Psychosocial Care And Adjustment Of Children And Families With Sickle Cell Disease: The Nigerian Perspective

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Abstract

Nigeria is a country with one of the largest number of sickle cell disease (SCD) patients in the world. Many affected children and their families experience many adverse psychosocial effects. Most SCD clinics and other outlets of SCD care in Nigeria focus mainly on the physical well being of affected children with little or no concern about prevention or management of these associated psychosocial complications. This has negative implication for management and manageability of the disease. This paper is aimed at reviewing psychosocial care and adjustment in sickle cell disease with focus on the present status, problems and possibilities in Nigeria.

This is a review article on psychosocial care of SCD children and their families, using manual search for literature in library, internet and textbooks.

The psychosocial component of the care of SCD patients in Nigeria is still deficient and need to be improved. Major problems of psychosocial care of SCD patients in Nigeria include: insufficient attention to data gathering on problems and coping strategies, inadequate health education and public enlightenment on coping strategies and shortage of trained human resources, social welfare services and infrastructure.

Sustained commitment to tackling these problems will upgrade psychosocial care for SCD children and their families in Nigeria. This is achievable if the knowledge and skill of psychosocial care is made available to all groups of health professionals involved in health care delivery to children; with the mental health professionals spearheading the initiative.

Key words: Sickle cell disease, children and family, psychosocial care, adjustment**.**

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Introduction

Sickle cell disease is a term used for a group of disorders in which there is concurrent inheritance from both parents of sickle cell genes. The commonest types of the disease in Africa are homozygous form called Sickle cell anaemia (HbSS); and the heterozygous forms namely: sickle cell HbSC disease; Sickle cell thalassaemia disease (HbSThal) and sickle cell high persistent foetal haemoglobin disease (S-HPFH).[1,2] Sickle cell disease (SCD) is about the commonest chronic medical condition affecting children in Nigeria with an incidence put at about 2-3%.[2,3] Nigeria is a country with one of the largest number of SCD patients in the world. It is estimated that 2-3 million Nigerians have SCD.[4]

Sickle cell disease is a chronic debilitating disease in which affected individual have episodes of crises which affect their physical, psychological, social and economic lives and those of their families. Sickle cell anaemia patients may start to have symptoms as early as 6 months of age while those with SC disease may not be symptomatic until 5 years of age.[1, 5] Physical features and complication of SCD are varied; often multiple, multi-systemic and many arise from occlusion of blood vessels and increase destruction of red cells. The typical crises are usually associated with pain, body weakness and anaemia which can be severe, sometimes life threatening requiring hospital admissions and blood transfusions. Anaemia could be haemolytic, aplastic or due to sequestration of blood into the spleen.[1,5,6] Other complications of SCD include infections (bacteria, malaria) acute chest syndrome, eye damage, gallbladder disease, ulcers, avascular necrosis of the hip, neurological problems such as stroke, and renal damage.[7-12]

Previously many patients with SCD died from organ failure at the age 20-40years.[6] Better understanding and management of the disease has helped to prolong life to 50years and beyond.[6] Treatment is directed at relieving symptoms, avoiding crises and limiting or preventing complications. Although cure is now possible for some category of sickle cell anaemia patients through bone marrow transplantation, finding donors is difficult, procedure still carries high risk and it is expensive[6]; certainly not what can be contemplated for majority of SCD patients in developing countries like Nigeria, for now. Treatment may also include the use of the following:

analgesics, antibiotics, anti-malarias, folic acid, blood transfusions, hydroxyurea and Nicosan to limit frequency of crises; and surgeries for, gallbladder, eye, hip joint diseases, and for priapism and leg ulcer. Antenatal diagnosis and genetic counselling are preventive methods made available to parents. In addition, SCD patients are encouraged to avoid the following: strenuous physical activities, smoking, low oxygen environments, infections, inadequate fluid intake and emotional stress.[1,2,5,6]

SCD also has a lot of psychological and social complications for children and their families because of the considerable stresses it exerts on them.[13-16]

Children with SCD could be impaired psychosocially in some or all of these five areas. First area is, psychological functioning: They may exhibit various emotional and behavioural reactions like excessive anger, insomnia, restlessness, fearfulness, increased dependence, nightmares, anxiety, over-inhibited behaviours, social withdrawal, guilt, misery, unhappiness, fear of abandonment, loneliness, feeling of hopelessness, crying and reduced self-esteem, self-pity, depression, preoccupation with disease, enuresis, uncooperative behaviour and conduct disorders.[7,15,17-21] Second is, academic functioning that is, school attendance, performance and interactions: the SCD child may suffer repeated school absenteeism which may lead to school underachievement, failure or drop out[17,22] Third area is, poor social functioning i.e. relationship with peers at school and at home this may be due to shyness, loneliness, lack of close friend, inability to play games of choice, feeling of being different, inferiority complex and restriction of movements and interactions.[15,17,20] The fourth is, physical functioning i.e. how much illness, deformities, delayed growth and maturation disrupts day to day life and quality of life;[17,23] and the fifth area is family functioning i.e. relationships with family members; SCD may result in sibling jealousy, unrealistic demand on siblings, overprotection or neglect;[15] these problems may be a source of peer teasing for the affected child.[15,17]

The family is the main agent of socialisation, its structure and functioning can affect a child's adjustment to illness, also illness can impact negatively on family members.[24-26] The disease can negatively affect the work, marriage, physical health, emotion and life of parents of affected children.[13,14] Other described psychosocial effects of SCD on the family include financial difficulties, marital disharmony, domestic abuse, divorce, sibling neglect and jealousy, grief, depression, resentment and guilt. Parental fear of complications of the disease, social and economic failures and potential for early death of the affected child and feeling of guilt may lead to neglect or overprotection, anxiety and or depression.[18,27]

Despite the knowledge of the above problems the attention paid to physical treatment still overshadows the need for psychosocial interventions for obvious reasons, firstly, the physical need is often acute or life threatening and it is usually what brings the patient to hospital. Secondly the features of psychosocial problems are hardly reported spontaneously i.e. they need to be extracted from the patient however in the child this could be difficult. Nevertheless, psychosocial problems that are undetected may have serious consequences for the child.[28,29]

Psychosocial interventions in childhood

The childhood period appears to offer a unique opportunity for psychosocial intervention in SCD. Firstly, many of the psychosocial problems identified in the adult SCD patient may probably be carry-over from childhood. Secondly, the child's growth and development and coping mechanisms, may be overwhelmed by SCD if psychosocial intervention is not carried out. Also, unresolved conflicts and difficulties may precipitate major psychological problems in late childhood or adolescence or adulthood. Hence, it becomes imperative to identify these psychosocial stresses and coping mechanisms so that they can be modified positively before adulthood.

If the psychosocial problems in SCD children and families are not prevented or minimized they can affect the child's management or manageability. The risk factors for their occurrence must be minimized. Families that already have risk factors must be identified and treated specially since family risk factors for psychiatric disorder in childhood are multiple and additive.[30] Risk have been observed to increase with the number of such family's adverse factors as marital discord, low social status; large family size, maternal and paternal psychiatric disorders.[30,31] It has been reported that children with two family risk factors have a fourfold increase in rate of disorder.[30]

Psychosocial care and adjustment

Psychosocial care is everything that is done to help people with physical illness particularly chronic ones and their families adjust to the illness while helping already well adjusted ones remain as such.[29]

The whole area of psychosocial care falls under the subspecialty of consultation-liaison psychiatry, which involves the application of holistic (biopsychosocial) approach to clinical work.[32,33] This area of psychiatry has been described as the subspecialty concerned with the diagnosis, treatment and prevention of psychological morbidity among

physically ill patients in all types of health care facilities.[34]

Coping with physical illness

Central to issues of adjustment and maladjustment to chronic physical illness are coping strategies, which are essentially methods, used by patients and their families to adjust to chronic illness. Coping strategies can also be explained as all techniques, be it cognitive, motor activity, emotional expression, etc used by an individual to manage (master, tolerate or minimise) a major stress and its attendant negative effects in order to allow him achieve personal and social goals.[35-37]

Successful coping results in proper adjustment which implies that the person is functioning effectively despite the handicap. Coping strategies are diverse, probably individualized; the important thing is whether they are positive or negative; positive coping strategies alleviate effect of stress while negative ones aggravate it.[3,38-40] Patients and families should be helped to identify their coping strategies, decide whether they are positive or not; modify if negative, and reinforce if positive.

Coping resources may be explained as all attributes, that is, personality, self-concept, socioeconomic status, demographic factors, etc of the individual patients and their family that are under their control which can mediate a negative or positive coping response.[24-26] The identification and utilization of coping resources is vital to adjustment to chronic physical illness, inability to utilise coping resources may result in maladjustment.[26] Psychosocial care should not only assist the children and their families identify their coping resources but also help them to utilise them. An important dimension of psychosocial care is that coping strategies can actually be learnt and utilised.[3,38,39]

Psychosocial assessment

With the pivotal role of psychosocial assessment in psychosocial care delivery it has been suggested that it should be part of the clinical assessment of any patient with physical illness.[33,34]

The ideal psychosocial care approach in the child with chronic physical illness translates into a comprehensive assessment of the child and family functioning. Therefore, data gathering should be a continuous process because the impact of physical illness is a dynamic process. Important changes in the child and family need to be assessed and managed continuously[29] this can only be done if data is obtained and updated regularly. The ideal psychosocial assessment should provide answers to the following questions as suggested by Leventhal.[29] How has the illness affected the performance of the child at home and with peers at school? How has the child adjusted to the illness physically, psychologically and academically? What impact has the child's illness on the family and its members? And how have they adjusted to the burden of the child's illness?

Obstacles to psychosocial data gathering and assessment

Developing detailed and reliable information of the child and family can be difficult because data on human behaviour and relationships are complex; topics are sensitive and may remind the participants of sadness associated with the illness.[29] The patients and family or even teachers at school tend to minimise or misinterpret psychosocial problems in the affected child sometimes because of ignorance or vested interest.[41-43]

The child may also minimise his problem because of anxiety about the reactions of the parents; many times the child's problem may be manifestation of the malfunctioning of the family which the parents may want to conceal. Psychosocial assessment may also be affected by the stage of development of the child. There is however some agreement that structured interview can be a reliable and valid method of gathering data on psychological disorders in children above seven years of age.[41-43] Also for the reason that a child may behave differently at home and at school it is ideal to obtain data from both sources when possible.

Comprehensive psychosocial assessment though desirable is expensive, time consuming and complex. However, not all children with physical illness can and need be assessed with equal depth and completeness. This is logical since not all children with chronic physical illness suffer enough psychosocial distress to be maladjusted, available literature suggests that majority do not.[44] Therefore, the depth and completeness of assessment should depend on the severity and specific need of individual cases.

The reasonable approach therefore, is to first do psychosocial screening to detect those who have problems and then a more comprehensive data can then be gathered and appropriate care provided. Simple, short and easily administered screening questionnaire can be developed to identify patients who are at most need of psychosocial intervention.[3] Research into this aspect is very vital to the provision of psychosocial care especially in developing countries.

Psychosocial care providers

Physicians who provide excellent medical care to chronically ill children often times are not trained in psychosocial aspects of paediatrics. They are unable to adequately explore psychosocial family issues.[29,44] In developed countries other specially trained staffs such as social workers compensate for this limitation by providing the major portion of

psychosocial care[29] Physicians also often feel they do not have adequate time to collect this type of data whereas some of the data can be collected as part of the regular schedule of clinical work.[3,44] In some situations they may actually fail to remember or be favourably disposed to asking psychosocial questions.

The issue of who is best placed to provide psychosocial care has been of concern.[44] Psychiatrists, Psychologists, Social workers and some specially trained Nurses may be best placed to provide psychosocial care by virtue of their training and experience, however, they may not be available or cost effective in some settings especially developing countries.

Ideally the psychosocial management of the child is a multidisciplinary task involving the services of primary physicians, paediatricians, psychiatrist, social workers, psychologists, school teachers, guidance and counsellors and others; with someone acting as the co-ordinator for effective integration.[44] The multidisciplinary approach enjoys wide support.[3,15,29]

Psychosocial care methods and techniques

What is actually done in the process of psychosocial care delivery will depend on the psychosocial problem /diagnosis, socioeconomic and cultural background of the patients, the available social welfare support systems, and the medical infrastructures available to the care provider or the providing institution.

Whichever, psychosocial domain is affected be it, psychological , academic, social, physical and family functioning the probable methods of dealing with psychosocial problems in the child and his family are (i) psychotherapy (ii) physical or drug therapy, and (iii) preventive methods.[15,17,18] Psychotherapy may be directed at the individual SCD patient or to a group as in marital and family therapies.[45] Marital therapy is indicated in SCD children' families in which there are severe marital difficulties, in this case treatment is given to both parents only, while family therapy is indicated where several family members have significant psychosocial problems that is, the whole family is treated. Physical therapy using drugs may be indicated among patients and their family members with definite or characteristic psychological diagnosis. The three levels of prevention, primary, secondary and tertiary[46] are relevant to psychosocial care in sickle cell disease.

Primary prevention aims at avoiding completely the incidence of SCD or its psychosocial consequences on the family. Genetic counselling (retrospective and prospective) backed by the use of modern family planning methods is a simple method of reducing the incidence of SCD.[2,20,47] Other primary preventive measures applicable to SCD[18,48-50] include a deliberate attempt by the physicians to (i) assess and reduce risks of psychosocial problems in the child and his family; (ii) adequately inform parents, family members and the school about the disease, its academic and social effects and the supportive role they should play; (iii) encourage home tutoring to minimise school underachievement; (iv) encourage engagement in sedentary hobbies (e.g. chess, craft, etc) which will create opportunity for psychosocial interactions with peers without tasking physical reserves; (v) encourage free communication between the patient and his family members and (vi) help parents know what to do about such problems as discipline, overprotection, peer teasing, and sibling jealousy.

Secondary prevention of psychosocial problems of the SCD child and his family is aimed at reducing the prevalence of these problems by early detection and prompt management. The introduction of consultation liaison psychiatry at all levels of health care should take care of this aspect of prevention;[34] While tertiary prevention deals with how to minimise the effects of psychosocial maladjustment when they have already occurred. This implies rehabilitation of the patient with the goal of restoration of normal or close to normal functioning, example restoring functioning in a malfunctioning family through marital or family therapy.

Nigerian Perspective

In developed countries affected by SCD well organised comprehensive psychosocial care for SCD children and their families is the norm. Usually SCD centres with multidisciplinary team of care givers run programs that are strong in both physical and psychosocial components. In this kinds of setting psychosocial interventions ensure that problems are identified and tackled promptly, coping skills are identified early, modified or re-enforced as apt or may even be taught if inadequate.[7,22,40]

In Nigeria this standard of care is still not obtainable. There is an urgent need to take responsible decision to alleviate the suffering of these children and their families. There must be a deliberate attempt to organise a comprehensive psychosocial care as part of a broad base national sickle cell control programme; this has always been advocated.[4]

While there may be several reasons why a more organised psychosocial care is desirable for Nigeria, two attract special attention: the potential of psychosocial wellbeing of these patients and their family to aid their physical wellbeing and the need to guarantee and secure adequate psychosocial development of affected children.

It may not be possible to detach medical manageability of chronic physical diseases (that is ability to effectively manage and prevent crises, which

requires patient's cooperation) and their psychosocial handicaps.[51] There probably exists a direct relationship between the two, psychosocial handicap contributing to poor manageability and vice versa. An effective psychosocial care programme for SCD children has the potential of assisting their physical wellbeing and makes medical care more cost effective.

Chronic physical illnesses can alter the psychosocial development of the child by affecting factors connected with motor and social competence such as; self-control, self-esteem, self-concept, future ambition, etc.[52] Proper psychosocial development enable the child have the right interaction with the environment to become a well functioning (psychologically and socially) individual in his family and in the society.[52,53] Organised psychosocial care can help reverse or minimise the negative impact of chronic physical illnesses on psychosocial development and its behavioural, emotional and social consequences. Early psychosocial intervention in childhood offers the advantage of reducing the risk of psychosocial handicaps being carried into adult life and the society is better for it.

The argument for a well-organised and comprehensive psychosocial care for SCD children and their families in Nigeria underscores the need to examine its present status, problems and possibilities.

Present status

In the last three decades in Nigeria the interest in psychosocial impact of SCD has grown in scientific literature. Most of these efforts have focused on one or more of these three areas. (i) Establishing the prevalence of psychosocial problems, their magnitudes and correlates using standardised and semi-structured instruments; (iii) assessing coping strategies in SCD sufferers and their families and (iii) suggesting management approaches to psychosocial problems in SCD.

With regards to the first area, Famuyiwa and Asuni in 1991[25] designed a 22 item standardised schedule to measure the burden of care on the family of SCD patients. Other examples of screening instruments that have been used in Nigeria for assessing the psychosocial impact of SCD includes: 12-item version of Goldberg's General Health Questionnaire (GHQ) and 33-item modified version of Franfurter Befindlicheitssakala (FBS);[3] 60-item version of GHQ and Leeds Scale for self-assessment of anxiety and depression used among adult SCD patients.[54] While among children population one study used Child Behaviour Questionnaire of Rutter (Scale A and B),[55] another on psychosocial impact of SCD on children and their family used Rutter Scale A, Reporting Questionnaire for children (RQC) and self reporting questionnaire (SRQ) in their mothers.[56] and a third study on psychological complications of childhood chronic illness used the youth version of the Computerized Diagnostic Interview Schedule for Children, version IV (C- DISC- IV) to assess for diagnosis of emotional disorders in SCD children while General Health Questionnaire (GHQ–12) was used to assess for psychological distress in their mothers in this same study.[57]

Apart from these instruments, structured questionnaires have been designed and used to study the psychosocial impact of SCD on patients and their families in Nigeria.[13,19,50] These studies irrespective of methodology, socioeconomic, demographic and cultural background all confirmed that SCD exert significant psychosocial burden on patients and their families.

On the coping strategies, information and literature is still very scanty but there is a notable contribution from a study[3] in which they reported that majority of adult SCD patients in Nigeria did not actively adopt any coping strategy for their psychosocial distress. In that study "praying to God" was the commonest reported method of coping this was also the most reported coping method used by both SCD children and their mothers in another study;[56] the high level of religiosity in Nigeria may explain the finding in both studies. In addition, both studies stressed the difficulties existing in collecting data on coping strategies in Nigeria. It was recommended that education on coping strategy be a regular feature of counselling activities at the SCD clinics, SCD clubs, print and electronic media. Also emphasised is the development and validation of standardised screening instruments for information gathering on coping strategies.[56]

On the third area of focus involving the development of management approaches to psychosocial problems of SCD, the following suggestions have been made. (i) The encouragement of self help groups like SCD clubs and other social support organisations where families can interact and share experiences and also learn to develop and use positive coping strategies;[3,20,56] (ii) genetic counselling backed by use of modern family planning methods to reduce the risk of additional burden of having more SCD children in families;[2,20,46,56] (iii) psychosocial care methods in SCD e.g psychotherapy, physical therapy and preventive measures;[15] (iv) the need for training of health care providers dealing with children and their families in psychosocial care; (v) free medical care for children to minimise the psychosocial impact of SCD and (vi) encouragement of consultation-liaison psychiatry in the health care system.[56]

Problems

The problems militating against the development of psychosocial care in Nigeria could emanate from two broad areas namely its organization

and its utilisation.

Based on the amount of scientific literature in this area, there is little attention devoted to organised psychosocial care in Nigeria. There is need to sensitise health policy makers to this type of care. Consultation-liaison psychiatry is still underdeveloped in Nigeria, even in the tertiary health centres. Even if the plan to develop consultation-liaison psychiatry were perfected it would be handicapped by the inadequacy of mental health professionals who will coordinate it. It will equally be even more difficult to attract them to the rural areas where the majority of the affected patients and their families live.

Perhaps the most vital limiting factor to the development of psychosocial care is the unavailability of funds. Funds allocation to the health sector is grossly inadequate sub- allocation to childhood diseases is largely and justifiably consumed by the infective diseases, leaving little or nothing to activities like child psychiatric services or delivery of psychosocial care. The depression in the Nigerian economy has led to near collapse of social welfare and support systems, which are positive agents of psychosocial rehabilitation. The poor state of basic infrastructures and health records are also obstacles to the development of organised psychosocial care.

Lack of awareness and understanding of the nature of psychosocial problems in SCD may lead to under-reporting by parents even in the limited outlets (SCD clinics) where some form of psychosocial care occurs. It is imperative to expand the scope of outlet of care to primary health centres also, reducing the level of poverty and illiteracy will enhance utilization of services when and where available.

Possibilities

The improvement of psychosocial care in Nigeria lie in the proper planning and investment directed at: (i) effective service delivery and co-ordination; (ii) research and training; and (iii) health education, public enlightenment and advocacy.

The main objective at the national level must be the introduction of some forms of consultation-liaison at all levels of health care. A minimum level of psychosocial care for every child with chronic physical illness should be defined.

A developmental approach to the introduction of psychosocial care implies that the tertiary health centres will develop a standard; and based on a collaborative strategy, psychosocial care is systematically spread down the other levels of health care.

Using this model for SCD clinics in the tertiary centres implies that psychiatrists as co-ordinators can organise and offer comprehensive psychosocial care in the context of consultation-liaison psychiatric units. Within the framework of a well funded programme extension services can be developed that will take psychosocial care into the national sickle cell programme, which ideally should involve all levels of health care and the community.

There must be increased funding and encouragement for research into psychosocial impact of chronic physical illnesses, methods of coping, modes of management and their effectiveness. The knowledge and skill of psychosocial care must be taught to all health workers dealing with children and their mothers, while physicians must be exposed at both undergraduate and postgraduate levels.

Activities in health education and public enlightenment must be intensified to increase community awareness. The print and electronic media, school teachers, sickle cell clubs, community leaders, and other non-governmental organisations must all be encouraged to get involved. Lastly, mental health professionals must advocate for a better deal for children with SCD in terms of resource allocation to psychosocial care. At the institutional level, they must advocate for the introduction of properly organised consultation-liaison psychiatry at all levels of health care.

Conclusion

There is presently inadequate attention paid to the psychosocial care of SCD children and their families in Nigeria. Studies on the impact of SCD, coping strategies and psychosocial care of this group of children are still few.

There will probably be no major improvement in the psychosocial care of this group of patients until some minimum form of consultation-liaison psychiatry is introduced at all levels of health care.

There is an urgent need for more research and funding of this area of care, unless this is done a substantial population of children and their families who need help may not get it, while remediable problems continue to hinder their development and well being.

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