

Relationship Between the Quality of Life in Patients with Intractable Diseases and the Information Telecommunication Service

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This study evaluated the relationship of the quality of life (QOL) of home-care patients having intractable diseases with motor disabilities and the use of information telecommunication services. The investigation was carried out primarily with a questionnaire and interviewing for those incapable of writing. From the answers, the 171 patients were divided into high- and low-QOL groups based on the mean (32.5) and the median (33.0) values. Using a 2-by-2 contingency table, the activities of daily living (ADL), depression score and accessibility of information telecommunication services were compared. Both groups showed significant differences in the QOL, ADL and depression scores. The study suggested that the QOL of home-care patients with intractable diseases were related to ADL and depression. If ADL and depression are maintained at an adequate level, patients can be engaged in outside activities, receive stimulation and increase their motivation. In providing information about subjects familiar to patients with intractable diseases, such sources as the circulating neighborhood newsboard (*kairanban*), newspapers and mass media are very useful to improve their QOL. Furthermore, devices that support their living should also be developed with regard to their private likes and dislikes.

Key words: accessibility of information; home-cared patient; intractable disease; quality of life; Parkinson's disease

In Japan, measures to improve the quality of life (QOL) of patients with intractable diseases and their families have been implemented since 1996 (Horiguchi et al., 1996; Nimura et al., 1997; Yanaka et al., 1997). However, relevant reports lacked what kind of information patients need and how they want to utilize information telecommunication services. The purpose of this study was to evaluate the relationship between the QOL of home-cared patients with intractable diseases having motor disabilities and the use of information telecommunication services.

Subjects and Methods

Subjects

This study was conducted between May and

November, 1998 in Kyoto Osaka and Shiga Prefectures: 210 patients with intractable diseases having motor disabilities were recruited through the cooperation of the Kyoto Branch of the Friendship Association of Parkinson's Disease. Informed consent for the enrollment in the study was obtained from all patients.

Methods

The investigation was carried out primarily with a questionnaire, and interviews were made when patients could not fill out the questionnaire. The contents of the questionnaire were: i) demographic information including usage of health care and welfare services, and their accessibility to information telecommunication services; ii) activities of daily living (ADL) assess-

Abbreviations: ADL, activities of daily living; QOL, quality of life

Table 1. Characteristics of subjects studied

| | |
|--------------------------------|--------------|
| Number of subjects | 149 |
| Age (year)* | 64.7 ± 10.1 |
| Male/female ratio | 66/83 |
| Disease | |
| Parkinson's disease | 96 |
| Ossification of the PLL | 14 |
| Malignant rheumatoid arthritis | 9 |
| Spinocerebellar degeneration | 8 |
| Others | 22 |
| ADL score* | 106.2 ± 27.6 |
| QOL score* | 32.5 ± 9.8 |
| Depression score* | 12.0 ± 6.1 |

* Mean ± SD.

ADL, activities of daily living; PLL, posterior longitudinal ligament; QOL, quality of life.

ed by using the functional independence measure; iii) QOL evaluated by the scale for neurological intractable diseases (Hoshino et al., 1995) and iv) the severity of depression using the Toho University Scale (Abe et al., 1972).

The subjects were divided to 2 groups of high and low QOL scores according to the mean and median values of the total QOL score: high- and low-QOL groups. The ADL score, depression score and accessibility to information telecommunication services were compared between the 2 groups.

Statistical analysis

Data of QOL, ADL and depression scores were expressed as mean ± SD. For statistical analysis to test differences between groups, a chi-square test with a 2-by-2 contingency table was used. *P* values of less than 0.05 were regarded as statistically significant.

Results

Of the 210 patients, 171 patients (81.4%) answered, and adequate answers obtained from 149 subjects were analyzed, consisting of 66 males (44.3%) and 83 females (55.7%) with a mean age of 64.7 ± 10.1 years (Table 1). Parkinson's disease was observed in 96 patients (65.7%), and other patients had ossification of the posterior longitudinal ligament, malignant rheumatoid arthritis and spinocerebellar degeneration (olivopontocerebellar atrophy).

The mean duration of the diseases was 10.7 ± 8.5 years. A full ADL score is 126. In this study, the mean ADL score was 10.9 ± 22.9. The independence level was 69.8%.

Concerning the depression score, level 16 is considered to be borderline, and the mean in our subjects was 12.0 ± 6.1. Significant differences were observed in the QOL, ADL and depression scores (Table 2).

The mean and median values of the total QOL scores in the present study were 32.5 and 33.0, respectively. Table 3 shows the sources of information in which significant differences were observed between the high- and low-QOL groups. The use of a telephone showed the highest frequency among the sources, followed by the use of the neighborhood newsboard circulated by the local community (*kairanban*), gardening, hobby-learning activities such as pottery, practicing sports or pastimes, expert physicians available in the neighborhood and shopping.

The scores for the use of the telephone, gardening, learning activities and practicing sports were higher in the high-QOL group as

Table 2. Mean QOL, ADL and depression scores compared between high- and low-QOL groups

| Group | Number of subjects | Age (year) | Score | | |
|----------|--------------------|------------|-------|-------|------|
| | | | QOL | ADL | SQR |
| High-QOL | 75 [32/43] | 65.2 | 40.1 | 114.8 | 13.9 |
| Low-QOL | 74 [34/40] | 64.2 | 24.8 | 104.1 | 9.9 |

[], male/female ratio.

ADL, activities of daily living; QOL, quality of life; SQR, masked depression screening test.

Table 3. Sources of information compared between high- and low-QOL groups

| Source | High-QOL | Low-QOL | P value |
|---------------------------|-----------|-----------|---------|
| Telephone | 59 (78.7) | 42 (56.8) | 0.05 |
| <i>Kairanban</i> * | 30 (40.0) | 15 (20.3) | 0.01 |
| Gardening | 29 (38.7) | 13 (17.6) | 0.005 |
| Hobby-learning activities | 18 (24.0) | 6 (8.1) | 0.009 |
| Sport-practicing | 13 (17.3) | 4 (5.4) | 0.001 |

(), percentage.

*Neighborhood notice-circulating system applied in all local communities in Japan.

ADL, activities of daily living; QOL, quality of life.

The 2 groups show significant differences in all sources: examined with chi-square test with a 2-by-2 contingency table.

expected, probably reflecting their more positive attitude toward the involvement in activities.

Figure 1 shows the sources of information. More than 70% of the subjects mentioned newspapers, followed by government-issued public relations newsletters and magazines, and newsletters from general patients aid associations. Figure 2 shows the contents of information that the subjects obtained through these media: information concerning diseases, health care and medicine ranked high as expected.

Discussion

This study suggested that the QOL of home-cared patients with intractable diseases is related to ADL and depression. If ADL is maintained at an adequate level, patients can find access to outside activities, receive stimulation and increase their motivation. This thought is also applicable to depression. If depression is milder, patients may feel better and be inclined to take some action. Therefore, in maintaining

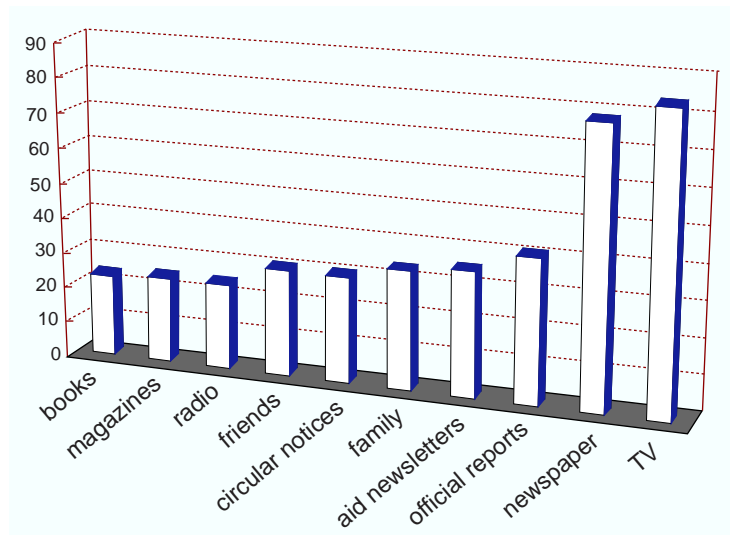


Fig. 1. Sources of information for patients with intractable diseases under home care: circular notices mean the *kairanban*, the circulating neighborhood newsboard present in all local communities in Japan; aid newsletter, newsletters from general patient aid associations in local districts.

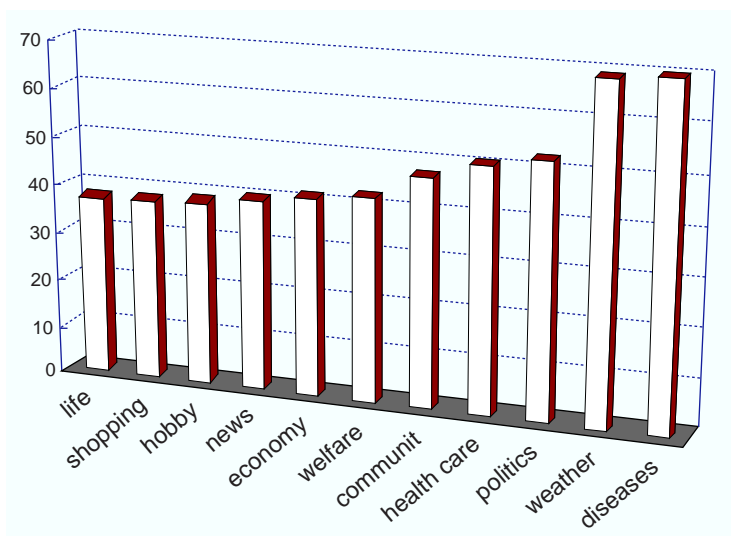


Fig. 2. Contents of information the patients liked or felt interested in.

ADL, some intervention must be devised or measures to assist them should be improved.

Using appropriate measures may improve the living environment and increase assistance in living. Emotional support should be considered in the early stage for depressed individuals. It is also important to plan mental health care around some key persons.

Inadequacy of the contents of information also affects QOL: lack of information leads to lack of interaction, and refusal of communication deteriorates QOL. The *kairanban* (circulating neighborhood newsboard), an important source of information for home-care patients with intractable diseases, provides information concerning activities in the local community and organizations useful for patients' living (Asahi et al., 1998). So, it makes sense to provide information concerning matters and subjects familiar to patients with intractable diseases by means of the *kairanban* as well as newspapers. Moreover, distribution of information through mass media as well as more effective use of the *kairanban* must be considered in the future.

The use of such media may become restricted for patients with progressive diseases such as

Parkinson's disease without further development of devices for supporting their living. Therefore, some devices should be developed also in combination with private wishes of patients.

In conclusion, i) the high-QOL group showed higher ADL scores and lower symptoms of depression than the low-QOL group; ii) the high-QOL group showed more frequent utilization of the telephone and involvement in learning hobbies and practicing sports; iii) the high-QOL group used as an information source the *kairanban*, the circulating neighborhood newsboard, much more frequently; and iv) the high-QOL group got information regarding hobby, travel and shopping more than the low-QOL group. Our findings showed that information offered to patients with intractable diseases under home care improved their QOL, and that information offered by the telecommunication system will play an important role in the near future. In order to improve the QOL in patients with intractable diseases, adequate information on telecommunication services seemed to be vital.

References

- 1 Abe T, Tsutsui M, Namba T, Nishida K, Nozawa A, Kato G, et al. Studies on the self-rating questionnaire for the screen test of masked depression (SRQ-D). *Seishin Shintai Igaku* 1972;12:243–247 (in Japanese with English abstract).
- 2 Asahi T, Yoshiyama H, Asahina M, Arai K, Imamura M, Sueyoshi F, et al. [Trial use of videophone in treating intractable neurological disease.] In: Koseisho Tokutei Shikkan “Tokutei Shikkan Ni Kansuru QOL” Kenkyuhan, ed. Fukuhara N, chairman. Han Kaigi program, Heisei 9 nendo [1998 program for conference of the study group]; 1999 Jan 24; Tokyo. Okata-cho (Niigata, Japan): the study group; 1999. p. 34 (in Japanese).
- 3 Horikawa Y, Eguchi I, Enatsu K, Aoike I, Hashiba M, Suzuki Y. [An experimental computerized system of medical information for home-treated patients with intractable disease.] In: Koseisho Tokutei Shikkan Nanbyo Care System Chosa Kenkyuhan, ed. Hirose K, chairman. Kenkyu Hokoku, Heisei 7 nendo. 1996. p. 81–84 (in Japanese).
- 4 Hoshino A, Shinozaki I, Niino S, Fujita T, Minowa M. Development of criteria in assessing the quality of life for intractable neurological patients. *Nippon Koshu Eisei Zasshi* 1995;42:1069–1082 (in Japanese).
- 5 Niimura K, Kinugasa A, Koshio S, Fukuda M, Iuri T, Tanigaki S, et al. [Quality of life (QOL) and perception of illness in home-treated patients with intractable neurological disease.] In: Koseisho Tokutei Shikkan “Tokutei Shikkan Ni Kansuru QOL” Kenkyuhan, ed. Hirose K, chairman. Kenkyu Hokoku, Heisei 9 nendo. 1998. p. 106–116 (in Japanese).
- 6 Yanaka S. [Home treatment for patients with intractable neurological disease.] In: Nippon Kango Kyokai [Japan Nursing Society], ed. Proceedings of the 27th meeting of the Japanese Nursing Society, “Chiiki Kango”; 1996 Oct 24–25; Hofu, Japan. Tokyo: Nippon Kango Kyokai; 1996. p. 38–45.

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