

Enhanced psychosocial support as important component of neuro-palliative service

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Abstract: There are unmet palliative care (PC) needs for psychosocial and spiritual distress of neurology patients such as bad stroke as well as in chronic neurodegenerative diseases. As such, psychosocial support to both patients and their caregivers should be enhanced in order to provide comprehensive neuro-PC. The first step in developing this type of support/program was to recognize the main psychosocial care needs of the population. Once these were determined, a program was specifically devised to meet those needs as efficiently and effectively as possible. Several studies have shown the importance and value of psychosocial support for terminally ill patients. Generally, the psychosocial aspects of PC generally receive little or no attention in such studies due to financial limitations and, perhaps more importantly, because PC remains an evolving concept. Recent studies of psychological therapies have yielded relevant results in terms of effectiveness and have shown improvement regarding life meaning and well-being in end-of-life patients. However, there are still gaps in providing psychosocial support to the advanced neurology patients opted for PC.

Keywords: Enhanced psychosocial support; advanced neurology patients; caregiver burden

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Introduction

The growing prevalence of chronic illness in developed countries gives a significant challenge. Chronic illness and its treatment negatively impact the physical and emotional well-being of both patients and family members of the patients, particularly caregivers (1).

Even with the growing acceptance of palliative care (PC) for end-of-life care, it has become increasingly clear that patients and their families require not only physical care but also comprehensive psychosocial care.

Although all aspects of PC including the emotional and social support components have steadily evolved and improved over time, in most case this improvement has been ad hoc rather than systematic (2). As a result, psychosocial and spiritual needs are often unnoticed or considered secondary to physical and treatment-related needs.

The UK National Service Framework for Long Term Conditions (3) supports life-long care for people with long-

term neurological conditions (LTNC). It focuses the need for provision of neurology, PC specialist services to support patients throughout their illness and to the end of their lives. In recent years, PC services have increasingly accepted the needs of non-cancer patients (4), especially in rapidly fatal neurological conditions such as motor neuron disease (MND) (5,6). In general, neurological conditions have a longer and more variable time course—it is often hard to decide exactly when a patient is entering the terminal stages of life. Symptoms are varied, and many patients have complex disabilities which include cognitive, behavioral and communication problems and physical deficits. For these reasons, guidelines increasingly propose early referral to PC services (7,8). Moreover, many neurology departments now have specialist nurses with specific experience in the management of specific neurological conditions, who also provide long-term support for patients and their families (9).

In fact, there are unmet PC needs for psychosocial and spiritual distress of neurology patients such as

stroke patients with poor prognosis as well as in chronic neurodegenerative diseases (10-14).

For this reason, psychosocial support to both patients and their caregivers should be enhanced in order to provide comprehensive neuro-PC. The first step in developing this type of support/program was to recognize the main psychosocial care needs of the population. Once these were determined, a program was specifically devised to meet those needs as efficiently and effectively as possible.

Several studies have shown the importance and value of psychosocial support for terminally ill patients (15,16). Generally, the psychosocial aspects of PC generally receive little or no attention in such studies due to financial limitations and, perhaps more importantly, because PC remains an evolving concept. Recent studies of psychological therapies have yielded relevant results in terms of effectiveness and have shown improvement regarding life meaning and well-being in end-of-life patients (17-19).

The idea for the need to develop a new method to psychosocial care of terminally ill patients and their families arose from previous studies carried out to assess the status of PC programs in western countries (20,21). These studies acknowledged several key but underserved areas in the public health and PC realms in need of improvement: the emotional, social, and spiritual aspects of care, as well as care during the bereavement process.

In the United Kingdom, a large-scale initiative called "Improving Access to Psychological Therapies" was developed to improve depression and anxiety disorders (22). There, a lot of patients were successfully treated with low-intensity interventions (e.g., guided self-help). Prominently, more than half of the patients who received at least two treatment sessions (including the assessment interview) were considered to have recovered. Significantly, treatment gains were largely maintained at 10-month follow-up. These findings support the benefit of such approaches and served to assist inspire our own efforts in Spain.

Rabow *et al.* (23) carried out a controlled trial involving 50 patients with advanced chronic illnesses with a life expectancy ranging from 1 to 5 years and compared these to a control group of 40 patients. All the intervention patients were treated by an interdisciplinary palliative medicine team called the "comprehensive care team", composed of a social worker, nurse, chaplain, pharmacist, psychologist, art therapist, volunteer coordinator, and three physicians who addressed physical, emotional, and spiritual issues. All team members (except for the volunteer coordinator) were experts in PC. The program integrated various

interventions, including consultation with the primary care physician (PCP), case management, volunteer and group support, chaplaincy consultation, and artistic expression. In the intervention group, PCPs received multiple PC team consultations, and patients obtained advance care planning, psychosocial support.

In Hong Kong, Chan *et al.* conducted a randomized controlled trial of enhanced psychosocial program for 31 patents with end stage renal disease (ESRD) opted for conservative treatment (24). The enhanced care included on-site support by PC nurse and social worker in outpatient setting, home care support, respite care and bereavement care to these ESRD caregivers. The study resulted in significant reduction in caregiver burden and anxiety of caregivers of ESRD (24). Additionally, those with high risk for readmission had a significant reduction in acute admissions after receiving the enhanced care program in a local quality improvement project (25).

The improved psychosocial care program adopted a proactive, comprehensive and multi-disciplinary approach for the both patients and caregivers. It emphasized on symptom advice and prevention since renal palliative patients usually suffered from heavy symptom burden (26) and an important proportion of them had frequent emergency department attendance (25).

Previous study showed that higher symptom scores of patients was related with increased caregiver burden (27,28). Many caregivers, in fact, were stressful when handling medical emergencies of patients. Remarkably, emotional aspect of caregivers are important predictors of caregiver burden of end organ failure patients (29). The enhanced support session would consist of psychoeducational sessions on the day of patient joint clinic follow-up with nurse, social worker and doctor. Patients and caregivers were assessed by PC nurses and a selected social worker in each clinic session. The PC nurse assessed the symptom burden with assessment tool, provided symptom advice with use of pamphlets, monitored drug compliance and provided psychosocial-spiritual support. Role of the social worker included providing advice for financial issues and placement problems, social support, and arranging respite care for caregivers.

Irrespective of a requirement for healthcare professionals to support family caregivers, the reality is that in many instances such support is often less than optimal (30). Patients and their families' psychosocial needs are frequently considered either secondary to those of the patient, or disregarded; there is neither consistency nor a systematic approach to assessing needs. Furthermore, caregivers are

often not aware of available support, as they usually have inadequate prior exposure to death and dying, and feel excluded from information and care planning (30). Health professionals should recognize that providing psychosocial support to family members, as well as patients, presents an enormous challenge, and they may not be resourced or have the required skills to provide such support. Enhanced psychosocial support appeared to be a useful and effective way to address and solve their problems in this regard.

The benefits of enhanced psychosocial support in PC would consist of the following:

- (I) Improve patients' quality of life and symptoms: it could improve patients' symptoms and their quality of life in end organ failure disease (29). For MND patients, multidisciplinary clinic with enhanced psychosocial care resulted in better quality of life (31).
- (II) Improve caregiver burden and stress: both cancer and end organ failure patients opted for conservative treatment had reduced caregiver burden and anxiety after getting enhanced care (24).
- (III) Implement advance care planning: the PC nurse and social worker could assist ACP through communication among patients, families and healthcare staff, thus reduce unnecessary interventions (24,31).
- (IV) Reduction of healthcare cost acute admission: providing symptom advice and improving drug compliance to patients could result in reduction of acute admission for end organ failure patients (25,29).

In conclusion, given the complexity of neurology diseases and unmet PC needs, an enhanced psychosocial support/program should be integrated into neuro-PC service. The model of care would be multidisciplinary with proactive method and regular assessment is important.

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Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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