The characterization of perceived social support of HIV-diagnosed adolescents

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Abstract

The main objective of this investigation was to characterize social support in adolescents diagnosed with HIV. A qualitative study with a hermeneutic interpretation approach was carried out. As a result, it was evident that the participants have networks that provide them with support in their different functions: family, peers and health institutions. Their results support that family is one of the networks with more influence and it has a multidimensional function in the provision of support. Additionally, there were beliefs regarding health and disease that promote fears and limit the relationships that the adolescent establishes in terms of revealing the diagnosis to other networks.

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1. Introduction

The increase of HIV/Aids has become a social problem in which the adolescent community has become involved. According to worldwide studies undertaken by the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2011) 34 million people currently live with HIV in 2010, 17% more than the numbers reported in 2000. The number of people that have contracted HIV/Aids in Colombia from 1985 to 2011 was 75,620 and the numbers are in constant growth in underage populations. This reflects a considerable growth in the number of people that have contracted the virus, and at the same time reflects the need to guide services and intervention programs, for

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improvement in the quality of life and social wellbeing (Ministry of Health and Social Protection [MSP], 2012).

In Colombia, according to the MSP (2012) the global number of HIV young people diagnosed is 6,687. This number represents 20% of the population that currently suffer from HIV in the country. Also, 286 adolescents between 15 to 19 years old are HIV positive, which represents 4.3% of the population. Of these reported cases in the country, 175 people (2.6%) are under age, of which 83 (1.2%) are younger than 15 years old. This shows the importance of integrating family support in HIV-diagnosed infants and the accompaniment adolescents, given that this is an area which requires more research and information (Beltran and Sierra 2011). Due to the focus of the different health organizations such as OPS (2010) and UNAIDS (2011) on the importance of treatment and development of the HIV diagnosed adolescent population, it is necessary to recognize that since the first reported case of HIV/AIDS in Colombia, there have been more than 1,000 people born infected. This demonstrates that the adolescents that are living today with HIV are the first generation with vertical transmission (from mother to child). This is the target population of this research. Additionally, the United Nations Population Fund (UNFPA 2011), recommends the direct approach and intervention with adolescent population and juveniles because they are the base population of the country and hence striving for their quality and psychological wellbeing is going to have a determinant impact on the society’s future, and the possibility of its development.

In relation to this issue, different research has concentrated on the approach of HIV and the chronic disease through a social support concept. The study of this variable has been tried in different situations that imply a psychological adjustment and mental wellbeing. Investigations carried out with migrant population, with family members of people diagnosed with chronic disease, and the evaluation of community networks, have found that social support is a factor that contributes to the reduction of stress and improving the quality of life. It was also found that the support network to which these individuals belong provides them with a useful mechanism to help them face situations of adjustment disorders, which contributes to wellbeing and mental health (Garcia & Herrero, 2006; Hernandez, Pozo, Morillejo & Martos, 2005).

This research defines perceived social support from a functional perspective as “a multidimensional construct with different categories, the main ones being the provision of emotional support, material support and informational support” (Barron, 1992, p. 223). The emotional support is related to the affective aspects that have to do with the expression of feelings and emotions. The informational support is the orientation, the information and the advice of people that can be given to the individual when needed and finally the material support is related to the help or direct material assistance that provides the sensation of wellbeing and perception of value for the support network (Gracia, Herrero & Musitu, 2002).

2. Method

This research had a qualitative nature, which indicates that there was a closer investigation of the day-to-day life of the people involved, from particular cases that allow the generation of knowledge of the social network (Bonilla & Rodriguez, 1997). From this perspective, the study was focused on the interpretative – hermeneutic approach that proposes to comprehend people’s reality through the construction of the sense that the participants demonstrates in their speech (D’Aloisio, 2009). The population for this investigation included six (6) adolescents between 15 and 18 years of age, diagnosed with HIV by vertical transmission and one (1) carer for each juvenile as secondary source of information. The sample was non-probabilistic, given that it was selected in an intentional way, taking into consideration the specific characteristics of the population (Hernandez, Fernandez & Baptista, 2010). Also taken into consideration was the need to highlight confidentiality, the ethical nature with which the data was handled, and the fact that participation was voluntary and a consent form was signed by the carer and with confirmation from the underage adolescent.

2.1 Instruments

In this research two semi-structured interviews were designed and used. The interviews were conducted with adolescents who were the primary source of information and their respective carers, who were a support population and a secondary source of information.
2.2 Procedure

Initially the study and its objectives were presented to the participants, also the signature of the consent form and the informed consent took place. Following this, the semi-structured interviews with the adolescents and their carers took place and they were performed by two researchers. Once this process was finalised the transcription and categorization of the data was done with the Atlas. Ti 6.2 Software. Following this, the results of the project were noted, highlighting the analysis of the content of the data. Finally, a discussion was held of the results, using the Consensual Qualitative Research (CQR) analysis method.

2.3 Treatment of the Results

One of the main contributions of the proposal was the treatment and the analysis of the result through the CQR method presented by Hill, Knox, Thompson, Nutt, Hees & Ladany (2005) for the processing of the information. This method makes reference to a consensus between the researchers and two auditors, experts in the subject, who accompanied the reading of transcript interviews and the respective categorization of the data; this was done with the goal of obtaining an objective view of the reality and to avoid possible biases that could potentially hinder the investigation process.

3. Results

In this section we present the results obtained from the 12 semi-structured interviews with six adolescents diagnosed with HIV through vertical transmission and 6 primary carers. The adolescent participants in this investigation are currently enrolled in a health institution that they attended to regularly. Within this institution they are part of a support group for adolescents with HIV by vertical transmission and also regularly attend medical checks and psychological consultation. With regard to the carers, it was found that the type of bond they have with adolescents varies in relation to the structure and the family dynamic, because in most cases, the parents of the adolescents have passed away and the adolescents have been cared for by their closest family members (extended family); in this case there are uncles and a cousin. Table 1 shows the demographic data of the participants.

### Table 1. Sociodemographic Data of Participants†

<table>
<thead>
<tr>
<th>Adolescent</th>
<th>Age</th>
<th>Gender</th>
<th>Academic Level</th>
<th>Carer</th>
<th>Age</th>
<th>Gender</th>
<th>Relationship</th>
<th>Strata</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1 Melani</td>
<td>15</td>
<td>Female</td>
<td>Sixth</td>
<td>C1 Nidia</td>
<td>41</td>
<td>Female</td>
<td>Aunt</td>
<td>1</td>
</tr>
<tr>
<td>A2 Fernando</td>
<td>15</td>
<td>Male</td>
<td>Seventh</td>
<td>C2 Juana</td>
<td>42</td>
<td>Female</td>
<td>Aunt</td>
<td>1</td>
</tr>
<tr>
<td>A3 Alexandra</td>
<td>15</td>
<td>Female</td>
<td>Ninth</td>
<td>C3 María</td>
<td>32</td>
<td>Female</td>
<td>Mother</td>
<td>2</td>
</tr>
<tr>
<td>A4 Verónica</td>
<td>18</td>
<td>Female</td>
<td>Eighth</td>
<td>C4 Adela</td>
<td>24</td>
<td>Female</td>
<td>Cousin</td>
<td>2</td>
</tr>
<tr>
<td>A5 Angélica</td>
<td>16</td>
<td>Female</td>
<td>Ninth</td>
<td>C5 Mery</td>
<td>47</td>
<td>Female</td>
<td>Mother</td>
<td>2</td>
</tr>
<tr>
<td>A6 Mayra</td>
<td>17</td>
<td>Female</td>
<td>Graduate</td>
<td>C6 Alfredo</td>
<td>48</td>
<td>Male</td>
<td>Uncle</td>
<td>1</td>
</tr>
</tbody>
</table>

3.1 Characterization of the Support Networks

It was found that all cases networks were formed mainly by three groups: (1) family and/or carer, (2) health institution which they have subscribed to and (3) peers. The type of members varies depending on the relationships that the adolescent maintained. In the family, there were siblings, cousins, grandparents, uncles and aunts as

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† Real names were changed to protect the participants’ identity and confidentiality.
members of this social network. In the case of the health institution, the medical staff, the psychologist and the
support group were the most important people in the participants’ discourse. Lastly, with regard to the peers, the
participants mentioned people from school, generally from their same grade, and people that lived in the same
neighbourhood years before. A common element that was observed in relation to the characteristics of the network
was that their parents had passed away due to HIV; this was the case of adolescents like Fernando, Melani and
Veronica and their uncles and aunts, grandparents or cousins are in charge of taking care of them. This was
different to the case of Angelica and Alexandra who live with their mothers and Mayra who was adopted, and
there is no information about the status of her biological parents. Taking into consideration the structure of this
social network that the adolescents belong to, and the people that are part of it, the results of the social support
perceived Social Support by the adolescents are as follows:

3.2. Perceived Social Support

- Emotional Support
  As for the emotional support in the results, it can be observed that adolescents that belong in the support group
  refer to their family as the most predominant network, because it is they who encourage them to keep going and
  are a voice of support during difficult times. This is evident in Mayra’s discourse:

  "At that time my grandmother died too ... It hit me very hard for what I was going through like at that time and on top
  of that I get the diagnosis, then you do not know anything about it, I thought I was going to die ... (cries) ... then
  Alfredo (uncle) gave me a voice of support to move forward that was normal... and that’s it! At least one has someone
to lean on, someone to talk to, to tell him things "(Mayra, 17 years).

  On the other hand, we find that within the health institution to which they belong to, the psychologist and
  support group members are instrumental in providing spaces where the adolescents can express themselves, feel
  loved and valued by the network. Veronica's story below:

  "Interviewer: "Who do you feel you could go to when you have a problem? – to the support groups because first, they
  have the diagnosis also and second they have gone through the same, like we understand each other very much”
  (Veronica, 18 years).

  Finally the peers and partners network is the least predominant in their accounts, due to the adolescents having
  concerns regarding the disclosure of the diagnosis to their networks. However, as is evidenced in Alexandra’s case,
she expresses that thanks to the support and companionship of her boyfriend she has been able to overcome
difficulties in her adherence to treatment:

  "He (boyfriend) sometimes when I'm sad, makes me feel better, even if only with his company, when he is with me, he
  tells me that he supports me, that I should take them (the tablets), that he wants to see me well" (Alexandra, 15
  years).

- Material Support
  It was found that adolescents refer to their family, in this case uncles and grandparents, as the social network
  from which they receive and perceive material support. The adolescents usually relate this support with the care
  related to their treatment, such as providing them with the medication, taking them to appointments and check-ups
  at the health institution. The carer assumes these responsibilities but they also see it as a challenge to transfer that
  responsibility back to the adolescents. Sometimes this is done as a way of encouraging the adolescents to take the
medicines, as evidenced in Alexandra’s discourse:

  "My aunt said “I’ll help you to buy all you need for school, but you have to make an effort” (talking about taking the
medication), because my grandmother and my aunt are the ones sponsoring me to buy my uniforms, shoes
"(Alexandra, 15 years).

  Regarding taking the medications, these are provided by the health department, however the process of
collecting them, the daily administration, and the commitment to the appointments imply a responsibility that the

  carers take over. This is evident in Alfredo’s story:

  "I have told her that there are difficult things ahead because you are now in pediatrics, but you are becoming an
adult and it’s not the same thing because you will have to fight for the medication. Well I haven’t mentioned it to her, but it will be hard for her (...) because now is where we must surround and embrace these patients because they are not children anymore, they are adults "(Alfredo, Uncle).

- Informational Support

With regard to the informational support perceived by the adolescents, these refer to their family, the psychologist at the Health Institution, the support group and to a lesser extent their peers who are people that they can turn to and receive advice regarding their diagnosis. The advice and guidance received from the support group is highlighted as a reliable and trustworthy source of information, because from their perspective they share the experience of living with HIV. The following Melani and Mayra’s speeches are noted:

"Andrea (a psychologist at the institution) also gives me advice, like to keep going. Well that gives me happiness and joy because I know I can go my way and I know I can live for many more years it doesn’t matter that I have HIV" (Melani, 15 years).

"Because they (the Support Group Members) are going through the same as you, they are going to understand you more, they will advise you more, then one feels like the same, because they have the same, like you lean on, we all lean on, we give each other support, we give each other advice and that "(Mayra, 17 years).

Finally, it is evident from the results that the adolescents refer to three predominant support networks: family, health institutions and peers and partners, with the family performing three of the basic functions of the social support from the perception of caring support, guidance, advice and financial contributions or provision of details. The health institution is perceived as the provider of meeting spaces and guidance regarding the diagnosis. On the other hand, the peers and the partners are less evident within the adolescents’ networks.

4. Discussion and conclusions

According to the adolescents and their carers’ discourses, the following represents the analysis of the results obtained with the research process, taking into consideration that the objective of this research was to characterize perceived social support in adolescents diagnosed with HIV, specifically identifying the support networks that they report to, and the functions that these perform, and the recognition of their strengths and difficulties.

The family is the most predominant social network in the adolescents’ discourse. This network is formed by uncles, cousins, grandparents and to a lesser extent the biological parents because in most cases these have passed away. According to the above, the person in charge of the adolescent changes, and therefore, according to Dominguez (2007), the structure of the network changes under conditions of bereavement. However, according to the issues raised by Madariaga, Abello & Sierra, (2003) this depends on the maintenance of the network and the interaction between its members who contribute to the generation of support processes that provide the possibility of sharing experiences to potentiate resources. In this case the family proves to be the only network that provides social support in three dimensions: emotional, informational and materials referred by the adolescents and the carers. This network, as it demonstrates all the functions of social support, represents one of the most important factors favouring the process of living with HIV.

In relation to the emotional support provided by the family, it is worth noting how the perception that family has of the adolescent is related to the perception that he/she has of him/herself in relation to HIV. In this sense the family’s support encourages a life plan for the adolescents, as well as the recognition of their abilities and potential, and creates an environment open to all the possibilities of their existence (Jiménez, 2010). However, Rolland (2000) states that although the family plays an important role in the support and monitoring of HIV, it can sometimes show excessive attachment to the adolescent.

In this sense, in the account of one of the carers it is found that within the family that are also overprotective behaviours that may impact in the human development of the adolescent at both psychological and social levels, and therefore influence the adolescent’s response and adaptation to the disease. It is important to highlight, the way that the diagnosis is conceived within the family, as this will impact positively or negatively on the construction that the adolescent has built as a fact of living with HIV, and the meanings that he/her attributes to it.

It was also revealed in the accounts of the adolescents that when the relationship with their family is stable and
pleasant, there is a feeling of wellbeing and genuine motivation to take the medication. This relates to the approach of Barron (1992) who explains that the greater the perception of support, in this case the family support and emotional relationships that are woven within, the greater the psychological adjustment and the feeling of psychological discomfort perceived by the adolescent is less. This is related to the way in which the adolescent lives with HIV and therefore with their adherence to the treatment.

By contrast, when the family relationships are conflictive, the perception of support decreases and thus feelings of loss are generated, loss of sense of life, carelessness in taking the medication, as well as the occurrence of psychological disorders and depression (Nava & Vega, 2008). This shows an evident relationship between the wellbeing perceived from the relationships that are built within the family network and the adherence to the treatment.

On the other hand, specifically in the functions of the support, in this case the informational, the family is recognized as a network that provides advice and guidance regarding situations of everyday life and situations related to the diagnosis that do not require specific knowledge (Gracia et al., 2002). This should be considered for the structuring and development of programs that promote adherence to the treatment, health and prevention promotion, since the role that the family plays in these processes has a passive position of the knowledge that they have of the diagnosis and the guidance they can provide to the adolescent.

With respect to the material support perceived by the adolescents, this comes mainly from the family, mentioning aspects meaningful to them as gifts, going out to different places, paying for the medication and administering it. The latter locates the adolescents in a passive condition in regard to their treatment. According to this situation, even though the family has accompanied the adolescents positively in their development and adaptation to the environment, at some point in their life they could start developing the opposite role as a harmful agent, because they assume responsibilities that in the near future they should assume themselves. This is supported in Gomez (2008) and Helms (2008), claiming that the differentiation process can lead to difficulties during the adolescence phase, as they now require the care of adults, however it may increase their dependence and affect their process of autonomy.

Another of the difficulties observed by in adolescents is related to their family who, in trying to protect them, have instilled a sense of reality that they must take care of themselves but at the same time contribute to the generation of fear and stigma in their relationship with HIV. This situation according to Cabral & Garcia (2009) contributes to the adolescents not considering the possibility of having a partner or friends who can support and advise them in relation to their life with HIV.

Regarding the health personnel of the institution to which they belong to and the provision of social support they receive, the adolescents refer in accounts given to the psychologist from the institution as one of the agents that dominates their accompanying processes, and therefore in the perceived emotional support. In this case, adolescents perceive in him/her a person that they can talk to, share their painful and comforting experiences, (Jiménez, 2010).

According to the description of the support networks, we find that within the health institution there is another micro network which is the support group. This one is perceived as the provider of informational and emotional support, given that by sharing experiences with other adolescents with the same diagnosis and at the same stage of life, this facilitates the expression of life experiences, a feeling of understanding and a space where they can build knowledge and meanings (Correa, Arrivillaga & Salazar, 2007).

Another fundamental aspect to take into account is the composition of the support group, that although most adolescents relate their permanence and content with this network, one of the adolescents pointed out the lack of continuity in the process of its members, due to the possible death of a member of the group and therefore the breakdown of the network. This according to Sluzki (1996) cited by Castañeda & Niño (2005) has to do with the fundamental characteristics of social networks in terms of loss of the network size due to the death of its members and therefore the loss of integration between members of the network.

The peers (friends) are another significant network and are perceived by adolescents, more so for those who have disclosed their diagnosis, as a network that provides emotional and informational support in difficult times. In regards to the importance of peers in adolescence, it is found that peer relationships will influence identity formation, since teens are undertaking a process of differentiation from their caregivers. However, it appears that
the fear of disclosure of diagnosis is related to the fear of being excluded from the network and thus losing the company and support that this provides (Pérez, 2006). In group discourse, a strong fear of disclosure of the diagnosis to their peers is prevalent, considering that only two adolescents had revealed the diagnosis to one of their close friends. This is in line with the issues raised by Orcasita, Peralta & Valderrama (2010) and Gomez (2008) who speak of the adolescent’s fear of disclosure due to stigmatization and judgment values.

Finally, it was found that adolescents perceive and receive social support in different functions according to the support network that provides it. From a holistic approach to health and the disease, it is important to involve networks such as the family and the health institution as well as the peers and partners, in order to promote this view of the subject from its potential and capacity as it is, which contributes to the perception of HIV as a condition of life that can be taken from an active and purposeful position.

In relation to the above, the importance of involving the family in the clinical process has been noted because it was found that the way that the family interprets the HIV affects how the adolescents relate to their diagnosis. From the point of view of the clinical and family intervention, it is necessary to perform an assessment of the beliefs that are woven within the family, the issue of banning the adolescents from disclosing the diagnosis to their other networks was especially recognized. In this regard, it is proposed to perform simple accompanying processes including methodological strategies such as case studies, role plays, seminars and support groups for carers where there is more confrontation with the ideas that are built around the diagnosis, and different health areas like medicine, psychology and social work.

In regard to the importance of the support networks, the peer and partners are one of the networks that are reduced by the fear that teens were reluctant to disclose the diagnosis, and the fear of transmitting HIV in a sexual encounter. Accordingly, it is necessary to work to strengthen of the structure of these networks, so that teens know the care they should take with their diagnosis, the actual possibilities of transmission and the myths about the consequences of the disclosure of the diagnosis. Also in relation to the impact of the support group in other scenarios of the adolescents’ lives, it was found that in most cases the adolescents only have contact with the group at its meeting place, the network does not move to other spaces and in most cases they only have contact when there is a meeting scheduled or a specific encounter.

In this regard, it is important that health institutions working with adolescents with HIV can generate the strengthening of ties between its members, and the implementation of projects with extramural impact. These issues involve the linking from the National Policy on health and education for the empowerment of youth networks and resources to support the health institutions in the developing of strategies that allow the connection of external support networks in order to promote knowledge regarding HIV. Finally, for future research work with adolescents with HIV by vertical transmission, it is recommended to address the issues related to the fears of adolescents, with emphasis on the disclosure of diagnosis to other networks (peers, partners, school environment), due to the fact that the adolescents are at the stage of restructuring and building new networks, a limitation in the relationship is evident due to the fear that HIV diagnosis is discovered or revealed.

Reference


