ABSTRACT

Background and objectives: Hantavirus is a pathogen that causes a viral disease with an acute and severe presentation, and a high mortality rate. In face of a sudden loss, some families may not conceive the complete absence of the deceased relative. Thus, we sought to understand the changes that took place in a family after the death of the provider by Hantavirus Pulmonary Syndrome (HPS). Methods: A descriptive exploratory study with a qualitative approach of the type case report. Data collection took place between October and December 2016 through recorded individual interviews and using questions about family dynamics after family provider’s death of HPS, which were assessed by content analysis in the light of Roy’s theory. Results: It was observed that the illness and death of the family patriarch weakened the family’s strengths and resources, leading to a period of mourning and despair. In addition, unemployment among other family members worsened socioeconomic conditions, seeing drugs as an alternative for support as it became a commercial activity, and the rise of a command in the region that culminated in the arrest of the wife, two daughters and a son of the deceased. Conclusions: In this case, it was evidenced that the family was weakened due to the illness and death of their loved one by HPS, and because of the lack of support and welcome from the reference social services, they chose to act in criminality and it ended up with the arrest of four members.

Keywords: Virology. Hantavirus. Changes after death.

RESUMO

Justificativa e objetivos: O hantavírus é um patógeno que causa uma doença viral com caráter agudo e grave e alta taxa de mortalidade. Em face da perda súbita, algumas famílias podem não conceber a completa ausência do parente falecido. Assim, procuramos entender as mudanças que ocorrem em uma família após a morte do provedor pela Síndrome Pulmonar por Hantavírus (SPH). Métodos: Estudo descritivo-exploratório com abordagem qualitativa do tipo estudo de caso. A coleta de dados ocorreu entre outubro e dezembro de 2016 por meio de entrevistas individuais gravadas e com o uso de perguntas sobre a dinâmica familiar após a morte por SPH, sendo analisadas por análise de
RESUMEN

Justificación y objetivos: El hantavirus es un patógeno que causa una enfermedad viral con un carácter agudo y grave y alta tasa de mortalidad. Ante la pérdida repentina, algunas familias pueden no concebir la ausencia completa del familiar fallecido. Por lo tanto, tratamos de comprender los cambios que se produjeron en una familia después de la muerte del proveedor por Sindrome Pulmonar por Hantavirus (SPH). Métodos: Estudio descriptivo-exploratorio con enfoque cualitativo del tipo estudio de caso. La recopilación de datos ocurrió entre octubre y diciembre de 2016, a través de entrevistas individuales grabadas y con el uso de preguntas sobre la dinámica familiar después de la muerte por SPH, que se analizaron a través del análisis de contenido a la luz de la teoría de Roy. Resultados: Se observó que la enfermedad y la muerte del patriarca familiar debilitaron las fortalezas y los recursos de la familia, lo que llevó a un período de duelo y desesperación. Además, el desempleo entre otros miembros de la familia empeoró las condiciones socioeconómicas, haciéndolos ver a las drogas como una alternativa de renta, lo que asumió el carácter de un comercio y el surgimiento de un comando en la región que culminó con la prisión de la esposa, dos hijas y un hijo del difunto. Conclusiones: En este caso, se evidenció que la familia se debilitó debido a la enfermedad y la muerte de su ser querido por SPH y debido a la falta de apoyo y acogida de los servicios de referencia social, eligieron actuar con criminalidad y por fin terminaron con cuatro miembros detenidos.


INTRODUCTION

Hantavirus pulmonary syndrome (HPS) is an emerging zoonosis, viral, acute, and severe disease. It has a variable clinical spectrum that has recently had its two clinical syndromes unified: hemorrhagic fever with renal syndrome (HFRS), endemic in Europe and Asia, and HPS or hantavirus cardiopulmonary syndrome (HCPS), typical of the Americas.5 Since the first HPS case in 1993, more than 2,000 cases have been confirmed in 16 Brazilian States. The State of Mato Grosso ranks third in HPS incidence, with 307 cases confirmed from 1999 to 2018 and the middle northern region of the state accounts for 75% of those cases.6 The relevance of the disease is related to its high lethality rate, which is 44%6 in Mato Grosso, and more importantly, the rapid evolution to death, which is around 24 hours after the onset of respiratory failure.3 Little is known about the impacts that HPS causes in families, especially during hospitalization and after the death of the relative, who is usually the provider, since in the majority of the cases, the disease affects adult males in the economically active age group.4,5 Death is considered a determinant of mourning, and it is believed to influence the intensity and duration of the symptoms. Sudden death, such as that typical of HPS cases, is conceptualized as an unexpected death and causes a rapid pace change in the family context, which can be a devastating experience. Before the loss, anguish can become more complex and prolonged. Thus, a variety of mental health problems such as depression and alcohol and drug abuse or dependence have been reported.5 Family disorganization represents an important factor promoting the practice of delinquency. In fact, the relation between family disaggregation and psychological problems that can lead to criminality is frequent. The experiences of abandonment, rejection and/or absence of the maternal and paternal figures are reported with much suffering and sadness by young prisoners6 and pointed out by these as one of the main causes for involvement in criminality. Considering this scenario, the present study sought to investigate the changes that took place in a family after death by HPS of the relative who played the role of provider.

METHODS

A case report study, in which a descriptive exploratory design was used, with a qualitative approach in the light of Roy’s Adaptation Model. Qualitative research is the one in which the researcher aims at a better understanding of the human behavior and experience, attempting to understand the process through which people construct and describe meanings.8 The Adaptation Theory of Callista Roy characterizes the adaptive responses of individuals through four adaptive modes: physiological mode, self-concept, role performance and interdependence, developed to structure the evaluation of behaviors generated by stimuli.9 Data collection took place between October and December 2016 via recorded individual interviews using
guiding questions that addressed the themes related to changes in the family dynamics after the death of the provider due to Hantavirus infection. First, the objectives of the study and the way the activities would be conducted were presented to the family members. After that, an Informed Consent form was provided and signed by the family members, who had all doubts clarified, and then the interviews were scheduled. Thus, data collection continued until the saturation of information and the emotional aspects were fully investigated.

Data was transcribed verbatim, organized in a systematized way using a numbering and classification system, with an alphanumeric type coding, where the first consonants refer to family member, followed by an Arabic number that corresponded to the sequence of interviews.

Data was analyzed using the Technique of Content Analysis, which is a set of communication analysis techniques based on systematic procedures and objectives to describe the content of the messages. This technique is composed of three stages: pre-analysis, material exploration, and treatment and interpretation of the results. Pre-analysis consists of the organization of the material to be analyzed in order to systematize the initial ideas. The exploration of the material consists of the definition of categories, identification of the units of record and the context of the participants’ speeches. Treatment and interpretation of results consist in highlighting the information for analysis, culminating in the inferential interpretations.

All ethical aspects in research were respected, starting the study only after the approval of the Ethics Committee in Research with Human Subjects (CEP) from the University of the State of Mato Grosso (Unemat), under the protocol number CAAE 50417815.8.0000.5166 and opinion 1,457.621/2016. Participants signed the Informed Consent Term, as recommended in Resolution 466/2012 and international agreements on civil and political rights, and international guidelines for biomedical research - Council for International Organizations of Medical Sciences.

RESULTS AND DISCUSSION

Description of the family

This study was performed in a peripheral district of the urban area of Campo Novo do Parecis - Mato Grosso, Brazil. This city has been chosen because it has recorded the largest number of cases in the country. The family was chosen because it was the only one in which there was a relationship between crime and death of the patriarch by Hantavirus. The family was composed by 10 members; the 50-year-old father, who was the head of the family and the main responsible for the financial maintenance and harmony of the family, his 41-year-old wife who worked as general service assistant at a private company and their eight school-age children. The family head performed his professional activities in a municipal agricultural farm planting and grain harvesting. On March 2nd, 2007, he started to present signs and symptoms such as fever, headache, dry cough, myalgia, low back pain and dyspnea. He went to the hospital on March 8th, with increased respiratory distress. At the first visit, the medical exams showed hemoconcentration, thrombocytopenia and diffuse pulmonary infiltrate and the patient was transferred to the Intensive Care Unit (ICU) of Tangará da Serra, 150 km away, suspected of having HPS, but unfortunately the patient died on March 19th, 2007. Serum testing was performed using the Elisa Hantec kit (Oswaldo Cruz Foundation, State of Paraná, Brazil) and the result was positive for anti-hantavirus IgM and IgG.

One year after the father’s death, the youngest member of the family, a 12 year-old child also died in an automobile accident and this event impelled new changes in the daily life of this family.

As shown in figure 1, after the patriarch’s death of HPS, four family members were arrested for drug trafficking. The patriarch’s wife and two daughters (29 and 23 years old) were serving time in the female public prison of Tangará da Serra – MT, and a 30-year-old son in the male prison of Campo Novo do Parecis - MT. The other family members who did not get involved in crime or delinquent behavior lived in different places and one of them was still in jail.

Figure 1. Family genogram, highlight for the death of the family maintainer by SPH, Mato Grosso, 2017.
them, a 21-year-old woman, was a sex worker.

Impact of the illness in the family

Providing care for a family member with severe and progressive illness can be stressful and lead to loss of family relationships, since the whole family is often involved in caring, and in the instrumental and/or emotional support. This reflects on great suffering before the death of the relative and difficulties related to the sad experience.12

There are familial characteristics capable of affecting the process of sadness, expressed in an individual and specific way, such as potentialization or minimization, depending on the level of communication among family members and family cohesion. Family functioning also plays a role in the possibility of depressive symptomatology and involvement with drugs, with a chance of long-lasting effects, even after overcoming family sorrow.12

In situations of vulnerability, the integrity and health of the family are exposed to risks, mainly due to the difficulty of recognizing and reacting before the sad event. In the face of the problem, the family members become susceptible, overwhelmed by their fears, longings and doubts, and they experience moments of fragility of affective relationships, unemployment, losses and separations, as shown in the reports of families that have experienced the loss of one of their members. These families express intense distress, and a confuse speech. Reticent speeches, heartache, lack of overcoming, impotence, revolt, grudge and impatience, often used as defense mechanisms to deny negative situations.12

The comprehensive analysis of the narratives on the changes that took place after the death of the family provider in the present study clearly showed the figure of the father as vital for the preservation of the family structure that was dilated.

Patriarch’s wife: “Oh, after my husband died I suffered a lot. (...) and my life was filled with suffering, and then three of them (children) entered into the world of drugs.”

Daughter 1: “Difficult, very difficult ... because of this I ended up in jail ... when he died we were very young, right ... and then this world came, the world of drugs, crime, it messed all our lives up, my father was the mainstay of the house, we do not obey my mother very much, these things right, thus this messed all up, and it broke our whole family.”

Daughter 2: “It has changed a lot, I started using drugs, I started getting tattoos, and I lost my children....

Daughter 3: “Look, everything changed, changed a lot, you know... it’s like, my father was the only one providing in the house, my father died right, went away to be with God, that changed everything, broke our family, things were never the same, although I was little, but it changed a lot, and it’s still like this today, a kind of disorganized family but we keep moving on”.

Drug use, trafficking, and violence issues in Brazil have multifactorial causes and are central themes of political and social discussions in the country.13 The changes that occurred in adolescence over the centuries show evidence that in the twenty-first century there is a need for a longer stay of adolescents under a paternal home and the need for family guidance for the development of their identity, so that they have security and assertive direction in the social insertion and autonomy for the adult phase that will follow. There are also punitive systems as reflections of a historical construction, in which prisons and deprivation of liberty are forms of punishment for acts deemed as illegal.14

In the search for pleasure and to forget their fears or difficulties in the family context, such as socioeconomic setbacks and others, young people find drugs to be an effective strategy. These chemical substances are capable of altering the functioning of the organism, and many cause a feeling of pleasure and affect the user’s behavior, modifying perceptions, sensations and mood, and softening the problematic reality and weak social relations.15

Drug consumption is a phenomenon characterized as a global public health problem related to economic and social aspects such as the difficulty of access to services, social inequality and violation of social rights, involving various sectors of society. Associated with this way of life are exclusion and stigmatization, in relation to socioeconomic aspects. There is a need to change this scenario in which consumers are beneficiaries of social policies, in order to make them active in this process of building social policies that really impact their quality of life.16

The narratives in the present study show that the family tried to adapt to reality through involvement with crime, as a response generated by the stimulus of the father’s death. This can be contextualized through the Roy’s adaptation model, where the subject is considered an adaptive and holistic being, visualized in the form of a system in which the inputs correspond to the stimuli and the outputs to the responses generated, which are control processes, such as coping or feedback mechanisms.179

In response to criminality and negative events, control and prevention campaigns, programs and policies against drugs are implemented, and support and dialogue within families and the social circle of individuals are stimulated. There are challenges to develop strategies capable of dealing with and addressing drug dependence, and there is a need to increase evaluative research in this area.18

In some moments during the narratives, emotions surfaced when the speakers associated the current family disorder with the father’s death caused by Hantavirus infection.

Patriarch’s wife: “And because of this [the death] I went through many things, a lot of suffering (crying).”

As observed, even after 10 years of the event, healing remains in progress and remembering the event is still painful, whether due to the condition of patriarch’s wife being the responsible or the expected responsible for the care of the children and the well-being of the hou-
seholders, because such responsibilities are pre-conceived and demanded by society. Besides that, we considered that the patriarch's wife responsibility was also noted in other situations after her partner's death.

The discourse of the patriarch's wife points to elements described by Roy such as the inclusion of conditions and circumstances that influence the behavior and development of the subject in the environment, in this case the family context, corresponding to the impact provoked in the home and between the entities. The long-lasting feeling of loss is still evident, which in the light of the Roy's theory, can only be overcome by promoting the integrity of the person, that is, by providing conditions of survival, growth, reproduction and domination.

It is evident that a family rearrangement after the loss was necessary. In the case analyzed herein, the expected success was not achieved, leading the family to disorder and entry into the world of crime, resulting in arrests and further suffering.

The narratives revealed that beyond the expansion of the patriarch's wife relation with her children, the death of the father led to crime, highlighting the disease as the cause of this problem.

Patriarch's wife: "All it caused was harm. Because then my son got involved in the world of crime, and then ended up here in jail."

Patriarch's daughter 1: "(...) this destroyed our family; because of this disease ... he left to work and did not come back."

As presented in this study, the feeling shown by some young people is revolt before the loss of the father and/or patriarch's wife, considering the possible damages that the event brings about in the family and the commitments these young people have to make early in life without an adult as a reference to support them and the relationship with the patriarch's wife. Other reports also point out the involvement with drug trafficking after the loss of the father caused by diseases such as hantavirosis.

At the same time, divorce of parents has also been found to be directly related to homicides, reinforcing the idea that the family structure has a strong influence over delinquency, where the patriarch's wife continues to raise children alone, but has less free time due to the fact that work activities are multiplied. The children become exposed to the community, which sometimes is disorganized and violent, and this may even lead to psychological complications and crises of sexual identity.

Dealing with the loss of a relative also leads to social discomfort. The community begins to see the family in a prejudiced way, due to the disease being infectious and due to the lack of knowledge of the modes of transmission. This is portrayed by Roy when he addresses the issue of role playing, representing the role of individuals in society from the perspective of their pattern of social interaction with others, whose perception is what leads towards a behavior resulting from regulatory mechanisms.

Patriarch's daughter 2: "It destroyed our family, because my mother used to be better seen by society, and then right after my father died, people started seeing us as criminals (...)"

Patriarch's daughter 3: "(the disease) took away the life of a person we loved, which was my father; unfortunately, the whole family was restructured, right, unfortunately that happened to us."

Reciprocal support from family members positively influences the process of adaptation to situations of loss and the family environment can be decisive for psychosocial morbidity. However, the feelings of revolt and non-acceptance of reality were sustained by the children, reflecting disobedience to the patriarch's wife, with histories of discussions after onset of drug use. Besides the income for family maintenance, psychological support was needed for the passage of children into adulthood.

Society began to treat the family with prejudice and discrimination due to the fact of the consumption and commercialization of drugs. This behavior is often associated with delinquency, aggression, robbery and homicide, causing exclusion and marginalization of these individuals as a form of defense against the stigma imposed by the community and escape from the negative reality linked to them.

The patriarch's wife also experienced moments of emotional and economic difficulties, due to the extreme situations that occurred. In addition to the father's death, patriarch's wife adaptive response should be considered. This can affect several dimensions of life, such as health, work, leisure and even the relationship with other family members, as well as the routine and domestic dynamics, generating disorganization in the family core and chronic stress.

The patriarch's wife states that she was responsible for the care of the eight children, a nephew and a granddaughter. She faced several challenges to keep on this role. With this, they found in drug trafficking an opportunity of economic supply that contributed to increase the family income.

Patriarch's wife: "I stayed with the children, all underage children, and I was alone, I am alone up until today, and thus, I suffered too much. And then it ended up that the boys got involved in this world of drugs and the consequences came. (...) He was the one who provided for the house, right? Me and him, right? He worked and I worked (...)".

The quest for independence in the adolescence is a central goal, as well as the search for professional identity and insertion in the labor market, that is, the search for recognition by society and financial independence.

The daughters believe that if they had not lost the father, they would have led their lives and not have got involved with drugs and crime, seeking for other forms of financial support for their own expenses and to help in their house, a work considered worthy by society.

Patriarch's daughter 1: "... if he were alive I would not be here... if he were alive, he would not even..."

let us know what drugs are in our life, because before he died we were totally different”.

The lack of support provided by the State and the need to provide for the family coupled with unemployment and lack of opportunities favor the practice of crime, which is an environment where individuals feel welcomed and often benefited. However, it is important to reflect that it is up to the family to direct their children to study and work honestly, with shared responsibility.

Drug-related crime offers to those involved a range of material and symbolic resources, as well as economic autonomy and circulation linked to the state of power and valorization. However, insofar as these subjects are given the opportunity to rethink their actions and enter new cultural spaces, sharing social relations, the sense of belonging to the criminal network becomes marginalized, losing relevance.21-23

Access to preventive and curative actions by health services and professionals are advocated by the guidelines of the Ministry of Health in the promotion of integral attention to alcohol and drug users. Primary health care should be available to the community through health education in addition to the referral of resources for this purpose and the creation of links with other sectors in the search for holistic health promotion.14

The lack of articulation with community resources such as churches and training courses has been pointed out by health professionals, as well as the importance of the Family Health Strategy (FHS) resources. In the FHS, the work of Community Health Agents (CHA) becomes fundamental due to the fact that they carry out activities that require greater contact with the population.13

It is noteworthy that a support network for these families is particularly important as a method to prevent crime and violence. In the State of Minas Gerais, a program that is part of the State’s Public Policy for Crime Prevention, created through a dialogue among several representatives of the government, has been expanded, with an increasing number of young people assisted each year. This is a result of a multidisciplinary partnership and acts in the support networks articulated with public resources and institutions that assist the participants and aims at both social protection and strategic intervention, including the availability of artistic, sporting, cultural and leisure workshops as means of social control.21

Social support is defined as the individual’s perception of being loved and esteemed, integrating a network of multiple commitments.16 The absence of embracement of families by society and the support offered through social protection networks, such as Social Assistance Referral Centers (Cras), stands out in this case. Social protection must ensure family survival, including income, autonomy, and accommodation - the right to food, clothing and shelter. In this context, Cras act as state public units located in areas of social poverty and responsible for the execution of basic social protection services, organization and coordination of social assistance networks.24

Support from these networks is especially needed in situations of chronic diseases, traumas, losses, ecological transitions and old age, where actions for violence prevention, strengthening of skills, greater feeling of belonging in the community, and quality of relationships prevail. This is accomplished by a set of effective strategies in the fight against moments of crisis for the reduction of pathological symptoms such as depression and vulnerability to risky situations.25

With high fatality rates, HPS represents a serious illness that routinely exposes families to the loss of loved ones. In the present study, the occurrence of death due to this viral zoonosis may be related to family disruption, which resulted in drug addiction and marginalization of family members, justified as the only strategy found to meet their needs. Without the family’s provider, the patriarch’s wife and later her children, started drug trafficking. Despite recognizing that this was not the most morally adequate way of life, but rather a cause of harm in different ways, it was what they adapted to provide the support of the household.

Thus, the importance of social protection networks to the relatives of people who die due to HPS is emphasized, because in circumstances such as the expressed in the present report, the subjects tend to have their life projects interrupted and are led to trajectories of risks, exposed to situations of violence and activities related to the experience on the streets.

As a limitation of this study, it is important to emphasize the difficulty of locating all other family members; however, the technique used in the interviews favored the achievement of the objectives outlined.

Therefore, communities as well as social and health services and institutions must be aware of the contexts of social helplessness, since they are devices with competence and responsibility to receive and provide care to these people.

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HANTAVIRUS AND CRIMINAILTY: DISEASE AND FAMILY


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HANTAVIRUS AND CRIMINALITY: DISEASE AND FAMILY