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WORKING WITH BLACK SLE PATIENTS: A CHALLENGE TO MEDICAL SOCIAL WORK

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SUMMARY

Systemic Lupus Erythematosus (SLE) is a connective tissue disease, the cause of which is unknown. It affects females more than it affects males. The cause of this disease is unknown cause and it is difficult to diagnose. This complex disease is highly systemic in nature as it affects the central nervous system, the dermatological, musculoskeletal, gastro-intestinal, reproductive, renal, haematopoietic, cardiopulmonary systems. The psychosocial impact of SLE on patients and families calls for continuous medical social work intervention throughout the medical intervention period. The manifestation of SLE affects the individual's ego, self-esteem, self-image, personal relationships and social participation. The nature of the disease demands a multi-disciplinary approach in the treatment process.

INTRODUCTION

This article challenges medical social workers working with patients with Systemic Lupus Erythematosus (hereafter referred to as SLE). It is based on an exploratory study carried out over a period of a year at the Chris Hani-Baragwanath hospital in Soweto, Johannesburg. The hospital is a referral hospital and hence patients come from various areas.

The study, which was quantitative in nature, explored the experiences and psychosocial impact of Systemic Lupus Erythematosus on black patients and their families. Data were collected through person to person questionnaires from a sample of 26 respondents who were purposely selected from a population of patients with SLE attending the Out-Patient Lupus Clinic at the Chris Hani-Baragwanath hospital. The ages of the respondents ranged between 16 and 40 years.

THE CLINICAL ASPECTS OF SLE

Systemic Lupus Erythematosus is a chronic inflammatory disease of unknown cause which produces symptoms varying from the very mild to the life threatening. The disease is slowly progressive and often involves the skin, joints, serous membranes (pleura and pericardium), kidneys, hematological and central nervous systems (Buergin 1983:987; Buergin and Paskort 1991:2065; and Parke and Rothfield 1998:448.) Some of the risk factors mentioned by Ball (1986:98) include race, sex and heredity in which dark-skinned people are more prone to the disease than other races.

Whereas SLE is generally reported to be rare in some parts of Africa, Tickly *et al.* (1996:261, 263) maintain that the disease is not uncommon in South Africa. In as much as they are prone to the disease, research shows that Blacks have a worse prognosis associated with increased prevalence of renal disease and certain autoantibodies. Sex is also seen as a contributory factor linked to a possibility of abnormal oestrogen metabolism. In this study on exploring the psychosocial impact of SLE on black patients and their families, conducted in 1996/7 at the Chris Hani-Baragwanath Hospital, 25 of our 26 respondents were females. Females are affected more than males and are affected more during their child-bearing years. Heredity and other environmental factors like viral

infection, over-exposure to ultraviolet light and x-rays, physiological factors and emotional stress and x-rays have, according to Casterline (1983:1720), also been recognised as exacerbating disease activity.

SLE is extremely variable in its severity, ranging from a relatively mild disorder to a rapidly progressive one affecting many organ systems; there is no characteristic pattern of progressive organ involvement, nor is there predictability for which systems may be affected first. The following gives a picture of the extent to which organ systems become affected: **neurological involvement** includes organic brain syndrome, schizophrenia, affective disorders, strokes, seizures, neuropathies, transverse myelitis and aseptic meningitis, amongst others. Arthralgia with morning stiffness, degeneration of the hip, ischemic bone necrosis and osteoporosis are evidence of involvement of the **musculoskeletal system**. **Dermatological involvement** includes alopecia, lesions and rash on the face and neck. **Haematologically**, enlargement of the liver and spleen is experienced by few patients, but these organs would, in most patients, return to normal size.

The **reproductive system involvement** in females manifests in either stillbirths and/or spontaneous abortions, which are said to be common in untreated patients with active disease, as well as cessation (amenorrhea) or extended period (menorrhagia) of menses. Common **gastro-intestinal** problems expressed by patients include serositis, anorexia, nausea, vomiting, diarrhea, upper and lower gastrointestinal bleeding. Clinical evidence of **renal involvement** present in most patients with SLE includes hematuria, proteinuria and various kinds of nephritis. The renal system is usually the last system to be affected and signifies death as kidney involvement may lead to severe kidney failure (Lima *et al.* 1995:190; Mallya 1983:63; Parke & Rothfield 1988:456; Ramos *et al.* 1996:295; and Rothfield 1989:1030.)

Complex as it is, SLE, according to Reichlin (1995:1), can be a difficult disease to diagnose. The reason is that many symptoms of SLE mimic those of other illnesses. A 1992 American Rheumatism Association's Revised Criteria for Classification of SLE is used for diagnostic purposes whereby an individual must show at least four or more symptoms of those reflected in the classification criteria. Treatment is aimed at achieving remission. Thus the course of the disease is characterised by periods of remission and relapse. It is important to note that treatment has its own contra-indications, of which the medical social worker must be aware. Prognosis, according to Casterline (1983:1723) and Emery (1994:130), is said to be more favourable for those who do not have renal or neurological involvement or a superimposed bacterial infection.

The study revealed that most patients were affected in at least three systems that varied from patient to patient. However, most had alopecia, amenorrhea and musculoskeletal problems which caused difficulty in doing household chores or working early in the morning.

PSYCHOSOCIAL IMPACT OF SLE AND THE MEDICAL SOCIAL WORKER'S ROLE

Any kind of illness brings with it personal and familial experiences different from an individual's normal way of living. These experiences also have a psychosocial impact on a person's life. Both patient and family's experiences of illness, hospitalisation and treatment are influenced by several factors, namely socio-cultural issues, family dynamics, personality, lifestyle, perspective on life, environment, religion, nature of illness, period of hospitalisation and treatment procedures, to name a few. These factors will differ from person to person depending on their unique circumstances. In the black community, the psychosocial impact is influenced more by cultural and religious beliefs; this was evident in this study.

The involvement of the different organ systems exposes patients to fatigue and frustration. Fatigue, according to Melvin (1982:20), can become disruptive to the patient's lifestyle, and their familial and social relationships. Adult patients may feel too tired to play with their children, maintain a job, have sexual relations or to participate in social events. Frustration, as Lilliston (1985:11-13) believes, is brought about by continuous pain as medication may not ease the pain completely. More frustration is brought by a change in lifestyle, which is influenced more by a change in diet and scheduled appointments with physicians as the patient becomes more dependent on the medical staff. Frustration and poor self-image lead to grief and mourning which refer to the sorrow that follows deprivation or loss of a form of functioning, or loss of hopes and reduced expectations. Mourning is necessary if the individual is to cope with the disease. Social workers therefore, as according to Erfling (1980:171), have the skills needed to increase patients' and families' ability to cope with chronic illnesses and the orientation to try to further institutional and community understanding and responsiveness to the needs of those with rheumatic related diseases. An assessment of patient's understanding or perception of illness is important. The following section summarises the impact of SLE on the patient and family and the roles of the medical social worker (Modisane 1998:37-57.)

DERMATOLOGICAL SYSTEM

The family may react with mixed feelings to alopecia, cushinoid appearance, photosensitivity, and lesions. The obvious effects of skin rashes, lesions, alopecia, and cushinoid appearance may cause social isolation. The skin rashes and lesions may be regarded as signifying some communication or message from the ancestors and thus warrant consultation with either a traditional or a faith healer. Relationships within the family will depend on the family network in supporting the patient in getting a wig or protective clothing. The family may also discourage social activity to either protect the patient from societal attitudes or to protect themselves from being asked questions about the patient. In this regard, the medical social worker should allow the patient to express his or her feelings so as to explore their feelings and assist in coping with the presenting situation. It is important to explore possibilities and means of getting wigs (or hats), protective clothing and sunglasses. However, a patient used to wearing a cloth around her head (*tuku* in Setswana) may not need a wig.

CENTRAL NERVOUS SYSTEM

The involvement of the central nervous system, according to Melvin (1982:44), predisposes the patient to anxiety, depression, confusion, hyper-irritability, hallucinations and paranoia. A stroke, psychosis, seizures and organic brain syndrome prevent the patient from engaging in social interaction and social activity. The patient may have problems or difficulty eating, washing, walking and communication, and thus become frustrated. The patient may be unable to perform normal domestic chores and this may prompt feelings of uneasiness within the family. Embarrassment cannot be prevented. A stroke in the black community is also regarded as a sign of witchcraft, the perception being that the individual has trampled on "wrong and bewitched" ground. The immediate family may not believe in this, but the extended family may recommend consultation with either a *sangoma*, a traditional or faith healer. The roles of a medical social worker would thus include: helping the patient and family acknowledge the physical condition and find ways of coping; reassuring the patient and family of the medical social worker's support and multi-disciplinary team's willingness to help; encourage the family to report behavioural changes; and encouraging and referring the patient for rehabilitation.

MUSCULOSKELETAL SYSTEM

Pain is the most unwanted experience, but unfortunately many SLE patients develop rheumatoid arthritis. Frustration, according to Erfling (1980:180-181), is a common emotion for all human beings, but for the rheumatoid disease patient it can be a constant companion. Frustration is caused by the difficulty in getting out of bed, getting off the stool, brushing teeth, combing hair, lifting the coffee pot, opening the car door, climbing stairs, walking and holding the phone. All these moments of frustration can and do occur daily. Adding to frustration may be the belief that the patient has been bewitched – what in Sotho is termed *o tshwarisitswe*, meaning “he/she was given something to hold which affected his/her hands”. The Sotho term *o tshwarisitswe* has different meanings and is used in this context to signify witchcraft.

Many patients, as Erfling (1980:180-181) holds, lose their ability to participate in groups and organisations. Often architectural barriers or an inability to sit in one position for any length of time can prevent rheumatic disease patients from attending church services or participating in organisations. The rheumatic disease patient who has experienced some disability, according to Erfling (1980:180), has experienced some degree of death of self. It may have been the working self, the socially outgoing self, the athletic self, the independent self or the healthy self. This, the researcher believes, may lead the family, friends and society to sympathise with the patient. Hip replacement predisposes the patient to surgical operation. Loss of self is coupled with loss of identity following disability.

In this regard the medical social worker's roles and tasks are to encourage ventilation of feelings so as to lessen depression; promote awareness that the mourning process is not only normal, but also necessary if the individual is to cope with the disease; facilitate support groups whenever possible; educate family and patient on the psychological and side-effects of living with chronic illness, and then introduce to both patient and family some means of coping; and prepare the patient for surgery, for example, hip replacement, by exploring and alleviating fears and promoting an understanding of the details of surgery.

DIGESTIVE SYSTEM

The complications of the digestive system may be perceived on the basis of expectations and the family's belief system. If the patient was not informed about these manifestations, their implications may be perceived differently. For example, a female who has been wanting to be pregnant may assume that nausea and vomiting indicate conception and yet that may not be the case. Diarrhoea may make the patient wonder what he/she “ate” that does not agree with him/her. In traditional belief the patient may feel bewitched though eating something – what is normally referred to as *sejeso* or *isidliso* in Sotho and Zulu. An individual is restricted from normal social interaction when experiencing nausea, vomiting and diarrhoea. Feelings of guilt and blame are common as it appears that the patient *has* to control the nausea, vomiting and diarrhoea. Failure of the patient to do so may lead to strained family relationships. Children may adopt escapee roles and choose to disengage. Embarrassment and frustration are common. The family may have mixed feelings of understanding, sympathy or tolerance, and rejection or acceptance.

The medical social worker is then expected to acknowledge the family's “shopping around” and the belief that the patient might have “eaten something”, and emphatically remind both the patient and the family of the initial diagnosis of SLE; and clarify misconceptions about “pregnancy” since the vomiting may be misperceived, by choice, as an early sign and symptom of pregnancy, especially if the patient is a married female with no children. In her experience of three years the researcher dealt with only one case of this nature, where the in-laws were putting pressure on the

woman about the need and importance of having children in a marriage as a way of proving womanhood.

REPRODUCTIVE SYSTEM

Women with SLE, according to Melvin (1982:45), have a higher incidence of miscarriages, premature births, and stillbirths than women in the general population. Frustration, anger, disappointment and helplessness follow these fatal abnormalities. The patient's ability to decide on when to have children is stripped from her and her partner, as she first has to consult with her physician or rheumatologist. In a culture where children are a primary source of pride, as in the black community, the patient suffers a great deal. She may be called names. For example, the in-laws may pass remarks, figuratively, in an African language saying: "There are no flowers in the flower pot on the table", meaning "The womb is barren". The patient is stripped of her pride in her womanhood. This may promote an unhealthy marriage. The husband may have children outside of wedlock. In some families men are not necessarily encouraged to have children outside wedlock, though it may be acceptable to.

For patients in remission or with a mild disease activity, as Melvin (1982:45) believes, pregnancy may present a fear of genetic transmission of the disease to the foetus. Some patients may have to terminate pregnancies and this is weighed against socio-cultural and religious beliefs. Patients who have had no children may not want to terminate the pregnancy. While **amenorrhea** (cessation of menstrual periods) may be disturbing to one patient, it may promote a misconception about pregnancy to the other patient. Of the 25 females in the study, 17 (71%) were severely affected in their reproductive systems and two miscarried and terminated pregnancy.

Medical social work intervention should include reproductive and sexual counselling; communication with the patient's partner on the implications of the disease and the frustration it causes the patient and her partner; and where possible, encourage the couple to engage temporarily in related or unrelated foster care as this may boost the patient's ego.

RENAL SYSTEM

The renal system is the last system to be affected and it signifies imminent death. In this stage the doctor may disclose that the patient is terminally ill. The experiences and psycho-social implications, according to Brey & Jarvis (1983:204) and Peterson (1985), include crises brought on by illness, depression, anxiety, behavioural changes in bed rest due to oedema (swelling of the bodily or parts of it) and glomerulonephritis restricting mobility, and change of diet. Assessment procedures for dialysis include assessment of home circumstances; this may evoke feelings and thoughts that assessors are invading the family's private space. The illness may lead to loss of relationships as the patient spends more time in hospital. Difficulty in regaining sexual functioning results in loss of sexual relationships. Haemodialysis may require that patients give up their school or job. Women diagnosed with chronic glomerulonephritis and who become pregnant appear to be susceptible to spontaneous abortion (Farley & Miller, 1985:963.) Incontinence can follow illness and disability. Relatives and patients can find this the most distressing and demeaning feature of disablement. As the patient becomes terminally ill, he/she may experience the normal stages of death. The renal system is mostly the final system to be involved, and the focus may shift from traditional healing to seeking God and being open to be prayed for by different church groups and/or religious faiths.

Most patients in the study had hematuria and some also had other kidney-related illnesses. Six patients had kidney failure and were on dialysis and five were terminally ill. It is imperative for

the medical social worker to know that the involvement of the renal system signifies that the patient is terminally ill. This will enable the medical social worker to identify feelings and reactions associated with terminal illness, and thus be able to render counselling on death and dying, following which the family may need bereavement counselling.

The roles and tasks of the medical social worker, according to Brey and Jarvis (1983:205-208), include an assessment of the patient's and family's circumstances for the treatment programme, for example haemodialysis; rendering and facilitating a support system; encouraging and facilitating family relationships; advocating for the patient to apply for illness benefits as the patient's chances of resuming work or school are minimised. The medical social worker may need to place the patient in a transitional home for accessibility to treatment, especially when the patient is on haemodialysis. In situations where there is no transitional home, arrangements should be made with the referring hospital to provide transport. Whenever possible, the patient should be assisted with unfinished business so as to face death with self-respect and dignity. The medical social worker should also prepare both the patient and the family for death. Death and dying counselling may be inevitable; the patient and family should be helped to go through the stages of death with their feelings explored.

Most of the respondents in this study had good support systems that enable them to endure the clinical intervention. However, they also mentioned the importance of an established support system like a support group or an established after-care "session". Fifty percent (n = 13) of the respondents felt they still had a social life, while the other half did not. The respondents who believe they have a social life are mostly those feeling positive about themselves. Those without a social life either had achieved periodical remission of less than a year, or were too sick and didn't belong to any social club or had slim chances of resuming employment or school activities.

Unemployment cannot be overlooked when working with patients from an economically disadvantaged background. Out of the ten respondents (38%) who didn't leave their occupation, four still belonged to social clubs but one of them, however, was unable to participate. Nine (56%) out of 16 respondents (62%) who either had no occupation or left their jobs belonged to a social club, and seven (44%) of them were unable to participate due to disease activity. Less than 50% of the respondents felt they could resume their occupation – school or employment. This reflects the fact that a period of remission does not guarantee that patients may resume their occupations. A medical social worker is, therefore, expected to assist with applications for disability grants and material assistance.

SLE AND HIV

The question in the minds of most patients is: *what kind of disease is this?* The nature of the disease, diagnosis, and treatment seem to be more complicated and life threatening than the Human Immuno-deficiency Virus (known as HIV). However, it is interesting to note that HIV infection is not common in SLE patients. In her practical experience, the researcher was exposed in a period of two years to only one patient with the SLE-HIV association. The association between SLE and HIV is said to be extremely rare. In fact, it is so uncommon that it has led to speculation that lupus may be protective against HIV infection (Illiopoulos & Tsokos 1996:328; Cimmino *et al.* 1996:317). A fascinating hypothesis, formulated by Cimmino *et al.* (1996:320) is that steroids and other immuno-suppressive agents used in SLE may hamper HIV infection and the development of the Acquired Immuno-Deficiency Syndrome (AIDS).

RESEARCH FINDINGS

In summary, the main findings of this study include:

- The complexity of the disease and “shopping around” resulted in physicians making the appropriate diagnosis long after the onset of illness.
- Most patients' occupation was affected and as a result most were dependent on disability grants, albeit that there were some who were unemployed and all come from a socio-economically disadvantaged background. The chances of resuming employment or school were minimised by the relapses.
- More patients were affected in more than two organ systems and due to disease activity chances of long-term remission were limited.
- The complications of the dermatological, reproductive and musculoskeletal systems were experienced severely in the sense that patients felt such complications resulted almost in a loss of their social and sexual lives and a loss of self. (Refer to Figure 1 for affected systems.)
- Family reactions ranged from fear/anger/apathy to understanding/support and sympathy. Twenty-two of the twenty-six respondents had support systems and thus coping was not as demanding, though this did not ease the anxiety. Social clubs played a major role as some could still participate.
- Sexual life was affected and thus there was no fulfilment in sexual relationships.
- The complexity of the reproductive system not only led to a lack of fulfilment in sexual relationships, but it also contributed to problems with in-laws.
- Lay persons and professionals other than hospital personnel were consulted before and after diagnosis. This also depended on the individual patient's belief system, that is, the consultation with a homeopath, traditional healer and/or church minister. An interesting finding was that 8 patients (31%) in the study had consulted with more than one professional/lay person other than hospital personnel and the number increased to 10 (38%) after diagnosis, a finding which calls for recognition of outside resources as members of the multi-disciplinary team.
- Eighteen respondents consulted with the whole team, which included the rheumatologist, rheumatology nursing sister, medical social worker, occupational therapist, dietician, physiotherapist and speech therapist. Twenty-two were seen by the social worker and 16 of these benefited from medical social work services. A medical social worker should be available from initial hospitalisation/diagnosis throughout the treatment period.

Ideally, SLE patients should be seen by all members of the multi-disciplinary team as their disease complications warrant this, namely the dietician, physiotherapist, occupational therapist and social worker, amongst other team members. However, this sometimes becomes impossible as some patients may not be able to keep the appointments due to financial constraints.

The medical worker, according to Pigg (1989:789), often acts as a liaison person, aiding communication between care providers and patients, and guiding the other care providers to recognise the emotional reactions of the patient. This is supported by the recommendation that the respondents would prefer to have a medical social worker at the initial stage of diagnosis and throughout intervention (Modisane, 1998:77-80).

CONCLUSIONS

The study found that most patients are diagnosed months after their first contact with the medical doctors, and this promotes feelings of uneasiness and uncertainty in patients. However, news of confirmed diagnosis, in spite of the mixed feelings, bring an underlying relief that, at least, the patient will know what he/she is suffering from. The desire for a sexual relationship and also children is hampered by the complications of the reproductive system. SLE impacts severely on the lives of patients, their partners and their families. Families and partners of SLE patients become uncertain of how to respond in trying to help patients cope with the disease. Despite the uncertainty of their responses to the patients' needs, families of SLE patients *are* supportive. The complications of the reproductive system make it difficult for a woman to conceive at a time agreed on with her partner. This then threatens her relationship with in-laws.

The role of the medical social worker should be actively visible, throughout treatment, in educating patients about the disease and allowing them to express their fears, feelings and thoughts. The medical social worker should have an understanding of the patients' culture and seek to understand how the patient perceives his/her diagnosis. The impact of Systemic Lupus Erythematosus is best summed up in a statement made by one of the SLE patients treated at the Chris Hani-Baragwanath hospital in 1995: "...the most frustrating thing about SLE is not the patient's inability to comprehend the nature and complexity of the disease, but the helplessness of the people keen to help, yet not knowing how..." (Modisane 1998:95). This statement conveys the innate helplessness, hurt and frustration that leads to anger. It also challenges the role of the medical social worker in making proper assessment and intervention so as to enhance the patient's coping skills and to educate support systems closer to the patient.

A CHALLENGE TO MEDICAL SOCIAL WORK – RECOMMENDATIONS

The nature, diagnosis and treatment of this disease poses a challenge to medical social work:

The medical social worker should be involved in case work and group work methods of social work. However, community work should not be left out, as it is in the community where the patient performs his/her social roles.

The community and other welfare organisations dealing with other disabilities similar to SLE complications should be educated about SLE and encouraged to employ SLE patients. Protective workshops should be considered as a useful resource.

The medical social worker should liaise with resources, for example, identify a resource that would assist patients and be accessible. For example, a resource may provide patients with wigs, sunglasses and hand gloves as these involve the major problems faced by female patients since photosensitive patients need sunglasses and hair loss may necessitate that patients wear wigs. Such

a resource should not be out of patients' reach in terms of transport and finance. However, a means should be devised by the medical social worker.

The medical social worker should liaise with the referring hospitals' social workers so as to promote awareness on the needs of SLE patients, and encourage continuation of services essential to the patient concerned.

More research in this field of study should be conducted so that literature will be available to promote awareness of SLE. This would equip medical social workers with intervention skills.

Whenever possible, there should be a medical social worker attached to the rheumatology unit so as to allow the medical social worker to acquire (more) knowledge about the disease and also belong to the multi-disciplinary team.

It is also vital to encourage the patient to recognise that she/he has a role and a positive contribution to make in life, however small it may be. After all, human beings have a need to be wanted and belong.

The medical social worker must promote awareness in the multi-disciplinary team. The patient, the family, and traditional and faith healers should be part of the multi-disciplinary team. Rehabilitation of patients with chronic illnesses requires a holistic approach to the problems of disease and disability. Not only must the idiosyncrasies of the illness and its manifestations be understood but, as Erling (1980:196) maintains, there must also be consideration and understanding of the total patient with his/her unique personality, reactions to illness, relationships and social support systems. Understanding of the patient as a unique individual from a unique environment will surely promote an individualised and non-judgmental intervention by a medical social worker.

The patients' informal and formal support systems and/or resources should be identified and included in the multi-disciplinary team. This will facilitate proper and healthy communication and promote a holistic approach to treatment. Support groups which will focus on coping with illness and disability should be founded for patients, partners and families.

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