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Psychosocial Dimension of Children with Chronic Disease: A Case Study in Malaysia

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ABSTRACT

Psychosocial issues have been seen as minor in medicine despite the importance for holistic medical care involving emotional, spiritual and psychological domains. Most patients with chronic conditions have complex and complicated psychosocial needs especially when dealing children with life limiting conditions. These needs have a dynamic extension to patients' care as their impact can also affect the extended family members. Across the trajectory of the illnesses, the pattern of psychosocial needs changes and, this demands attending physicians to perform accurate psychosocial assessment and understanding issues from patients and caregivers perspective. Non-judgmental decision making is essential to avoid friction and misunderstanding between the healthcare providers and caregivers especially during the consultative process. Resolving psychosocial issue may involve various techniques from moral support, bridging the services to helping the family, counseling on relationship issues and many other areas. There is a need to equip healthcare workers with different skills in order to deliver a better psychosocial care and input even after the bereavement period.

Keywords: *Psychosocial, Palliative care, Life limiting illnesses, Supportive care*

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Introduction

Psychosocial assessment is an important aspect in the management of any chronic cases. The emphasis has been minimal in the current medical management despite the mastery of this skill is considered necessary in the undergraduate and postgraduate training programmes (1). Psychosocial issues are issues pertaining psychological development and their interaction with social environment. It involves assessing humanistic values that helps one overcome personal catastrophe and foster resilience to facilitate normalcy and prevent long term consequences.

Impact of chronic illness is enormous. It goes beyond the individual and family members' life affecting financial, relationship, activities, recreational, mobility and social well-being (2). In children, it impedes developmental, functional, education, socialisation and communication ability. Stability of psychosocial dimension enhances a more acceptable environment for a better outcome and quality of life.

Case

A is a four year old boy referred by the district hospital with history of abdominal distension for a month. He has been having poor appetite, weight loss and lethargy for the last four months. He was brought by her mother following unimproved symptoms. The examining medical officer noted a palpable mass on the left abdomen and directly referred the patient to tertiary hospital for investigations to rule out malignancy aetiology. Final result confirmed the finding of neuroblastoma. There was no distant metastasis noted.

Socially, he is the fifth child out of six children in the family. His father, a 50 year old builder, had recently passed away following a motor vehicle accident. His mother is a 38 year old housewife and has been living with the grandmother after the family's sad demise. Mother has become the sole 'breadwinner' due to the financial hardship. Her grandmother looks after the patient with his siblings during the day. It was reported that the children have only once a day meal and the grandmother controlled the food stock in the house.

His treatment has been delayed due to unavailability of transport and caregiver in the hospital. The medical team visited the family and found that children were left in unkempt condition, without properly available meals and inappropriate hygiene care. This has led to social concern and child protector referral. After discussion with mother, his sister was allowed to accompany him for continuation of treatment despite being under age. In one incident, his sister was caught sleeping with her boyfriend in the oncology ward. That has prompted complaint from other parents. At the same time, his mother brought a new "father" figure following the fiasco. Case conference was initiated to assess the social circumstances and to find appropriate solution to the complex psychosocial issues. The goal of care was discussed to achieve better compliant of the patient's treatment and support from the social perspective was essential as part of the management of the case.

Discussion

There are several key issues that have to be highlighted in this rather complex psychosocial case:

1. What can be done as healthcare provider when dealing with a complex case of psychosocial dilemma?
2. How do we resolve conflicting interest between the caregivers or extended family with the healthcare professionals? Do we really need to intervene when one see a cross cultural practices that contradict to healthcare providers' belief?
3. Do we consider neglect for these children who were unjustly treated when there were financial difficulty and poor community support?

Psychosocial approach largely represents our humanistic value in medicine. It has a diverse definition and certainly required careful assessment method. Better social circumstances would lead to a much stable family ties and consequently good health outcome. This creates a better environment and hope for the family and patients. Many factors that can affect the dynamic of psychosocial issues which include the marital relationship, presence of community and family support, financial strain, stress and grief, job satisfaction and career advancement. The consequences include better medical compliance, improved self-motivation and ability to resolve life conflict.

Physicians' competency in psychosocial medicine has been shown to improve patient satisfaction, cooperation, knowledge recall and health outcome (3). Psychosocial questions involved exploring patients' feeling, concern and expectation, stressor, social support, impact on health, belief and spiritual needs. This would result in better patients' care which include better patients' education, decision making process, addressing of the problems and resolution approach (4). Studies in industrial countries pointed out that people with poorer social economic background have poor psychosocial orientation which in turn caused poorer health outcome (5). They were noted to be resistant to risk changing behaviour. McGinnis and Foege stated in their study that the lower socioeconomic group was associated with higher death and disability (6).

Our illustrated case has shown the complexity of psychosocial dimension

that had hampered adequate medical care for this child. Prognostication of social impact can be achieved from a complete psychosocial history and assessment, but this is often inadequately stressed and explored. This reflects the attitude and knowledge of healthcare workers on the basic needs of the patients.

Because of the complex nature of the case, physicians often overinvolved in the patients' care which resulted in compassion fatigue. It may also result in stress, over burden and secondary traumatic stress. Approach for this case must be done professionally with adequate boundary of care.

The team visit to the family was considered as "Good Samaritan" or in the act good faith. We encountered a few dilemma during our home visit – patient was looked after by the older siblings when the mother went for work, most of the patient's sibling were not schooling, grandmother who rationed the food away from the patient, care neglect when younger sibling was found in unchanged nappy, and unavailability of mother. We believed that we were threading in a gray area. If this occurred in the West, the issue of child abuse or neglect of care will be raised. In the developed nations, the infrastructure and support in the community are good, hence neglect of care can be recognised because of social justice. In the East, family hardship and difficulties must be considered. The social outcome here largely depends on extended family involvement for daily survival and support. Although extended family support is available, however, factors like financial means, availability of extended service and social support can be challenging. Needs information is vital to educate parents to get help either within the community or by governmental institutions. Pressure and life uncertainty has been linked with much immature decision making that could eventually led to unwanted activities such as crimes, illicit drugs use, sexual assault and high risk behaviour. Parents and patients' perspective are often ignored because the contrasting views between the managing doctors and the family's expectation. These paradigm of opinions have caused friction and difficulties.

Ethic of community is the moral responsibility to engage in communal process to pursue the moral purposes of work (7). This is to complement other ethical framework especially in the educational context. The case illustrated here has highlighted many psychosocial problems. There were cultural, religious, personal and customary indifferences which affect the decision for this child. We noticed the coping strategy to their life hardship is to divert the challenges and turbulence by having someone special. This is depicted with what had happened to his sister and mother. Should a doctor impose his or her belief to what the family understanding and belief?

Referral to social worker was made to carefully examine family social viewpoint. Advice related to work, financial means and community concerns have been issued. Voluntary body such as Majlis Kanser Negara (MAKNA) was invited to provide some monetary relief. The socio-dynamic especially in this case has to be viewed differently. Community still has a moral purpose or obligation to address ongoing social issues in the context whether this is acceptable culturally and religiously.

We questioned her mother's decision on leaving her children unsupervised by adult considered as a form of neglect. This term neglect is perhaps relevant if the society is well supported. In our context, consideration on family's financial background and difficulties is a prerequisite before applying Child Act 2001 or referring to community child protector. The struggle for financial needs has led to medical compliance issue, defaulting treatment and social manipulation from other family members. Applying 'neglect' clause in the family who suffer financially is unjustified

before available family and community support to this unfortunate family.

Since patient is largely at home, the ethical challenge is rather different. In the hospital setting, the patients are considered as our client or guest. Somehow, the role changes when one enter the patient's house. Virtue ethics is mostly applicable for community problems which include justice, fidelity, self-care and prudence. This focuses on a person and what it means to human life. The concept may be difficult to correlate if the understanding of community behaviour differs from individual understanding on certain aspect of life. Applying to our case, it's important to allow two way and bilateral communication between the doctor and the parents. Identified psychosocial issues may not be easily remediable. Approach on this psychosocial plight should be pictured from different paradigm i.e. parental perspective. Understanding to as why they take the decision without resorting to legal action is paramount to achieve negotiable objectives. Respecting "by proxy" nature of decision making and assisting parents to make a correct choice will allow for a successful cooperation and continuation of care. The coping style for each family varies depending on their past experiences. Some may exhibit coping strategy by positively learning different life skills or negatively by exhibiting a destructive behaviour. Optimal environment is essential to ensure these individuals gain some sense of control by active participation or taking responsibility on their lifestyle. We believe, in our local context, especially in East Coast of Peninsular Malaysia, many difficult psychosocial issues can be resolved through graded discussion, negotiation, diplomacy process and effective therapeutic communication.

Conclusion

Most our chronic cases in the East of Malaysia are usually associated with complex nature of psychosocial problems. Capacity of helping our patients perhaps can be started when the family starts to identify and address the psychosocial needs. Support from the community end should be available all the time. Medical personnel should not be judgmental to as what have been decided by the patient or family, and most cases can be resolved through information and negotiation to reach the final resolution.

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