

## Educational Programs for Neurodegenerative Diseases

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### Abstract

As we cannot stop disease progression of neurodegenerative diseases, we have to consider neurodegenerative diseases as life-threatening illnesses and the objects of palliative care. Neurodegenerative disease patients and their families usually do not have much information about their diseases and often cannot choose their treatment and care options on their own. Before applying the principles of palliative care to the patients and their families, we have to give appropriate information about their diseases to them. But there were few educational interventions in neurodegenerative disease patients and their families and also few studies investigating the knowledge they had. Moreover all but one was the educational interventions for demented patients. All reports about the educational interventions in neurodegenerative diseases showed that the simple educational interventions might not reduce the burdens on the families, and one report for extrapyramidal diseases and cerebellar degenerations moreover showed that the simple educational interventions could not change the courses of natural degradation of the diseases and might produce depressive reaction, to the patients. In order to reduce the burdens of the families we have to support the families with physically, and in order to encourage the patients to accept their diseases we have to control their depressions and approach to them with the principles of palliative care.

**Keywords:** Education; Family; Neurodegenerative disease; Palliative care.

### Introduction

Neurodegenerative diseases (NDDs) have many symptoms, such as dementia, dysarthria and dysphagia, muscle atrophy, Parkinsonism, cerebellar ataxia and autonomic disturbance. These symptoms appear constantly along with disease progression. We cannot stop the progression of them at present. Therefore, we have to consider neurodegenerative diseases as life-threatening illnesses and the objects of palliative care [1-3].

In the books both Palliative Care for Non-Cancer Patients [2] and Palliative Care in Neurology [3] five key principles of palliative care were listed, which were cited from a statement of palliative care definitions of UK National Council for Hospice and Specialist Palliative Care [4]. The first principle was focusing on quality of life (QoL) with good symptom control, the second was whole person approach taking into account the person's past life experience and current situation, the third was the care encompassing both the person with the life-threatening diseases and those individuals who mattered to that person, the fourth was respecting for patient autonomy and choice and the fifth was emphasizing an open and sensitive communication extending this to patients, informal carers and professional colleagues.

Before applying these principles of palliative care to NDD patients and their families we must start with giving them appropriate information about NDDs. It helps them to choose their treatment and care options of their own, that are the fourth key principle of palliative care.

In order to know the way to give NDD patients and their families appropriate information about NDDs, I at first searched the studies of educational programs for NDD patients and their families but I could

find only few studies. So in order to know how much knowledge NDD patients and their families have, I searched again the studies about the knowledge of the diseases that NDD patients and their families had, but found also few studies.

So I had to write down this short review based on these few studies.

### NDD patient's and their family's knowledge about their diseases

I found two, four and no studies investigating the knowledge of NDD patients and their families that they had about dementias, extra pyramidal diseases (EPDs) and cerebellar degenerations (SCDs), and motor neuron diseases (MNDs), respectively (Table 1).

### Dementia patient's and their family's knowledge about their diseases

Robinson et al. [5] surveyed the dementia knowledge of the families having moderate to severe dementia patients in nursing homes. They examined 164 families and 279 staff in their nursing homes using the Dementia Knowledge Assessment Tool version 2 (DKAT 2) and showed that the scores of the families were lower than the staff. In addition the families answered less correctly than the staff to the items concerning to the terminal courses and symptoms about advanced dementias.

Andrews et al. [6] showed in her structured interviews to the 10 families having advanced dementia patients that the most of them had failed to grasp an idea that dementia read to death.

Both of them pointed out that the families lacked their knowledge about terminal situations of advanced dementias.

Robinson et al. [5] also pointed out that the lower scores of the care staff than the nurse staff. It was the important issue and the care staff might need appropriate educational programs for dementias.

There was no study investigating the knowledge of demented patients themselves. It could not be helped because dementia patients had been decreased in their abilities to learn their diseases.

	Patients	Families	Medical & Care staff
<b>Knowledge</b>			
Dementia	-	2	1
EPD and SCD	4*	2**	1
MND***	-	-	-
<b>Educational programs</b>			
Dementia	-	2	-
EPD and SCD	1	1	-
MND***	-	-	-

**Table 1:** The studies about knowledge neurodegenerative disease patients, their families and medical & care staff have, and the educational programs for them (Note: EPD: Extra pyramidal disease; SCD: Cerebellar degeneration; MND: Motor neuron disease.\*Three of four were only Parkinson's diseases, \*\*One of two was only Parkinson's diseases, \*\*\*Sloan and Borasio wrote the importance of telling the disease information to Motor Neuron Disease patients and their families and wrote the way to tell in the book, Palliative Care in Amyotrophic Lateral Sclerosis [11]).

### EPD and SCD patient's and their family's knowledge about their diseases

Yadav et al. [7] had asked Parkinson's disease (PD) patients and care givers to answer their questionnaires, and received 103 PD patient's and 69 caregiver's responses. They reported that both of them had correct knowledge about body part affected, pathology in PD, main drug treatment, epidemiology and effect of exercise. On the contrary, both of them had incorrect knowledge about surgery in PD and biochemical abnormality in PD.

Li et al. [8] examined 344 PD patients in single hospital using questionnaires and reported the PD patients lacked information about etiology, side effect of antiparkinsonian drugs, use of levodopa and surgical treatment.

Jitkrisadukul et al. [9] examined 108 PD patients in single center hospital using PD knowledge questionnaires and showed their gaps in the aspects of diagnosis, therapeutic options and disease course.

We also examined 34 EPD and 2 SCD patients and their families in single neurology clinic with questionnaires, and presented at the 4th annual meeting of the Japanese Society of Medical Networking for Intractable Diseases that these patients and their families did not have much information about their diseases, often could not choose their treatment and care options on their own and were often filled with anxiety [10].

All studies about knowledge that EPD and SCD patients had, were done in Asian countries. It might be because giving appropriate

information to them was cardinal fundamental in Western countries and they were given enough information individually without educational programs, because understanding the importance of giving information to them was obscure in Asian countries, or because the importance was overlooked in Western countries as it being excessive fundamental.

Other than our study indicated that PD patients had less information about treatment options, in particular about surgical treatment.

Li et al. [8] also pointed out that the neurologists had the insufficient knowledge about non-motor symptoms, differential diagnosis, therapeutic strategies and surgical treatment, though having sufficient knowledge about motor symptoms. This insufficiency of knowledge in neurologists was also another issue depending on the single hospital study, depending on the regional characteristics, or depending on universal issue.

### MND patient's and their family's knowledge about their diseases

I could not find any studies investigating the knowledge that MND patients and their families had about their diseases. But telling the knowledge about MND to the patients and their families has been a big issue. Actually Sloan and Borasio wrote the importance of telling the disease information to MND patients and their families, and wrote the way to tell the information to them in the book, Palliative Care in Amyotrophic Lateral Sclerosis [11].

### Educational Programs for Neurodegenerative Diseases and their Families

There were few educational interventions for NDD patients and their families [12-14]. All but one [14] was the interventions in dementias (Table 1).

### Educational programs for dementia patients and their families

Jansen et al. [12] showed in their meta-analysis that educational programs for care givers, mainly the families of demented patients, aimed at teaching skills relevant to dementia caring were not so effective in decreasing their burdens. On the other hand, Sørensen et al. [13] showed in their meta-analysis that their interventions for care givers, not restricted to educational programs, were effective but the effects were larger for increasing caregiver's ability/knowledge than for decreasing caregiver's burdens and depressions. There was no study investigating the educational program for demented patients themselves, same as the study investigating the knowledge that demented patients had.

### Educational programs for EPD and SCD patients and their families

There was only one study, we reported, about the educational program for EPD and SCD patients and their families [14]. In this study we could not improve the natural degradation of the QoL of the EPD and SCD patients in physical functioning and vitality scores of 36-Item Short-Form Health Survey version 2 [15]. As well as educational interventions in dementias, our study indicated that the only giving information about diseases to EPD and SCD patients and

their families could not reduce the burdens on the families. In order to reduce the burdens of the families having EPD and SCD patients we have to support them with physically (e.g. sufficient helper support) which is the third principle of palliative care, family care.

In addition to failing to decrease the burdens of the families with the educational interventions we also observed the degradation of the EPD and SCD patient's vitality and consider it might partially be in depressions after hearing bad news about their diseases. We considered these reflections might be not bad one because it was the fourth stage of dying "depression" which Elisabeth Kübler-Ross placed this stage lead to the fifth stage "acceptance" [16], but it might also be owing to the unfavorable way to give them disease information. In order to encourage the patients to go on the fifth stage of dying "acceptance" from the fourth stage "depression" we have to control their depression, using antidepressants if needed, with the first principle of palliative care, symptom control, and approach to them with the second principle of palliative care, whole person approach. In addition it might be also important to give them the information about their diseases according to the way to tell the bad news to MND patients [11].

Other than our study, Yadao et al. [7] concluded in their study that educational program for PD patients and their families might be useful, because most of their subjects attended their PD education program. But they did not show in their report precise educational program and the effectiveness of their program on the QoL of the patients and the on burdens of their families.

### Educational programs for MND patients and their families

There was no educational intervention in MND. As stated above, Sloan wrote the way to tell the information about MND to the patients and their families [11], and it might be the reason why I could not find the studies because giving appropriate information to them was cardinal fundamental particular in Western countries and they were given appropriate information individually without educational programs, or because the importance was overlooked as it being excessive fundamental.

### Conclusion

Giving appropriate information to NDD patients and their families is the first step for maintaining the QoL of them with applying the principles of palliative care. But for helping the NDD patients and their families to cope with disease progression, we have to plan the educational programs not only giving appropriate information to them with the methods telling the bad news to MND patients and their families, but also supporting the families physically.

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