



Psychological Approach in Managing Muscular Dystrophy Patients in Malaysia

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Dear Editor-in-Chief

Muscular dystrophy is a hereditary and progressive degenerative disorder affecting skeletal muscles, and often other organ systems (1). The real burden of muscular dystrophy in Malaysia is difficult to estimate, since the epidemiological data for each of muscular dystrophies and even for muscular dystrophies in collective are not available. There are not many researches focusing on muscular dystrophy in Malaysia. The few available researches related to muscular dystrophy in Malaysia are mostly revolving around the medical and genetic science aspects of it, not in the psychology and social sides of the disease. There is no official definition for rare diseases in Malaysia. Nonetheless, the unofficial working definition for rare diseases in Malaysia is that the rare diseases are diseases, which affect less than one in 4000 people in the population (2). About 3% of babies will have some serious birth defect worldwide while in Malaysia, there are around 600,000 births every year and therefore, there would be about 18,000 babies will be born with birth defects every year (3).

While there is a growing interest in muscular dystrophy research in the west, it is still attracting a very low number of researchers in Malaysia. Even among the limited available researches of muscular dystrophy disorder, most of the researches are focusing on the medical aspect of the disease (4). Counselling or other psychological help also usually is not part of the normal medical treatment

and assistant for the muscular dystrophy patients and the parents of the muscular dystrophy patients.

At the early stage of disease acknowledgement, it is normally hard for the patients to accept the reality that they are having an incurable illness. The patients can fall into depression and this depression can keep recurring throughout their lives due to the difficulty in coping with the disease. Sometimes, it is possible for the patient to develop an aggression. Sleep problem also is not a foreign issue to muscular dystrophy patients as psychological stress building up. Nevertheless, the role of psychologists is normally left unnoticed where most of the patients are not referred to the experts in the field of psychology and counselling. Moreover, it is not just the patients who have to face the psychological turmoil as the result of having this disease. Muscular dystrophy is a rare and unique disorder. Therefore, parents of the muscular dystrophy patients sometimes are left feeling lonely in facing all the challenges that come with this disease. Most of the time, they will be occupied by the children and are rarely having breaks for themselves. For the severe muscular dystrophy cases, the parents have to deal with the loss of their children and have to cope with the grief. In certain cases as well, the parents have to deal with the feeling of guilt, shame and blame. Hence, here, parents of the muscular dystrophy patients also

need a psychological intervention just like their children.

There are some encouraging results in improving quality of life of other chronic disease patients from psychological interventions (5). There are also many empirically supported methods to address the change in cognitive and behaviour among other chronic disease population such as behavioural therapy, mindfulness-based cognitive therapy and acceptance-commitment therapy. However, as far as muscular dystrophy is concerned and as far as the authors of this study know, there was only one psychological intervention trial involving the muscle disease patients (6). The lack of psychological interventions probably happens due to poor understanding that psychological factors can relate to quality of life and mood in muscle disease. Therefore, the researchers have limited knowledge on which psychological processes should be targeted by an intervention (7). Clearly, muscular dystrophy poses psychological challenges to both the patient and parents. Many aspects need to be tackled when it comes to the psychological management of muscular dystrophy patients. Due to the lack of a comprehensive psychological program and module for the muscular dystrophy patients in Malaysia, there is a potential for research in finding a proper psychological approach in managing the muscular dystrophy patients. Societal awareness is equally important. Their knowledge and understanding are useful in providing the necessary psychological and social supports.

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Ms Elna Herawati is herself a Muscular Dystrophy patient who is currently a PhD candidate in the relevant field under the supervision of Assoc. Prof. Dr. Nooraini Othman. The authors declare that there is no conflict of interests.

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