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European Ph.D on Social Representations and Communication
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***The childhood cancer: A representations research on patients and
primary caregivers***

Part I : Primary Caregivers

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Research Problem

Research Question:

- What do the representations have the caregivers about cancer?

Research Problem

Justification:

- The cancer was the second cause of deaths in the group of non-transmissible illnesses in the world. Which caused 13% of deaths from a total of 58 million (World Health Organization, 2006).
- The Leukemia is considered the most impactful cancer for the age groups from 0 to 14 years in England, Ireland, France, Australia and Denmark (Office for National Statistics, 2004).
- In USA and France for the age groups from 10 to 14 years (Cuevas, 2003).

Research Problem

Justification:

- In México in 2006 the malignant tumours were the third cause of death, (63 888). It represented the 12.9% from the total of registered deaths. Speaking about age group, the age group from 5 to 14 years was the second cause of deaths (Sistema Nacional de Información en Salud, 2005; Instituto Nacional de Estadística Geografía e Informática, 2008) .
- Specifically the leukemia caused the 52.2% of deaths and the tumours the 16.3% (Secretaría de Salubridad y Asistencia, 2005; Instituto Nacional de Estadística Geografía e Informática, 2008).

Research Problem

Justification:

- The SSA only has 132 physicians and 190 nurses to attend 100,000 people (Instituto Nacional de Estadística Geografía e Informática, 2006).
- Around 20 000 physicians got a degree by year and less than 5% of them got a post grade degree and finally just the 10% are practicing.
- Every year 7,000 children are diagnosed with cancer, 18,000 require treatment and approximately 2,200 passed away because either it was diagnosed late or the parents don't have money for the treatment.
- The Republic's Senate agreed to exhort to Federal Executive to strengthen the actions to attend and to prevent the childhood cancer (Gaceta del Senado 2008, México)

Research Problem

Antecedents:

- In the childhood cancer research has been researched several psychological dimensions like: Coping, emotions, attributions (Bashore, Smith, 2006; Ogle, 2006; Barrera, Laurel, 2005; Fleming, & Khan, 2004; Patterson, Holm, & Gurney, 2004; Weaver, 2004; Ow, 2003; Bloom, 2000; Woznick; Goodheart, 2002; Barbara, Kaplan, Fogel, 2001) but we want to know the representations where these dimensions are based on (Moscovici & Marková, 1998)
- Contents and two basic proceses: Anchoring and objetiving

Method

- Design Research (Janesick , 2003:52)
 - Preparation: Making decisions at the start of the project
 - Design of research questions
 - Selection of cases/Place
 - Negotiation of access
 - Selection of research strategies
 - Exploration and test: Making decisions after the project started
 - Design Interview
 - Implementation of interview
Transcription of interview

Method

- Design Research (Janesick , 2003:52)
 - Illumination: Making decisions at the end of the project
 - Data Analysis
 - Data reduction
 - Design Categories
 - Theoretical saturation
 - Relationship theory findings

Method

- Theoretical sampling
 - It lets us move towards on those cases based on our interests, therefore it contributes to the explanation of the phenomenon. In this way the case studies are added to reach theoretical saturation, it means, the time that no longer arise new dimensions or categories by the participants in relation to the object of study (Flick, 2004; Strauss, 1987).
 - Theoretical sampling applied in design research and in the analysis phase.

Discussion

Contents of social representation

Illness and poverty like criterions of social identity

- The illness is a criterion of social identity for primary caregivers based on the new conditions imposed by the disease. This is a form of identity, which the person stop doing things that are considered normal and now they are part of the group parent of children with cancer. They know the rules, beliefs, and inclusion and exclusion criteria and a common discourse (Tajfel, 1984; Wagner, 1994).
 - I used to complain a lot to God, why this is happening to me?, Why to my daughter?, Finally when I reached the hospital and saw many children suffering from leukemia, Then I said to the lord, I´m not the only one, there are so many children. I talked with the ladies that I met there and they told me “We also have these fears” and we started to comfort us by ourselves by holding us hands and I told them now you have to ***echarle ganas hasta que Dios quiera.***

Discussion

Contents of social representation

Illness and poverty like criterions of social identity

- The Illness define the status or the group identity, it is more evident in this time for chronic illness and because it is possible to live in that condition for many years (Herzlich & Pierret, 1987),
 - You don't matter about the leukemia until you are living with a child with cancer, until then you ask you by yourself, Why I am so selfish and I did not pay attention to those people when I was asked for? When they ask me for, I didn't replay them, as I told you, no one will take care about leukemia until you are suffering leukemia (MCPL, jun2008).

Discussion

Illness and **poverty** like criterions of social identity

- Poverty is another criterion of social identity. The care givers have to looking for resources for treatment, transport from their communities to hospital, etc.
 - The average monthly income per household is \$2926.47 Mexican pesos (160,2927 €)
 - According to the Consejo Nacional de Evaluación de la Política de Desarrollo Social (CONEVAL) the average income of households in patrimonial poverty is \$3072.00 mexican pesos. The next level is capability poverty, in this level the people can't pay basic resources (Basic basket), expenses related to health and education (Consejo Nacional de Evaluación de la Política de Desarrollo Social, 2007).
 - Although people in our sample have access to health services they must pay transportation and many times their food and lodging during the stay in hospital, because their communities do not have the necessary health services. reflecting the inequality of access to health services related to the region where they live (Muhutdinova, 2006).

Discussion

Illness and **poverty** like criterions of social identity

- Poverty is another criterion of social identity. The care givers have to looking for resources for treatment, transport from their communities to hospital, etc.
 - I was wondering, Why us? Why do people without economic solvency for all these costs ? (YLP, 2007)
 - I felt a lot of courage and I wondered, Why this is happening to me? Why have so many rich people, why to me? The doctor said me: This is a expensive treatment... and I have not money... is very expensive and very exhausting for the family ¿Why me?, ¿Why? (MMVG, 2008)
 - I have low-income and people like me need all the support and don't give you anything (ADM, 2008).

Discussion

The start of the road. The identification of the disease.

- In the beginning the illness relates to diseases that are not severe. similar to what happens with mental illness and minimizing the signs (Herzlich, 1969).
 - I thought the leukemia was like a fever, you are healing now and tomorrow goes, I didn't think that this course was so long, but in march we celebrate two years coming (FTH, nov2008).
- When the illness have not obvious physical signs related to progress or remission is difficult to caregiver to make knowable/cognoscible, I mean the CG can't objectify the illness (Moscovici, 1976), and the consequence are emotional.
 - I couldn't to see how the cancer is developing, just knew that it is a serious disease, because the disease is going to consume and we do not see how, so I really was desperate (ADM, mar2007).

Discussion

The start of the road. The identification of the disease.

The illness are objektiv in sings of abnormality in the body's patient. Some times the doctors in the beginning related the signs to not severe illness.

- She had flu, well it seems flu, but the doctor prescribed medicine for the flu but it was not controlled (MHH, 2008)
- He was very thin. He was tired and then the ganglio grew (ADM, 2008)

Discussion

The start of the road. The identification of the disease. The negative charge of the word cancer.

- The background of illness are related principally to the death. The diagnosis is not communicated openly to the patient .
 - It seems a very crude word. We feel very ugly, very aggressive for a child. When you say cancer always you think in death (ESG, sep2007).
- Herzlich & Pierret (1987), they say the word cancer appears to have a load of magic and say it's like to kill a person if he had not known before that had disease.
 - Not better I am going to say, but slowly because I do not know this, I think that maybe things could be taken towards a surprise or do not know how, he would feel bad for your health , then I said no (ADM, mar2007).

Discussion

- The treatment. The health is objectify in sings of normality, like things in relation with everyday life
 - He walked again and returned to his study. He was desperate to return to school (GBA, 2008)
 - Now he plays; he could not do before, just saw that other children were playing (MSG, 2008).
 - Sometimes I forget she has that disease. She listening to music, she sings, ride a bicycle. I see her very well. When I see her I asked if she really is sick (MMVG, 2008).

Discussion

- The attribution. The negative emotions are the fuel of cognition, negative emotions begin a state of cognitive dissonance and the onset of significant cognitive effort in seeking the reduction of dissonance in this case trying to answer the question about the causes of the disease in a child (Rime, 2009), so that one of the first questions that arise are oriented to hear the cases of the disease.
 - Oh no, it is terrible notice. When I received the diagnosis, I had many unanswered questions. Why this is happening to me? Why? (MCPL , jun08).

Discussion

- To understand is to explain and also a new event or object that we have no prior knowledge, through a causal explanation is a way to represent (Jodelet, 1986). The causal attribution. The spiritual significance and the personal significance .
- The causes to which parents do not use a scientific logic, but are influenced by both the categorization and social influence, elements that are socially constructed and based on cultural background (Hewstone, 1992; Hewstone & Jaspars, 1986; Moulin, 2005).
 - I do not know that I owe to life. That has treated me very badly. It is not the first problem I'm facing. Only God knows why (ADM, mar2007).
 - I do not know why he is sick. But we here in the Huasteca, we say that the disease comes from fright (susto). Before he fall sick, other children frightened by a big snake (JCMG, ago2007).

Discussion

- The personal significance .
 - I smoked and drunk a lot before, Could be why my child is sick? (GBA, ago2007).
 - When I was pregnant, I cut and I left a lot of blood. I had three months of pregnancy. It was an accident, I dropped the machete, so I tell my kids that maybe that caused the disease, they also tell me that is likely (MHC, oct2007).
- In all this quotations the CG seeks to restore the belief in a just world in one way or another (Deconchy, 1986).

Discussion

- The collective symbolic coping (religion). These are interpretations that capture some essential attribute of the phenomenon in images and beliefs according to local cultural reference (Wagner & Kronberger, 2002).
 - That eased my daughter. We practice a called religion new path, and make prayers, there is one person to lead this new path, make prayers, we just answered, and that eased my daughter and through Doctor's here, grabbed power, and thus eased (ZSL, ago2007).
 - When I feel sad, I was asking God to help me. The sisters of my husband and I were going to church and prayed (CDS, mar2007).
 - When my daughter was very serious, a friend gave my child, a doctor child and put him in the window (MCPL, jun2008).

Discussion

- ***Echarle ganas*** is an abstract concept. However it is understood that you are sending a message of support and motivation. Is like *warranted assertible* (Wagner & Kronberger, 2002).
 - She said me **échale ganas** (MHC, oct2007).
 - The doctor told me it is a serious illness , but we will try to **echarle ganas** (ADM, mar2007).
- Indicators from echarle ganas

Discussion

- The childhood cancer and its functioning.
 - The white cells end up with red cells. So she is pale (MHC, oct2007).
 - The disease is a force and medicine is another. If the medicine will not have gained at least maintain stable. If you start to get the blood I think that the disease is attacking stronger than medicine (GBA, ago2007).
 - The blood becomes water. The medication kills the bad cells and good cells left to be reproduce over and over (MCPL, jun2008).

Conclusion

- The importance about the symbolic context (Flick, 2002)
 - Social identity /symbolic context vs reflexive groups (Wagner, 1994)
- The importance of context in the social construction of the concept of disease, hence its importance for future interventions with CG.

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