



HELLENIC REPUBLIC

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Title of dissertation: **Adult’s opinions with Juvenile Idiopathic Arthritis on chronic pain and its influence on their daily life**

Abstract

In the culture of the western industrial and technocratic world, chronic pain is regarded exclusively as a medical phenomenon detached from the social and cultural conditions. However, chronic pain is not only created in the nervous system. It depends on social systems such as family, school, work and the state, as the surroundings influence the human biology and social as well as cultural forces shape human pain. What is more, the social role of people with chronic pain is influenced by social and cultural notions that prevail and according to which people who are sick and disabled cannot take on certain social roles and cannot fully control their life and their body.

The purpose of this survey is to understand how experiencing chronic pain and the social role of people with Juvenile Idiopathic Arthritis (JIA) can be influenced by social and cultural systems. More particularly, the aim of this survey is to put down the views and experiences of adults with JIA regarding chronic pain and to investigate how the interaction, the feelings and the practices that develop within the family, among friends, at school and at work influence the experience of chronic pain as well as the social role of these individuals.

For this reason nine (9) semi-structured interviews (seven individual ones and one group interview) were carried out with adults who suffer from JIA. The survey used qualitative research planning with the help of the phenomenological approach so as to report on

the experiences and the views of the sample holistically and in depth. Finally, the research data was analyzed with the help of the method of thematic analysis of content.

The findings of the survey uncovered the view of these individuals regarding the experience of chronic pain. Judging from the results it became apparent that chronic pain is a negative experience for these individuals and it leads to functional restraints and negative feelings. It was also verified that these people have been socially stigmatized and this relates to the ignorance of their surroundings about their illness and chronic pain as well as the “marks” that people with JIA bear on their body. The results also showed that the way that these people experience chronic pain is determined by the social and cultural systems and more particularly family, school, work and the state, as well as by the feelings that they develop with the people who are in pain and by the way that they support them and the quality of their support. As for the social role of people with chronic pain and the way that they are influenced by their social surroundings, there seemed to be various opinions among the participants. In certain surroundings, such as the family, the role of people with chronic pain seems to be equal to that of the other members but the individuals were regarded as “eternal teenagers”. On the contrary, among friends it was seen that people with chronic pain have an equal role. It is certain that in many surroundings there are social and cultural notions according to which people with chronic pain cannot take on certain social roles and are not treated by their surroundings as equals.

Keywords: Juvenile Idiopathic Arthritis (JIA), chronic pain, stigma, sociocultural systems