QOL-26) was considerably lower than that of the general population, while being female and having an occupation correlated with higher scores for some domains and/or overall QOL scores. The symptoms perceived by the subjects as distressing in their daily lives included numbness in the limbs, physical pain, disturbed sensory systems, limb dysfunctions, and fatigability. The measures commonly taken to relieve these symptoms included using medicines, taking a bath/going to

springs, and maintaining warmth. The common emotional support included interpersonal relationships, emotional fulfillment, self-discipline in daily life, and bodily health. Those certified as having MD showed no significant difference in any domains and overall QOL.

Conclusions: Palliative care providers should extend their targets for non-cancer palliative care and develop approaches for MD-specific total pain.

Introduction

Minamata disease (MD) was identified in the coast of Minamata Bay in Kumamoto Prefecture in southern Japan in 1956.¹ MD is caused by the ingestion of a large amount of fish or shellfish contaminated with MeHg included in industrial wastewater. In 1965, similar but relatively milder cases were found along the Agano River in Niigata Prefecture in northern central Japan, which were collectively designated as the “Second Minamata Disease” or “Niigata Minamata Disease.”² Patients with MD suffer from a set of complicated pains accompanied by various signs and symptoms, including sensory disturbance in the distal parts of the extremities, ataxia, disequilibrium, bilateral concentric constriction of the visual fields, impaired gait and speech, muscle weakness, tremor, abnormal eye movement, and hearing impairment. Mental disorders and disturbed taste and smell also occur occasionally. Patients also have mental and social problems, including loss of identity as a worker or a fisherman, stigmatization that leads to the refusal of friendship and marriage, and isolation in the local community caused by a diffused prejudice that the disease is contagious.³

As of May 2013, 702 patients in the aggregate were officially certified as having MD in Niigata, whereas for 1,376, the application was turned down.⁴ The strict criterion that requires the full set of symptoms to be present for certification as a patient with MD has generated a sense of unfairness among patients and caused divisions.⁵ It has also been criticized by the Supreme Court, which ruled in 2004 that a person with a single symptom should also be recognized as a patient with MD.⁶ The central government enacted a law (the Act on Special Measures for Compensation for Minamata Disease and Solutions to the Problems of Minamata Disease) in 2009, which aimed to “let those who should be given relief be given as much relief as possible.”⁷ The stigmatization of patients also caused them to receive insufficient access to healthcare resources.⁸ Patients who undergo discrimination are reluctant to visit medical or welfare facilities, whereas healthcare providers in their communities, including

public health nurses and visiting nurses, have difficulties in treating patients because they have limited knowledge and experience regarding their complicated ailments. The marked characteristic of patients with MD in Niigata is that most of their neurological symptoms are not observed in their outward appearance. In addition, mental and social pains need to be assessed and managed carefully. However, few studies have investigated the care and prevention measures required to relieve the symptoms of patients with MD. Because no effective cure has been developed for MeHg poisoning and patients are inflicted with multifaceted symptoms or “total pain,”⁹ the applicability of various palliative care approaches developed for other diseases should be considered to alleviate some of the patients’ widespread pain and distress as well as to improve their QOL.

The objective of this survey was to investigate the symptoms, pains, and sufferings experienced by patients with Niigata Minamata disease as well as their QOL and coping strategies.

Methods

We adopted the QOL model¹⁰ and the total pain model¹¹ for palliative care described previously as well as the International Classification of Functioning, Disability, and Health (ICF)¹² as a theoretical model. Patients with MD are prevented from living a healthy life because they have multiple chronic symptoms, age-related physical/mental hypofunction, and the agony of having the disease. Therefore, in the present study, we clarified the well-being of affected patients from the aspects of physical/mental function, society, spirituality, activities, social participation, as well as environmental and personal factors and examined the care necessary to improve their QOL.

Recruitment of participants

The survey was designed as a complete study of patients with MD who were accessible to the local governments of Niigata Prefecture and Niigata City. This means that the subjects included those who had been officially recognized as patients with MD by *Niigata-ken Niigata-shi Kogai Kenko Higaisha Nintei Shinsa-kai* (Pollution Victim Certification Committee of Niigata Prefecture and Niigata City) and those who had not been recognized by the Committee but had been issued a *techo* (health record book for medical and welfare records) by the governments to compensate for all or part of their medical and welfare fees. *Techo* was issued to those who were considered to have

ingested a significant amount fish and other foods polluted with MeHg in the Agano river before the end of 196 and who had some degree of sensory disturbance.¹³

The subjects were informed of the protocols used for data collection and analyses and then consented to inclusion in the study. A self-rating questionnaire was mailed to participants between November 2008 and March 2009. The questions included items regarding the catchment areas, types of certification, demographic characteristics, symptoms perceived by the subjects as “distressing” rather than merely “experienced” in their daily lives and measures taken to prevent such symptoms, emotional support, and the World Health Organization Quality of Life 26 (WHO/QOL-26).¹⁴ The WHO/QOL26 is a 26-item, self-reported measure designed to assess QOL. Twenty-four items measure four domains of QOL (physical, psychological, social, and environmental), and the other two items measure overall QOL and general health. The score for each question ranges from 1 to 5, and a higher score reflects a higher QOL. The present study used the Japanese version of the WHO/QOL26, which was created by Tasaki and Nakane in 1997.¹⁵ We obtained permission to use this measure in our questionnaire from its publisher, Kanekoshobo. The data obtained from the survey were analyzed using IBM Statistical Package for the Social Sciences (SPSS) version 22.

Ethical considerations

The study was conducted in careful consideration of the fact that the subjects were suffering from discrimination and prejudice in their communities that caused them considerable distress. The cover letter described the study objectives, methods, and duration as well as ethical considerations regarding the publication of the study results. Specifically, it stated the following: 1) participation in the study was not mandatory, 2) personal information and privacy would be protected, 3) the study would be conducted anonymously, 4) there were no advantages or disadvantages of participation or non-participation, and 5) the obtained data would not be used for purposes other than those described in the study objectives. The study was approved in advance by the Ethical Committee of the School of Medicine, Niigata University.

Results

The questionnaire was distributed to 681 subjects, 464 of which responded (a 68.1% response rate). Of the study respondents 187 (40.3%) were male and 272 (58.6%) were female (Table 1). Most patients (77.2%) were aged ≥ 70 years, and a

considerable proportion was aged ≥ 80 years (31.0%). More than half of the subjects ($n = 239$; 51.5%) lived in Niigata City (an area downstream of the Agano River). In addition, 14 (3.0%) and 176 (37.9%) lived in Gosen City and Agano City (midstream areas of the river), respectively, and 26 (5.6%) lived in Aga Town (an area upstream of the river), in which the responsible companies were located. Most subjects ($n = 408$; 87.9%) lived with one or more family members, and a small proportion ($n = 31$; 6.7%) lived alone. Although most respondents (83.0%) were unemployed, 59 (12.7%) had jobs. Just over one quarter ($n = 128$, 27.6%) were certified as patients with MD. A smaller proportion of respondents (14.9%) were authorized to receive support or nursing care. The currently treated diseases of the study subjects were hypertension (46.6%), heart disease (17.5%), diabetes (14.4%), malignant tumors (6.9%), and stroke (6.0%).

The differences in the total and average scores in the WHO/QOL-26 were analyzed using *t*-tests to compare two groups (Table 2). The overall average score was 2.62 points, and the average scores of questions related to physical, psychological, environmental, and social relationship domains were 2.56, 2.59, 2.68, and 2.95 points, respectively. An approximately normal distribution was observed for all the scores. When comparisons were made between genders, no differences were noted in the scores for most domains or overall QOL, except that the social relationship domain scores were significantly higher in females than in males (3.08 vs. 2.81, $P < 0.001$). Although there were no significant differences between age groups in overall QOL scores, the physical domain scores were significantly higher in patients aged ≤ 69 years than in those aged ≥ 70 years (2.76 vs. 2.52, $p = 0.001$). Employed individuals reported higher scores for the physical and psychological domains than unemployed ones (2.89 vs. 2.52, $P < 0.001$ and 2.86 vs. 2.55, $p = 0.001$, respectively). This was also observed with regard to overall QOL (2.80 vs. 2.60, $p = 0.006$). In contrast, there were no significant differences between individuals with and without emotional support in any scores. Individuals with an officially recognized requirement for nursing care had significantly lower scores in the physical and psychological domains (2.12 vs. 2.66, $P < 0.001$ and 2.22 vs. 2.67, $P < 0.001$, respectively) and overall QOL (2.37 vs. 2.67, $P < 0.001$) than those without it. However, there were no significant differences in any score between individuals with and without certified MD. When comparisons were made between subjects with and without currently treated diseases (hypertension, diabetes, stroke, heart diseases, and malignant tumors), there were no significant differences between groups in any score.

Table 3 summarizes the “distressing symptoms” felt by the respondents in their daily lives. Of the 440 respondents, the most common sites of physical numbness and physical pain were the limbs (74.8%) and the knees and/or lower back (60.5%), respectively. A small proportion of respondents reported that they experienced numbness in their perioral area, back, and one side of the body, whereas some reported pain in their neck, shoulders, head, and back. More than one-third of respondents reported some sensory system disorders, including having difficulty with sight because of narrowing of the visual field (36.6%), ringing in the ears, dizziness, dysgeusia, and dysosmia. Fatigability (38.0%) and an increased likelihood of falling (32.5%) were similarly prevalent, and some patients experienced cramps in their limbs and calves, trembling in the limbs, weakness in the upper arms, forgetfulness, anxiety, depression, and poor concentration. These symptoms worsened more frequently when patients moved their bodies, worked, did household chores, were tired, or the climate was cold or humid (Table 4). The symptoms commonly continued all day or occurred intermittently (particularly when getting up and at night). The effects of these symptoms on the patients’ lives were divided into eight categories: hindered activities, mental distress, physical distress, having difficulty working and performing household chores, hindered activities and social participation, hindered safety, require support or nursing care, and financial worries. The measures and efforts taken to relieve the symptoms were separated into five categories: physical therapy, pharmacotherapy, making lifestyle changes, recreation, and developing care resources in daily settings (Table 5). The use of medications, particularly poultices, was the most common measure. Exercising, rehabilitation, taking a bath, going to springs, massages, acupuncture, moxibustion, outpatient visits, and hospitalizations were also common measures taken.

Of all the study subjects, 211 (45.5%) had some emotional support, while 163 (35.1%) did not; 90 (19.4%) did not answer this question. Details regarding the subjects’ emotional support were categorized into four groups (Table 6): interpersonal relationships (e.g., the presence of and interaction with people), emotional fulfillment (e.g., pleasure and the desire to live), autonomy in daily life (e.g., roles, responsibilities, and manufacturing), and bodily health (e.g., going to the springs, taking a bath, using medicines, and exercising). The most common emotional support was the presence of family; interactions with other people for emotional support were also common. Overall, various types of emotional support existed among the subjects: a desire to live (e.g., the growth of children, the well-being of the family, and praying), pleasure, kindness from

family, learning about live, roles and responsibilities, manufacturing, support systems, going to springs, and exercising.

Discussion

The average score in the WHO/QOL-26 of the study subjects was 2.62, which is considerably lower than that of the general Japanese population (3.29) and comparable with that of patients with schizophrenia (2.69) and individuals with depression (2.81).¹⁶ When comparisons were made with similarly aged populations, the scores of the subjects aged 60–79 years in the physical, psychological, social relationship, and environmental domains, which were 2.56, 2.58, 2.91, and 2.61, respectively, were much lower than were those of the general Japanese population in the same age range (3.53, 3.38, 3.25, and 3.27, respectively).¹⁷ In addition, although the current subjects aged ≤ 69 years reported significantly higher scores for the physical domain than those aged ≥ 70 years, they did not report higher scores in the psychological, environmental, or social relationship domain or overall QOL. These data suggest that the negative impact on patient QOL could not be completely explained by their age. The complexity of the factors that influence patient QOL is reflected in comparisons made according to gender, occupation, currently treated diseases, and emotional support. In particular, being female correlated with a higher score in the social relationship domain, being employed correlated with a higher score in overall QOL and physical and psychological domains, and having currently treated diseases or emotional support had no effect in any domain or overall QOL. The fact that 43.5% of the responders answered “others” when they were asked about currently treated diseases suggests that the subjects suffered from a wide variety of diseases; therefore, a more detailed survey would clarify this aspect.

The current study focused on the symptoms that the subjects perceived as distressing in their daily lives and suggested that some palliative care needs had been reported insufficiently. Numbness in the limbs and disturbances in the sensory systems such as vision, audition, and olfaction are well known symptoms in patients with MD; however, in the present study, physical pain (particularly knee and lower back pain), an increased likelihood of falls, and fatigability were also observed. These symptoms affected the patients’ activities and social participation continuously in their daily lives and potentially accelerated their physical and mental dysfunction. In addition, difficulty walking, working, and performing household chores affected the fundamental daily life

and interpersonal relationships of affected individuals. Although some symptoms were common in the general aged population, the prevalence of physical numbness suggests that these were associated with factors other than aging.

The measures commonly used to relieve these symptoms included taking medications, taking a bath or going to the springs, and staying warm. Many subjects made an effort to perform exercise and rehabilitation despite their bodily pain. One subject described the reason for his or her effort as “I’m sore and having a rough time, but I don’t want to be unable to move.” This suggests that symptoms can be eased by the deliberate provision of palliative care, including physical therapy and pharmacotherapy.

Approximately half of the subjects had emotional support, which was mostly derived from interpersonal relationships. Some of these subjects, both with and without certified MD, described their experiences of discrimination and prejudice because of their disease, and their spiritual distress was rooted in a sense of meaninglessness. Examples of patient quotes include “I can’t express myself,” “I can’t make myself known as an MD patient,” “why do I have to have this?,” and “I can’t find any meaning to live on with this body.” Japanese individuals often have a firm sense of group identification.¹⁸ MD impairs the interpersonal relationships between patients and their family, kinship, and local community.¹⁹ Although many of the current subjects reported that they received emotional support from the people surrounding them, including family members, friends, and physicians, only a small number reported that they were estranged from family members and friends. This could be explained by the fact that the focus of this survey was the distress caused by the symptoms of MD and not the distress caused by being a patient with MD. Because the present study was performed in a questionnaire format, it is necessary to hold thorough interviews to clarify specific details regarding the spiritual distress of patients.

The present study clarified that one of the two official authorization criteria for health conditions predicts victims’ QOL, while the other does not. Although individuals with a requirement for nursing care had significantly lower scores related to physical/psychological domains and overall QOL, there were no significant differences in the scores of any domains or QOL between subjects with and without certified MD. It is reasonable that subjects who required a higher level of support or nursing care had a lower evaluation of their QOL for the physical domain. However, evaluations related to the psychological domain and overall QOL were also lower among patients who

required a higher level of support or nursing care. These results are important for devising appropriate care services and providing support to victims of the disaster, regardless of whether they are certified patients with MD.

While the palliative care needs of patients with Niigata Minamata disease revealed by our study had only been insufficiently known to healthcare providers, who are capable of intervening to sophisticate the measures taken by patients. Healthcare providers could extend their targets for non-cancer palliative care and develop MD-specific approaches, including symptom management for physical numbness and physical pain, psychosocial approaches for anxiety and depression, nursing service for hindered activities, and care for spiritual distress.

Conclusions

- The average score in the WHO/QOL-26 was considerably lower in the study subjects than in the general Japanese population. In addition, being female and employed correlated with higher scores for some domains and/or overall QOL.
- The symptoms perceived by the subjects as distressing in their daily lives included numbness in the limbs, physical pain, disturbances in their sensory systems, limb dysfunctions, and fatigability.
- The commonly taken measures to relieve these symptoms included the use of medications, taking a bath or going to the springs, and maintaining warmth.
- The common emotional support included interpersonal relationships, emotional fulfillment, self-discipline in daily life, and bodily health.
- Individuals with a requirement for nursing care reported significantly lower scores in the physical and psychological domains and overall QOL, whereas there was no significant difference in the scores reported by individuals with and without certified MD in any domains or overall QOL.
- Palliative care providers could extend their targets for non-cancer palliative care and develop approaches for MD-specific total pain.

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Table 1. Patient demographics and clinical characteristics

Sex		Employed			
Female	272	58.6%	Yes	59	12.7%
Male	187	40.3%	No	385	83.0%
Not stated	5	1.1%	Not stated	20	4.3%
Age		Certified as a patient with MD			
40's	6	1.3%	Yes	128	27.6%
50's	25	5.4%	No	322	69.4%
60's	66	14.2%	Not stated	14	3.0%
70's	214	46.1%	Authorized to require support or nursing care		
80's	129	27.8%	Yes	69	14.9%
90's	15	3.2%	Require support level 1	7	1.5%
Not stated	9	1.9%	Require support level 2	10	2.2%
Residential area		Require nursing care I			
Niigata City	239	51.5%	Require nursing care II	11	2.4%
Gosen City	14	3.0%	Require nursing care III	12	2.6%
Agano City	176	37.9%	Require nursing care VI	7	1.5%
Aga Town	26	5.6%	Require nursing care V	5	1.1%
Other	8	1.7%	Not specified	6	1.3%
Not stated	1	0.2%	No	368	79.3%
Living arrangements		Not stated			
Lives alone	31	6.7%	Currently treated diseases (multiple answers)		
Co-habits with spouse only	92	19.8%	Hypertension	216	46.6%
Co-habits with a non-spouse	18	3.9%	Heart diseases	81	17.5%
Co-habits with two persons	65	14.0%	Diabetes	67	14.4%
Co-habits with three persons	66	14.2%	Malignant tumors	32	6.9%
Co-habits with four persons	55	11.9%	Stroke	28	6.0%
Co-habits with five or more persons	112	24.1%	Others	202	43.5%
Not stated	25	5.4%	Not stated	77	16.6%

Table 2. Mean scores in the WHO/QOL-26

	n	Domains								Total	(SD)
		Physical	(SD)	Psychological	(SD)	Environmental	(SD)	Social-relationship	(SD)		
Overall average											
Average	335	2.56	0.57	2.59	0.62	2.68	0.52	2.95	0.66	2.62	0.48
Gender											
Female	183	2.54	0.55	2.59	0.58	2.71	0.47	3.08	0.57	2.64	0.44
Male	147	2.60	0.59	2.61	0.66	2.63	0.58	2.81	0.71	2.60	0.52
p		.282		.832		.135		.000		.460	
Age (years)											
<70	78	2.76	0.55	2.68	0.64	2.62	0.50	2.85	0.65	2.67	0.47
70+	250	2.52	0.56	2.57	0.61	2.69	0.51	3.01	0.63	2.62	0.47
p		.001		.194		.262		.056		.341	
Occupation											
Yes	51	2.89	0.58	2.86	0.66	2.74	0.60	2.90	0.63	2.80	0.52
No	274	2.52	0.54	2.55	0.60	2.66	0.49	2.98	0.64	2.60	0.45
p		.000		.001		.343		.400		.006	
Emotional support											
Yes	155	2.59	0.58	2.60	0.63	2.73	0.56	3.00	0.68	2.65	0.49
No	132	2.58	0.56	2.63	0.62	2.63	0.48	2.93	0.61	2.63	0.45
p		.899		.626		.117		.302		.678	
Authorized to require support or nursing care											
Yes	49	2.12	0.55	2.22	0.56	2.60	0.49	2.93	0.67	2.37	0.46
No	272	2.66	0.53	2.67	0.61	2.68	0.51	2.98	0.61	2.67	0.46
p		.000		.000		.292		.621		.000	
Certified as a patient with MD											
Yes	85	2.56	0.58	2.54	0.66	2.75	0.55	2.91	0.63	2.63	0.5
No	242	2.57	0.57	2.60	0.61	2.65	0.51	2.97	0.67	2.62	0.47
p		.911		.395		.144		.414		.843	
Currently treated diseases											
Yes	283	2.54	0.56	2.58	0.61	2.67	0.51	2.96	0.66	2.61	0.46
No	52	2.68	0.59	2.63	0.70	2.70	0.57	2.92	0.63	2.68	0.53
p		.106		.562		.733		.721		.381	

Table 3. "Distressing" symptoms felt by the subjects in their daily lives (n = 440, multiple answers)

Physical numbness (337)		Fatigability (167)	167 (38.0%)
Limbs	329 (74.8%)	Mental/cognitive dysfunction (13)	
Perioral area	4 (0.9%)	Forgetfulness	6 (1.4%)
Back	2 (0.5%)	Anxiety/depression	5 (1.1%)
One side of the body	2 (0.5%)	Poor concentration	1 (0.2%)
Physical pain (279)		Stammering	1 (0.2%)
Knees/lower back	266 (60.5%)	Sleep disorder (6)	6 (1.4%)
Neck/shoulders/head	36 (8.2%)	Cardiovascular symptoms (2)	2 (0.5%)
Back	7 (1.6%)	Excretory disorder (1)	
Sensory-system disorders (222)		Incontinence	1 (0.2%)
Difficulty seeing	161 (36.6%)	Others (1)	
Ringing in the ears	29 (6.7%)	Stomatitis	1 (0.2%)
Dizziness	26 (5.9%)		
Dysgeusia	4 (0.9%)		
Dysosmia	2 (0.5%)		
Limb dysfunctions (169)			
Likelihood to fall	143 (32.5%)		
Cramp/tension/trembling in the limbs	24 (5.5%)		
Difficulties in stoma management	1 (0.2%)		
Weakness in the upper arms	1 (0.2%)		

Table 4. Factors that worsen symptoms and their influence on patients' lives

Predictors for symptom worsening (multiple answers)		Influences on patients' lives (multiple answers)	
Activities (199)		Hindered activities (196)	
Moving bodies	83	Difficulty in walking	55
Working/doing household chores	39	Impaired mobility	48
Being tired	29	Difficulty in the activities of daily living	50
Staying in a similar position (sitting, driving)	19	Mental distress (63)	
Going out	19	Feel stressed, low morale, poor concentration, distress	22
Doing work with their hands (eating, taking medicine, putting on and taking off clothes)	10	Sleep disorder	16
		Future anxiety	15
No predictors (137)	120	Family relations distress (concerns related to family burden or feeling alienated from family)	7
Continued all day			
Occurred intermittently	17	Poor concentration	3
Time (95)		Physical distress (56)	
In the morning (when getting up)	49	Symptom-related distress	56
At night	35	Having difficulty working and doing household chores (55)	
In the evening	11	Having difficulty working and doing household chores	55
Seasonal conditions (temperature, humidity) (52)		Hindered activities and social participation (43)	
In autumn/winter (coldness)	46	Difficulty in activities/going out	29
On rainy days (humidity)	6	Difficulty in communications	12
		Difficulty in expecting others to understand	2
Mental conditions (1)		Hindered safety (24)	
Haunted by future anxiety	1	Probability of accidents/incidents (burns and falls)	24
		Require support or nursing care (8)	
		Require support or nursing care	8
		Financial worries (3)	
		Financial worries	3
		No influence (5)	
		Worried about nothing	5

Table 5. Measures and efforts taken to relieve symptoms (n = 353, multiple answers)

Physical therapy (211)		Recreation (27)	
Exercising/rehabilitation	61	Refreshment of the spirit	13
Taking a bath/going to springs	57	Peace of mind	8
Massage/acupuncture/moxibustion	49	Meeting friends	6
Keep warm (using a kairo warmer)	28	Developing care resources in	
Assistive technology and equipment	15	daily settings (6)	
Foot bath	1	Using daily equipment for care	5
Pharmacotherapy (168)		Asking family members for care	1
Using medicines	110		
Outpatient visits/hospitalizations	58		
Making changes in the lifestyle (60)			
Taking a rest	26		
Balancing activity and rest	12		
Acting slowly	9		
Living cautiously	8		
Using public care resources	5		

Table 6. Emotional support ($n = 211$, multiple answers)

Interpersonal relationships (122)		Autonomy in daily life (32)	
Presence of people (75)		Roles/responsibilities (13)	
Family members	61	Taking care of family members	4
Friends	8	Doing jobs	6
Physicians	6	Roles and obligations in society	2
Interactions with people (47)		Club/volunteer activities	
Interactions with family members	23	Manufacturing (11)	
Interactions with friends	13	Manufacturing	11
Interactions with people at a day center	6	Compensation system (8)	
Making friends	2	For officially disclaimed victims	5
Visits from home care staff	2	For officially recognized MD patients	3
Visits from volunteers	1	Bodily health (27)	
Emotional fulfilment (43)		Taking a bath/using medicines (18)	
Desire to live (13)		Taking a bath/going to springs	
Growth of children/well-being of the family	8	Using medicines	6
Praying	5	Exercising (9)	
Pleasures (11)		Exercise/rehabilitation	
Enjoying TV/radio	4	Preserving health	1
Going out with friends	2		
Singing	2		
Reading	2		
Going out alone	1		
Kindness from the family (10)			
Love from family members	7		
Understanding/support from family members	3		
Learning about life (9)			
Pursuit of the way of life	9		

