



REVISION ARTICLE

Social support perceived by relatives of children with acute lymphoblastic leukemia

Apoyo social percibido por familiares de niños con Leucemia Linfoblástica Aguda

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ABSTRACT

Introduction: social support has a great impact on the processes of adaptation to illness, recovery and rehabilitation. The perceived dimension of this category is a cognitive assessment that describes the degree to which the subject perceives the existence of sufficient and adequate support-providing relationships.

Objective: to study in depth the contribution of social support perceived by family members to the comprehensive care of the child with acute lymphoblastic leukemia.

Methods: a bibliographic review was carried out using national and international sources specialized in the subject based on a reflexive analysis from a theoretical point of view.

Results: many investigations agree that the true social support is the perceived one, arguing that if the subject does not perceive the help offered or the external resources that are available to him/her, these will hardly influence his/her health and well-being, especially in the case of relatives of children with diseases such as Acute Lymphoblastic Leukemia.

Conclusions: knowledge of the social support perceived by relatives allows us to obtain a more realistic view of the felt needs of families and children with acute lymphoblastic leukemia and contributes to the improvement of comprehensive care.

Keywords: Social Support; Leukemia, Biphentotypic, Acute; Child.

RESUMEN

Introducción: el apoyo social tiene un gran impacto en los procesos de adaptación a la enfermedad, la recuperación y rehabilitación. La dimensión percibida de esta categoría es una valoración cognitiva que describe el grado en que el sujeto percibe la existencia de relaciones proveedoras de apoyo suficientes y adecuadas.

Objetivo: profundizar en la contribución del apoyo social percibido por familiares, a la atención integral del niño con leucemia linfoblástica aguda.

Métodos: se realizó una revisión bibliográfica a través de fuentes nacionales e internacionales especializadas en el tema, se tomó como punto de partida un análisis reflexivo desde una visión teórica.

Resultados: muchas investigaciones coinciden que el verdadero apoyo social es el percibido, argumentan que si el sujeto no percibe la ayuda ofrecida o los recursos externos que están a su disposición, difícilmente influirán sobre su salud y bienestar, especialmente en el caso de familiares de niños con enfermedades como la leucemia linfoblástica aguda.

Conclusiones: el conocimiento del apoyo social percibido por familiares permite obtener la visión más real de las necesidades sentidas de las familias y los niños con leucemia linfoblástica aguda y contribuye al perfeccionamiento de la atención integral.

Palabras Claves: Apoyo Social Percibido; Leucemia Linfoblástica Aguda; Niños.

INTRODUCTION

The conception of health as the individual's psychosocial well-being has led to the analysis of multiple categories of a social, environmental and psychological nature. One of these is social support for its impact on the processes of adaptation to illness, recovery and rehabilitation. The development of the community approach and the understanding that health is not only an individual problem but also a problem of groups and society led to a break with the traditional models of analysis and research - centered on the individual - giving rise to the acceptance of the role that social factors play in the development of health. Therefore, the individual perspective is transcended to contextualize this individual in the framework of his or her interpersonal relationships, the family being perhaps the most important social support network for coping with the stress of chronic disease, which is even more relevant in the case of children and adolescents.^(1,2)

The optimization of support is one of the priority objectives of psychological intervention in the process of accompaniment and psychological support required by this type of patient.

At present there is a conceptual and methodological diversity in the studies carried out on social support, however, scientific interest in this category has been growing, especially in the last twenty years. The concept of Social Support has managed to capture the attention of numerous researchers and specialists despite its insufficient methodological and conceptual conception. It was mainly in the 1960s that the subject of social support began to become a relevant area of research within psychological science. The interest and attraction awakened by the term brought with it in the 1970s the emergence and increase of works whose essential research topic was social support and its concrete application in human health. From this period, different dimensions of the concept were studied, especially the emotional dimension, and reference was made to the functions of social support and its benefits. Subsequently, a proliferation of studies

on the relationship of the concept with health and social relationships was generated, as well as an attempt to operationalize it.⁽³⁾

At the end of the 1980s, a tendency towards a more integrative vision of social support emerged and criteria were combined with those that had been related up to that time, such as the interactive and interpersonal nature of the concept, the existence of relationships and social networks, the transaction of support resources, the subjective valuation of the subject and his or her needs, and feelings of integration and acceptance.⁽⁴⁾

A brief review of the background in this area reveals the general interest shown by several disciplines concerned with the human factor, such as epidemiology, sociology, gerontology, health education, psychology, among others.⁽⁵⁾ Throughout their development, a wide variety of definitions have been used.

Throughout its development, a wide variety of definitions have been used from structural-sociological and functional-psychological perspectives.^(1,6) These approaches should be considered as complementary rather than exclusive: each perspective represents different levels of analysis and is presented as a precondition for the next level.⁽⁷⁾

The most basic level in the conceptualization of social support is that which approaches it as "social integration". It does not refer to the quality of relationships but to the structural characteristics of a person's social network (number of contacts, type of contacts, friendship, etc.). This level is not able to explain the relationship between health and social support. Fundamentally, support seems to be constituted by resources that are "outside" the individual: the available links with others, the characteristics and nature of these links, the number and strength of a person's associations with significant others. The structure of support includes the size, context, reciprocity, accessibility, and the structure of interpersonal relationships.^(6,7)

The perspective of social support as "quality relationships" adds an important issue to the previous level. From this point of view, attention is paid to the quality of relationships, even if they are not very numerous. It alludes to the various ways in which quality relationships can influence health and psychological well-being: contributing to the satisfaction of needs for affiliation, meeting needs for affection, providing a feeling of identity and belonging, being a source of positive evaluation, providing feelings of control of the situation, etc.⁽⁷⁾

A third level is social support as "perceived help". This refers to the perception that in problematic situations there is someone to confide in and ask for support. The perception that there is help available from others can reduce the perceived stressful magnitude of an aversive event.⁽⁷⁾

Perceived social support is - obviously then - mediated by subjectivity, and although its measurement does not objectively reflect the quantity and quality of the helping relationships that people have, it does offer a measure of the support "that really exists" for that subject, which, although not necessarily the only one that influences his state of health, is the most effective, at least for him.⁽⁷⁾

The perceived dimension of this category is the cognitive assessment that describes the degree to which the subject perceives the existence of sufficient and adequate support-providing relationships.^(8,9,10)

According to Miguel Angel Roca Perara, a scholar of the subject in Cuba, social support is defined as the social resources accessible and/or available to a person, found in the context of interpersonal and social relationships and which can influence both positively and negatively the health and well-being of the individuals involved in the process. Its distinguishing feature lies in its interactive, dynamic and extensible character along the time dimension.⁽¹¹⁾

There are several types of social support described in the literature and aspects that can modulate its mode of expression such as types, functions, sources, contents, nature of the problems that require support for their solution, as well as the circumstances and the time of the life cycle in which it takes place.⁽⁴⁾

Instrumental support" is offered when instrumental behaviors are emitted that directly help those who need it; one helps another to do or finish the job, one takes care of someone. It is evident that any purely instrumental act also has psychological consequences.⁽⁷⁾

One type of support is called "emotional support". This includes empathy, caring, love, trust and appears to be one of the most important types of support in relation to health. Emotional support refers to the perception or experience that one is loved and cared for, esteemed and valued, and is part of a social network of mutual assistance.⁽⁷⁾

"Informational support" refers to information that is offered to others so that they can use it to cope with problematic situations. It differs from instrumental support in that the information is not in itself the solution, but enables the recipient to help him or herself.⁽⁷⁾

The importance of one type or another will depend in each case on the relevance of the source of support for the person and the particular problem requiring such support. In particular with regard to health, studies have described positive and unfavorable implications of this element on the subjective well-being of families and their patients, particularly those diagnosed with ALL, and there is a lack of a study of this variable in our province. The present work aims to study in depth the contribution of social support perceived by relatives to the comprehensive care of the child with Lymphoblastic Leukemia.^(7,12,13)

METHODS

The aim of this literature review is to deepen in the contribution of perceived social support to the comprehensive care of children with acute lymphoblastic leukemia for the recognition of the same as a protective factor that affects the evolution and treatment of these patients and the achievement of the process of psychological adaptation to the health condition. For this a literature review was conducted from national and international sources using the keywords: Perceived social support; Acute lymphoblastic leukemia; Children. For this purpose, databases were consulted through the website Pubmed, Scielo and the search engine in the last five years, performing an analysis and summary of the reviewed bibliography, finally leaving 23 that constituted the bibliography of the present research.

RESULTS AND DISCUSSION

The importance given to the diagnosis of acute lymphoblastic leukemia in pediatric age due to all the implications and characteristics of the disease constitutes a necessary scientific premise for the study of the variables that have an impact on its treatment and evolution.

The value of social support is unquestionable as one of the main stress buffers for patients, their families and the health team itself, and its search constitutes one of the most frequent coping styles in the face of the impact of the disease and treatments.^(14,15) This concept, which is generically and intuitively understood by common sense, is currently generating controversy in scientific circles as to which types or forms of social support are particularly relevant and have important effects on stress, health and psychological well-being in the face of certain health problems and how to cope with them.^(16,17)

When it comes to life experiences of the debut of a chronic hematological disease such as acute lymphoblastic leukemia in a child, there are individual crises and crises of the social systems in which the patient is inserted. In the case of pediatric age, the fundamental impact is on the family and particularly on the child's primary caregivers.^(18,19)

The family is an active entity in the comprehensive care received by these patients, playing a leading role in health actions in all phases of the evolution of the disease.⁽¹¹⁾ The necessary triangulation that occurs in the care of pediatric patients and their families means that importance is given to the family's own perceptions of the support they receive. Social support may play a role in this regard as an antecedent variable or as an intermediate variable. As an antecedent variable, social support can contribute to health, first, by creating a health-promoting environment that enhances people's well-being and self-esteem, second, by decreasing the likelihood of stressful life events, and third, by providing retrospective, confirmatory information.

As an intermediate variable, social support contributes to health by buffering the negative effects of stressful events that occur in the subject's life, influencing the interpretations of such events and the emotional responses to them, thus decreasing their pathogenic potential.⁽²⁰⁾

Like any other social system, the family in fulfilling its role as mediator in the health-illness process is interrelated with other systems; society, the family and the individual influence each other; children and their families are part of different systems, which in turn interact with each other (extended families, schools, leisure activities, health system, work, etc.), therefore, when a child is diagnosed with an illness, the different systems will be activated and will react in different ways. Among the resources that parents use to cope with stress are the support of the extended family, the health care team, community support, associations, religious support, the school, social networks of those affected by the disease, etc.⁽²¹⁾

All of the above reinforces the concept of considering the family as part of the health team as a caregiving agent, and underlines the need for the family to be trained and protected and to take into account all the resources available to them in order for them to recover their lost balance. For this to happen, they must have a functional social support network that is perceived as such.⁽²¹⁾

Due to the treatment that children with this disease usually undergo, the family often needs support from outside the family nucleus. Other members of the extended family are often involved in decision making and in taking on roles in the family nucleus, such as grandparents, aunts and uncles, etc. Having trusted people to whom one can express emotions, problems or difficulties, listen to their opinion, or simply have the feeling of being listened to and accepted as a person, has been shown to have a strong impact on the ability of individuals to cope adequately with difficult and stressful situations. Satisfaction with social support can attenuate the stress and anxiety of the parents of these children and, in addition, may be a protective factor for the development of psychological disorders in the future as well as for parental health and life satisfaction.⁽²¹⁾

Families who can receive tangible help, practical services and material assistance can be summarized in the more general concept of instrumental support, while categories such as social reinforcement, emotional support and affective support refer to socioemotional support. There is a certain degree of agreement that emotional support is the most important for a large number of problems, but each type of support undoubtedly serves a specific function. The way in which communication is established will condition the therapeutic nature of the health professional-patient-family relationship. The functions of communication in support can be: Cathartic and liberating of language, of recognition and consideration of the other, of acquisition of knowledge, of reinforcement of behavior modification.⁽²¹⁾

Emotional support, an essential type of support, is the creation of a therapeutic and bonding relationship, in which the patient and his family do not feel judged, nor marginalized, but understood and helped, to be able to confront, with respect, their fears, desires and needs. To support is to accompany the patient and his family in the physical, emotional, social and spiritual process of the disease, and this means: listening, informing, teaching, offering, caring and distracting. The emotional support that becomes real help is characterized by the following: It should not be assumed, but explored, it should not be generalized, but personalized, it should be offered based on the biographical profile of each individual. The best social support is: requested, perceived and accepted. These, among others, should also constitute goals in the comprehensive treatment of these patients and areas of training for the support networks of these families.⁽²¹⁾

All health professionals should provide minimum elements of emotional support and should be trained in counseling techniques to maximize their level of competence at the lowest possible emotional cost, and counseling should be offered in all situations in which patients, relatives and professionals require it. This information is very important for the practical applications that can be made when designing psychosocial care programs for families of children with this type of disease that take into account the specific needs of the parents.^(20,21)

Another relevant issue in the case of this disease is that both chronic and long-term problems threaten the availability of social support. Support providers may feel frustrated, as time goes by, when they see that their efforts do not offer improvement or positive results and there is little or nothing left to do, or when the subject is perceived as not competent to provide the necessary help and in this way the damage to his self-esteem contributes to his distancing himself from the individual he "should" support.^(22,23)

The effectiveness of the type of social support does not depend on a particular type; it depends on the type that, in particular, meets the needs of the individual. The type of social support that produces positive effects is not identifiable per se; it can only be explained in relation to a given problem and to the state of that problem.^(20,21)

Subjective functional measures appreciate how social support is perceived, how people evaluate the nature of the interactions that take place in social relationships, and assume that the best adaptive outcomes will be obtained in people who receive or believe they receive social support whenever they need it. This perception does not have to be based on a specific relationship, nor does it have to refer to the perception of effective help in a particular stressful situation. That is, it can have a connotation of expectation, of anticipated conviction that the required support will be available to them in case of need; as can be seen, this has a highly favorable effect on the individual's well-being, self-esteem, self-affirmation, sense of control and security. In summary, this perspective considers that the relationship between support and health is essentially mediated by the psychological representations of available support rather than by objective support relationships.^(20,21)

Support systems modulate the responses of individuals to life events. The assessment of how social support is projected from the perception of the relatives of children affected by ALL constitutes a scientific challenge in health care and would contribute to the design of more contextualized and personalized proposals for action according to the specific situation presented by the patient, the relatives and the lack of support needs. It also allows the members of the health team and other community sectors involved to act in a more coherent manner in order to have an essential impact on their integral health indicators, an indicator prioritized by the Maternal and Child Health Program in our country.^(20,21,23)

CONCLUSIONS

As can be appreciated, it is very positive to know the role that social support in its different dimensions can have on the parents of children with ALL during the disease, the positive impact it has on their life satisfaction and the protection it offers in the face of stress. These issues need to be considered in the daily practice of professionals providing psychosocial support in these cases. Knowing and enhancing the social support networks and the sources and types of help for parents of children with ALL is one of the therapeutic strategies that can be implemented by the professionals involved, since it can help to mitigate the negative effects of stress, perceive greater life satisfaction and, therefore, improve their quality of life.

Knowing how social support is perceived allows health professionals involved in the management of pediatric patients to obtain a more realistic view of the support needs, constituting a potential tool that contributes to the improvement of comprehensive care for the child with acute lymphoblastic leukemia in aspects prioritized and identified by the caregiver and the patient.

Conflict of interests

There is no plagiarism, no conflicts of interest or ethical conflicts related to the research, the document or the application.

Authorship Contribution

the authors participated in the conceptualization, research, writing – initial draft, writing – revision and editing.

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