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ABSTRACT

Although many workshops on sickle cell anemia have been held, it is still difficult to implement a comprehensive training program for sickle cell anemia clients in many communities. Research data on the topic are somewhat nebulous and insufficient political and social pressure have been exerted to change attitudes and take action towards the disease. Research has found no cure for the disease and treatment is palliative. Because sickle cell anemia is said to disrupt mental processes through environmental stresses, as associated with racism, the client may blame his physical attributes for the problems and societal pressures he faces. The 1978 questionnaire survey conducted (by this author) in South Bend, Indiana, indicates the need for counseling on the subject. In group counseling, the facilitator should be flexible enough to adapt to the needs of the client. The more verbal interaction that takes place, the more effective the counseling process will be. Current medical knowledge pertaining to sickle cell anemia shows that changes are occuring. The disease and the accompanying physiological crisis and complications can now be talked about. (Author/WI)

A Group Counseling Approach for Persons Who Work with Sickle Cell Anemia Clients

by
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This paper is an explication of the psycho, social and vocational aspects which might affect the counseling of sickle cell clients. It is to serve as a cross-reference source for physicians, nurses, educators, parents and counselors. These concerned persons can then utilize and implement this knowledge in meeting the needs of their students and clients suffering from the sickle cell disease, or possessing the sickle cell trait. Since there is a dearth of data written for non-medical persons, this article can be invaluable to counselors, teachers and selected community service workers.

At this time, a number of counselors, teachers, parents and other persons have participated in workshop sessions throughout the nation to facilitate a clear and concise understanding of sickle cell anemia.

These efforts have been powerful. However, for a number of reasons it is difficult to implement a comprehensive training program for sickle cell anemia clients in many communities. Two reasons generally account for the lack of understanding and implementation of programs:

1. Research data pertaining to the area is somewhat nebulous.

2. Social/political pressure has not been exerted by powerful pressure groups in America to bring about a change in attitude and action.

Research has found no cure for sickle cell anemia and treatment is palliative. Some doctors even disagree on the mode of treatment. The writer believes that the community should be educated about this genetic disorder, and that pressures be exerted on educational, health, and political entities to secure funds for further research. Thus, adequate procedures and strategies regarding the counseling of the sickle cell clients or potential clients will be further realized.

HISTORICAL OVERVIEW

Pauling and his colleagues (1949) were the first to clearly indicate the theory underlying the sickling process. They theorized that, in a non-specific way, the sickle hemoglobin molecules might be able to aggregate, or stack together in long chains because of the complementary arrangement of their parts. Moreover, the low solubility of a protein depends on the distribution of positive and negative charges that are found on the surface. The removal of lutumic acid could well result in a change of solubility (Foster, 1971).

Hemoglobin is the principle protein of man concerned with the transportation of oxygen. In short, hemoglobin carries oxygen from the lungs to the tissues and carbon dioxide from the tissues

to the lungs. Each molecule of hemoglobin consists of one molecule of globin to which are attached four molecules of heme (Foster, 1971).

Heme is an iron-prophyin complex, which basically accounts for hemoglobin color and its ability to enter into reversible combinations with oxygen. Globin refers to a small protein, and is composed of two alpha chains and two beta chains. The alpha and beta chains each consist of amino acid residues. Years of investigation have shown clearly that it is the globin part of the hemoglobin molecules to which changes occur that ultimately result in sickle cell anemia (Foster, 1971). There are, however, some differences between the hemoglobin of normal individuals and the hemoglobin found in sickle cell anemia clients as pointed out by Herrick. People who possess the sickle cell anemia trait, in a large number of cases, continue to act in a normal fashion. However, a number of persons have been found to have decreased physical ability and are unable to withstand certain stresses. In some cases persons find it difficult to withstand low oxygen content and this may be especially true for climbing high areas and doing strenuous activities. If these physical problems do occur, there is a strong possibility the person may collapse. All of the above problems, plus a number of psychological and social problems, put constant pressure on the client and his family. Sickle cell anemia is said to disrupt the mental process through environmental stresses, as associated with racism, which in turn

may influence one's perception of his body. The sickle cell anemia client thus, perceives external racism as being symbolic and may mistakenly relate this to his potential mental health capacity. He blames his physical attributes as being the cause of many of the problems and societal pressures that he faces.

The need for counseling for the sickle cell anemia client emerged as a result of a survey conducted by the author in the South Bend community. The findings related to this survey, although related to one community may be extrapolated to the nation as a whole. The findings related to this survey are given below.

METHODOLOGY

The purpose of the survey was to ascertain the professional knowledge of social service workers, public school counselors, and others who work with predominantly black clients. It was found that a great bulk of those individuals had a limited awareness of sickle cell anemia. The group surveyed consisted of 45 persons and each completed an open-ended questionnaire which was administered by the author during the fall of 1978. The questions asked were:

1. What is sickle cell anemia?
2. What segment of the American population is generally affected by the disease?
3. What are some possible psychological and social problems that can occur as a result of the disease?

4. Where can sickle cell anemia patients or potential patients seek medical help?

It was pointed out by a large percentage of individuals (75%) that they they lack sufficient training, information, and professional experience to work with sickle cell anemia clients. A large percentage (40%) also stated that they feel incompetent and frustrated with the counseling approach used with sickle cell clients. One of the most shocking and frustrating aspects of the survey related to a lack of awareness and knowledge of persons and agencies responsible for dispensing knowledge and training. Many of these people had not received systematic training themselves, and yet were responsible for assisting the sickle cell clients. One of the most common misconceptions according to Bowman (1975) is that sickle cell anemia causes panic and confusion. This feeling appeared in the survey. The source of this panic and confusion relates to a great deal of misinformation being passed on by various persons. It is also felt that a number of people who work with sickle cell anemia clients do not have a perception of the disease themselves, as was pointed out in the survey. With this in mind the author is advocating a sickle cell anemia group centered counseling approach. This approach should focus on the needs for the development of strategies for coping with the disease.

GOALS FOR SICKLE CELL ANEMIA GROUP SESSION

The facilitator in a sickle cell anemia group counseling session should be concerned with the establishment of positive and psychological relationships within the group. The facilitator

should also be a cautious and reflective listener, and should have the genuine interest of the group as his main goal. The group counseling process for sickle cell anemia clients should provide the opportunities for the client and other participants to interact in a free, accepting and belonging fashion. Thus, the avenues for group interaction and access to certain kinds of information will assist in the counseling process. More specifically, the general goal of counseling for the sickle cell anemia client can be the same as any other group counseling session. However, the group experiences should relate to the vital development and concern for social, emotional and psychological well being of the client. Other content, such as marital information and employment concern, should not be precluded. The facilitator should also strive to help the sickle cell client see the counseling process within both the cognitive and affective framework. The author believes that cumulative data, attitudinal formation, and feelings toward one's self and others should be a part of the group process. Avenues for discussion and support through constant sharing of common problems in a constructive manner for all participants should be advocated and provided. Some specific goals of the group counseling sessions for sickle cell anemia clients include:

1. To help each client of the group develop a knowledge and understanding of the disease as well as help him understand himself.
2. To develop the necessary social and interpersonal skills which will enable one to adapt to the changing complexities of his environment.

3. To increase one's ability to solve problems brought on by the disease and enter into regular social contact in his environment.
4. To increase one's sensitivity to the needs of others and increase his recognition of the responsibilities of others to him and of him to others.
5. To clearly define and articulate procedures for securing and analyzing data relative to the sickle cell disease.
6. To establish a framework from which self assessment and self determination can become a reality.

Basically, the primary focus of the group counseling approach for sickle cell anemia clients should develop and transmit a logical step-by-step procedure whereby the clients can affectively adjust to their environment. Group counseling requires a great deal of involvement on the part of the facilitator and the client. The conviction and total life of the client shall ultimately influence the facilitator's actions and the degree in which counseling is utilized.

A mental health approach should be used for which a better understanding and improvement in the management of the psychosocial problem surrounding sickle cell anemia can be obtained.

The author believes that one of the most affective means for coping with the adjustment problems that are related to sickle cell anemia is to form problem-solving reference groups. These groups should include persons who possess the disease or selected members of their families who are in constant contact with the clients as well as other people who have a dire interest in the

patient and the disease. The inclusion of family members and/or friends should prove to be very supportive. The group might also include colleagues and individuals who work in close proximity with the client. The sickle cell group centered approach can focus on a variety of activities to facilitate an understanding of the disease and to provide support to the client. The activities of the group can relate to the following areas:

1. Belonging and accepting one's way of life - Various aspects of life as they affect members of society can be discussed. The pros and cons of various types of the disease; what have other people done? How can you, as an individual, cope with these problems of life? These concerns can be discussed in this section.
2. Displaying affection - The importance of being loved and how important it is to make the person feel loved and wanted is an expectation in this area. Some activities might focus on how it feels to be an outsider; how it feels to be ostracized, and degraded. We should encourage the participants to display affection and to discuss the need for affection.
3. Valuing and sharing among persons - One should learn to share his perceptions about the clients who possess the disease. Client members should also learn to share their concern for themselves, as well as their family members, friends and colleagues. The sharing between two clients who have the disease should also occur, as well as discussions on how each has reacted to the disease.

4. Establishing new relationships - How can the client reorient his life to the degree where existing relationships are kept and new ones are developed. Here we should be concerned with facilitating more awareness of what goes on around the client and his environment.
5. Fostering self control and self discipline - In this area we should be concerned with avoiding dangerous pitfalls that might endanger the patient's health or create problems for his family members. Self control and self discipline should be practiced. Exercises should be utilized where the client gets an opportunity to role play this self control and self discipline, and personal types of activities that might make the client see self control and self discipline in a different perspective should emphasized.

Even though the topics mentioned above can relate to specific clients' interpersonal needs, there are other things that might be discussed in a group counseling session. The purposes of the group counseling sessions are to encourage the client and other participants to share their experience, to be self disclosed, communicate verbally and non-verbally, and to explore their feelings and concerns about various aspects of life in their particular situation with others. Facilitating the discussion of topics related to sickle cell anemia, is the primary focus of each area. Other topics that might be valuable to the groups can relate to

racism, disruption of the family, physiological and psychological affects of the disease, self concept and self esteem formation and self concept deterioration. The facilitator could also discuss topics relating to vocational training, outlook for the future, reproduction options, and treatment and cures.

The author believes that the sickle cell anemia group counseling approach should follow a generalized procedure whereby the facilitator should be flexible and adapt to the needs of the client. The more verbal the interaction between the client and facilitator, as well as among the various clients, the more effective and fruitful the group counseling process will be. The author believes that communication can be enhanced if ample time is allowed for each client to express his concern and participate in the discussion. In summary, current medical knowledge pertaining to sickle cell anemia does indicate that changes are occurring. This disease and the accompanying physiological crisis and complications can now be talked about.