

Social and psychological considerations



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Chapter 6

Social and psychological considerations

KEY POINTS

- Persons affected by BU may experience isolation, stigmatization, dependency, economic difficulties, depression, loss of self worth and fear.
- The stigma of the disease can be decreased through health education programmes that improve knowledge and understanding about the disease and its treatment.
- Motivation can be improved by involving affected persons in solving their own problems and empowering them to be in charge of their own daily care and exercises.
- Motivation is greater when the person has good skills, a sense of self-control, a support system and the opportunity to see someone else who has successfully overcome BU problems.
- The inclusion and participation of persons affected by BU in school, work, family, and community activities should be encouraged.

Communication can help the health worker identify socio-economic and psychological problems and difficulties by taking the time to listen carefully to both the person affected by BU and the family, in the hospital or outpatient clinic.

Asking questions can help to clarify the person's situation, feelings, and interests. This questioning can be carried out individually, or within groups of persons affected by BU.

It is important that privacy and confidentiality are respected. Remember to listen, and avoid giving too much advice. Encourage the person and family to explore possible solutions and – if needed – direct them to appropriate resources.

Social and psychological issues

These issues are very important in Buruli ulcer. Some of the common problems are segregation, stigmatization, dependency, economic difficulties, depression, loss of self-worth and dignity, and fear. The challenge is to provide care which encourages the person to manage his or her own life, and to participate actively in family, school, work, play, and community activities.

Referral to community-based rehabilitation (CBR) programmes may be needed. CBR aims to restore dignity, increase economic independence, reduce stigma, and achieve integration. CBR programmes should be holistic, encourage participation, be sustainable, integrated, gender-sensitive, and sensitive to special needs.

The following are three ways to encourage and restore dignity to persons affected by BU and their families.

- **Recognize** that the impact of Buruli ulcer on the individual and family is great. It has physical, psychological, social, and economic effects.
- **Respond** to the concerns of the person affected by Buruli ulcer, empowering his or her participation in making decisions and choosing interventions. This approach restores dignity and self-respect.
- **Reach** out to families and communities where Buruli ulcer is a problem. Help them understand the disease, how it is treated, and how to support the affected person through the rehabilitation process, so that full integration is achieved.

Stigma

Stigma is the reaction of society towards people with certain characteristics (for example, a deformity or an ulcer) which are perceived as abnormal and undesirable; the result is that such people are deprived of the same social inclusion and human rights as are enjoyed by others. Fears and misunderstanding about the disease can cause a person affected by Buruli ulcer (and the family) to be isolated or neglected by communities and health workers. Such discrimination can result in persons with the disease hiding or denying the problem, delaying early diagnosis and treatment. Fearful health workers may neglect to give the care needed to prevent or minimize disability.



Children can continue their education ▲ while in the hospital.



Encourage the children ▲ to complete their education.



Girls should be encouraged ▲ to complete their education.



Women and men may need to learn new technical skills that enable them to work ▲ in order to increase the family income.

Figure 6.1 Encourage educational activities

Fear, devaluation, and social inequality can also be a response to the physical deformities and scars that remain after medical and surgical treatment of the disease. These physical signs visually mark the individual and depart from societal standards of beauty. The disease may be viewed as a sign of a curse, or a punishment for some sin committed. Deformities may also lead many to believe that the person is unable to participate in activities and normal family, educational, and community life. These people may be viewed as a burden to themselves, their families, and their community. This stigma creates social and economic difficulties.

Overcoming stigma is an essential step to the integration of people affected by BU within the general health services and to restoring normal relationships

with their family and community. Stigma decreases as we:

- identify the fears regarding the disease, and then respond specifically to the expressed fears and risks – involve doctors, social workers, educators and religious leaders in the programme to help minimize stigma and alleviate fears and anxiety (one of the major fears is that the disease can be transmitted to others, but as far as we know, the disease is never transmitted directly from one person to another);
- improve knowledge and understanding about the disease – include key health workers, community leaders, and persons affected by Buruli ulcer in campaigns to inform the community about the disease; education can decrease ignorance and prejudice, and the community's participation facilitates rehabilitation;
- provide effective treatment for the disease; this develops confidence that the disease can be dealt with;
- increase self-confidence of persons affected by BU by empowering them to be in control; awareness, understanding, knowledge, skills, and encouragement will improve self-esteem and motivation;
- involve and empower HCWs to do their jobs more effectively; and
- develop support groups that will encourage participation and advocate for the needs of persons affected by Buruli ulcer.



The child can eat with his right hand although there is a severe deformity. Allow him to feed himself.



Educate the community about the disease and help affected persons return to their education and community activities.

Figure 6.2 Empower the person to participate

Motivation

The diagnosis of Buruli ulcer may lead to feelings of helplessness, anger, depression, and apathy. The affected person may not show any interest in interventions to prevent disability.

Most affected persons are children, and it is important to plan creative and imaginative exercises that are fun. Exercises and specific movements as part of an interesting activity have more meaning to affected persons, and will help them to be motivated to participate. Participation in such activities helps them see a goal which has been successfully accomplished, which reduces their sense of helplessness.

Motivation can be improved by involving affected persons in solving their own problems and empowering them to be in charge of their own daily care and exercises. Motivation is greater when the person has:

- knowledge that impairments and disability can be prevented or minimized;
- developed good skills for self-care at the hospital and at home;
- developed a sense of self-control over his/her own life;
- support from health workers, family, and community;
- an opportunity to see someone with similar Buruli ulcer problems actively participating with their family, in school, work, and in other community activities.

Inclusion and participation

Education

More than 70 percent of Buruli ulcer occurs in children under 15 years of age. Prolonged hospitalization can interfere with both their schooling and family lives. Arrangements should be made to ensure that children continue their schooling during hospitalization.

An important part of the educational process in the hospital comes from the selection of age-appropriate games to help their development and stimulate interpersonal relationships. Areas for play can be designed, and the play equipment can be constructed and adapted from locally available materials.

Family, work, and community life

Health education programmes can help inform the person, the family, the employer, and the community about the disease and how it is treated. When possible, the person should be treated as an outpatient and given home programmes for POD to reduce the physical and economic burden on the family. This will also facilitate their return to, and inclusion in family, school, work, and community life.



Parents and family are taught how to help and encourage the physically-challenged person. ▲



The community is taught how to enable inclusion and acceptance of the affected person ▲ in their community.

Figure 6.3 Facilitate participation in family and community life

Review questions

1. What are the most common social and psychological problems of children and adults affected by Buruli ulcer?
2. What causes stigma and how can stigma be reduced?
3. What helps motivate the individual, the family, and the health worker?