Resilience in children and adolescents at risk of poverty and with parents suffering from Huntington's disease

Claudia Idárraga-Cabrera[a]
Jorge-Manuel Dueñas[b]*
Mariana Pino[c]
Marianela Denegri[d]

[a]Department of Psychology, Universidad Del Norte, Barranquilla, Colombia.

[b]Department of Psychology, Area of Developmental and Educational Psychology, Universitat Rovira i Virgili, Tarragona, Spain.

[c]Social and Human Sciences, Universidad Autónoma del Caribe, Barranquilla, Colombia.

[d]Center of Excellence in Economic and Consumer Psychology, Universidad de la Frontera, Temuco, Chile.

*Corresponding author: jorgemanuel.duenas@urv.cat ;Department of Psychology, Universitat Rovira I Virgili, Carrer de Valls, s/n, 43007, Campus Sescelades, Tarragona-Spain.

ABSTRACT

The objective of this study was to assess resilience levels in a group of children and adolescents whose parents were afflicted with Huntington's disease and in a control group of children and adolescents at risk of poverty. We used a sample of 63 children and adolescents (65% girls), between 7 and 18 years with an average age of 12.67 (SD=3.07). The subjects were administered the questionnaire on resilience in children and adolescents, which consists of three factors: internal protective factor, external protective factor and empathy. The results showed that both groups had higher levels of resilience than the theoretical median. However, the control group performed better on the internal protective factor and the general resilience scale. The data suggests that resilience levels in children and adolescents do not increase when they are overexposed to adverse circumstances.

Keywords: Well-being, adversity, childhood, adolescence.

Introduction

Resilience has become particularly relevant in psychology research in recent years. Resilience is a person's ability to adapt positively to adverse situations and maintain or recover their emotional or mental health (Sturgeon & Zautra, 2010; Wu et al., 2013; Zarzaur et al., 2017). As well as being able to adapt to adverse or traumatic situations, resilient people possess fast and effective coping strategies and do not return to their previous state of mind (Shrivastava & Desousa, 2016). Clearly, whether people are able to adapt to challenges depends on their relationships with others as well as external systems and other processes. People can adapt to adversity because of resilience, which is based on interactive systems that co-develop in the biological and cultural evolutionary process. When initiated in childhood, these processes become protective factors because they safeguard children by building support systems into relationships with other people at home and in the community (Masten & Barnes, 2018).

Research in the field of resilience has focused on two areas: a) coping with illness and b) coping with social situations. In the first of these areas, studies suggest that people with low psychological resilience are more likely to suffer from depression, anguish and hopelessness (Toukhsati et al., 2017). In fact, a study of women with breast cancer found that their resilience levels and psychological well-being exceeded the average. The authors suggest that some people in traumatic situations can develop positive emotions which lead to growth responses and personal maturation (Guil et al., 2016). Pintado and Cruz (2017) studied resilience levels in children and adolescents diagnosed with cancer. Their data showed that more than half of the sample scored highly on different factors of resilience. Specifically, sense of humour reflected the highest scores and the authors regard it as important when evaluating resilience factors. It is present in more than 70% of the sample. In fact, it is not surprising that using humour is a positive mechanism in situations of adversity. It can help children and adolescents overcome hardship and maintain good

mental health (Julien-Chinn & Piel, 2019; McGrath & Kovacs, 2019), especially among children whose parents are ill or in unfavourable circumstances (Herbert et al., 2013; Walsh, 2016). Obviously, parents suffering from an illness — especially a chronic one — can negatively affect the well-being of their children (Bilsky et al., 2018; Goldberg & Short, 2016). However, some children living with sick parents may also experience positive effects.

Family resilience describes the process by which family members endure and recover from traumatic or adverse situations within the family unit. even when these situations affect only one family member (Suzuki et al., 2018; Ungar, 2016; Walsh, 2016). Most studies have focused on parent resilience when their children face adversity; however, few studies have examined resilience in children when their parents face adversity.

Resilience in Children with Sick Parents

Several studies have shown that children can be affected by parental diseases (Chen & Panebianco, 2019), especially if these are degenerative or life-threatening (Howell et al., 2016). This is due to the anguish of losing a parent and the changes and strain it causes in the family dynamics. Nevertheless, some children and adolescents with sick parents develop coping strategies including resilience to adverse situations or circumstances. A longitudinal study conducted in cancer parents and their young children and adolescents showed that family resilience was positively associated with communication between parents and children and negatively related to perceived stress (Chen et al., 2018). In addition, a study focusing on mentally ill parents reported that their children used practical problem-solving and emotional coping mechanisms (Pölkki et al., 2004). The emotional skills of children can be improved in a number of ways when one of their parents is ill. Firstly, it is recommended to have good social support typically from a sister, brother, or friend. Secondly, it is helpful to have a hobby, play sports or do an extracurricular activity.

Thirdly, it can be beneficial to visit other people and talk to them about things other than their parent's illness (Pölkki et al., 2004). Support from others, including health professionals, can strengthen children's resilience. It can also improve their ability to cope with the challenges of having a parent with a serious illness (Foster, 2010).

Huntington's Disease and its Impact on the Family

It is pertinent for this research to review the concept of resilience in the framework of a disease, in this case Huntington's disease, a fully penetrant neurodegenerative disease produced by a dominantly inherited CAG trinucleotide repeat expansion in the huntingtin gene on chromosome 4 (McColgan & Tabrizi, 2018). This genetic neurodegenerative autosomal dominant disorder can be clinically characterised as a triad of motor, cognitive and behavioural alterations (Pino Melgarejo et al., 2017).

Huntington's disease usually manifests in early middle age. It causes abnormal movements and has accompanying psychiatric symptoms, which may include psychosis; depression; and obsessive-compulsive disorder combined with progressive cognitive decline (McColgan & Tabrizi, 2018). The disease generates structural changes in the family, which depend on the number of people affected, their position within the family, and the stage at which the disease is diagnosed (Fernández et al., 2012). It is clear that the impact of the disease on children is complex. They find it extremely difficult to accept or tolerate the disease and may have problems with family reorganisation, and with the emotional condition of the caregiver (Fernández Hawrylak et al., 2012). Indeed, some children and adolescents act as caregivers or help to care for sick parents. This can lead to great emotional vulnerability, as well as difficulty to adapt to social changes and face the adversities of the disease.

The Present Study

Considering all the above, the objective of this study was to evaluate levels of resilience in two samples of children in adverse situations: children in poverty (control group) and children in poverty who also have relatives with Huntington's disease (experimental group). Similar resilience levels were expected in both samples. This expectation is based on research showing high levels of resilience in poor children and adolescents (Artuch-Garde et al., 2017; Fazel & Betancourt, 2018) and in children with relatives with chronic diseases (Benzies & Mychasiuk, 2009; Pölkki et al., 2004).

Method

Participants

The sample was made up of 63 children and adolescents (65% girls) and was divided into two groups. The control group consisted of 33 socially vulnerable people living in poverty.

The experimental group consisted of 30 people with a parent with Huntington's disease and of low socioeconomic status in Atlántico and Magdalena (Colombia). All the participants (control and experimental) belonged to socioeconomic stratum number one or below according to the Colombian socioeconomic stratification system, which is used to classify the residential properties into strata so that public utilities can be billed at different rates and subsidies allocated. The system provides for six socioeconomic strata: 1 = low-low; 2 = low; 3 = medium-low; 4 = medium; 5 = medium-high and 6 = high. All the participants belonged to level 1 of the beneficiary selection system for social programmes (SISBEN for its Spanish acronym). SISBEN identifies households, families or individuals who qualify for subsidies due to their employment status, income and housing.

The participants were between 8 and 18 years old, with a mean age of 12.33 (*SD* = 3.13). The control group consisted of 33 children and adolescents with social characteristics analogous to those of the experimental group. The experimental group was aged between 7 and 18 years with a mean age of 12.97 years (*SD* =3.03). To obtain two similar samples, the control group was selected through mate sampling using age, socioeconomic status, and sex criteria. The main objective of the research was to study resilience in children and adolescents. The experimental group data was collected from people belonging to an association of Huntington's disease patients. However, the control group participants were recruited through an association which helps children at risk of poverty and social exclusion.

Measures

Participants completed *The Resilience Questionnaire for Children and Adolescents* (González Arratia, 2011). It consists of 32 items and a Likert scale with five response options: from (1) always to (5) never. The questionnaire measures resilience in children and adolescents and includes the key skills, attitudes, and attributes found in resilient people. It helps to identify the areas in which people are strong and the areas that need to be reinforced. The questionnaire consists of three factors: a) Internal Protective Factor (IPF): functions that are related to problem-solving skills; b) External Protective Factor (EPF): possibility of having family and/or significant support for the person; and c) empathy and altruistic and prosocial behaviour. The instrument has an adequate factor structure. In our sample, a Cronbach alpha of α=0.84 was obtained on the general scale.

Procedures

The participants were recruited in different stages. First, the two associations were contacted and the research objectives were explained; both associations agreed to participate. Second, an informative letter was sent to the parents, explaining the objectives of the research and the data collection process. Eighty families agreed to participate, but only sixty-five signed the informed consent form. Third, two psychology professionals asked each participant to complete the questionnaire individually. Before conducting the questionnaire process, the psychologists informally interviewed the children in the presence of some of the parents. They were then invited to enter the room without the parents. Once in the room, the psychologists played a board game with the children or adolescents to break the ice and then administered the questionnaire. Although the parents had given their informed consent, the participants could decide not to participate in the study or take the test. In fact, two children decided not to continue. The participants' right to anonymity and the confidentiality of their specific results were guaranteed. The test was anonymous and was evaluated by someone other than the person who administered the questionnaire. Participants had as much time as they needed to respond to the questionnaires.

Data analysis

The normality of the data was analyzed using the Kolmogorov-Smirnov test. The analysis revealed that our data were not normally distributed throughout the sample ($p < 0.05$). For this reason, we conducted non-parametric analysis. Specifically, to assess resilience in the two groups, we used the program SPSS 26.0 for descriptive analysis, comparison of means and frequency analysis.

Results

After the necessary statistical assumptions (homoscedasticity and linearity) for analysing the distribution of normality of the factors on the resilience scale had been checked, the Kolmogorov-Smirnov test was used to measure the degree of agreement between the data set distribution and the specific theoretical distribution. The data showed that the factors do not have a normal distribution (internal protective factor, p=.025; external protective factor, p=.003; empathy, p=<0.05). Table 1 shows the descriptive statistics according to the type of distribution. The data shows resilience characteristics that are above the theoretical median.

Table 1

Descriptive statistics for the overall sample

Variables	Median	Interquartile range
Internal protective factor	61	15
External protective factor	50	7
Empathy	31	5.9

Taking into account the distribution of normality, the non-parametric Mann-Whitney U-test was performed. It analysed possible differences in the variables between the control and experimental samples. The results are shown in Table 2. Significant results were obtained in the internal protective factor (Mann-Whitney U-test= 290.5; p=.005; the average range of the experimental group = 25.18; the average range of the control group = 38.20) and in resilience (Mann-Whitney U-test = 330; p=, 023; the average range of the experimental group = 26, 5; the

average range of the control group = 37). Therefore, the experimental sample presents significantly lower scores than the control group on the different factors.

Table 2
Average ranges and Mann-Whitney U-Test

Variables	Group	Average range	*Mann-Whitney U*	*p*
Internal protective factor	Experimental	25.18	290.5	0.005
	Control	38.2		
External protective factor	Experimental	29.9	432	0.38
	Control	33.91		
Empathy	Experimental	27.93	373	0.09
	Control	35.7		
General resilience	Experimental	26.5	330	0.02
	Control	37		

In accordance with the cut-off points on the resilience scale (González- Arratia, 2011), subject scores were classified into three levels: low, moderate, and high. Table 3 shows the frequencies of both groups. None of the participants in either sample was classified in the low level. The subjects of both groups were mainly in the high level for all factors, and especially for

external protective factors. Significant differences were only detected when subjects were classified according to the IPF factor.

Table 3
Experimental group and control group frequencies

Variables	Experimental group		Control group	
	Moderate	High	Moderate	High
Internal protective factor	10	20	3	30
External protective factor	2	28	2	31
Empathy	9	21	6	27
General resilience	6	24	2	31

Discussion

One of the objectives of this study was to assess levels of resilience in two samples of children in adverse situations. Research results show that the level of resilience in children and adolescents in the circumstances studied is high in all of the factors evaluated by the scale. These factors are: internal and external protective factors and empathy (González Arratia, 2011). Both groups showed high scores primarily on external protective factors. These scores refer to the possibility of receiving support from a family member and/or significant acquaintance (González Arratia, 2011). This is consistent with previous studies that show the same values in children with sick parents or in situations of poverty and adversity (e.g. Herbert et al., 2013; Walsh, 2016).

González Arratia, Nieto and Valdez (2011) have also documented that children in situations with an ill family member develop skills to cope with adverse situations. These psychological resources that develop in family dynamics are related to Walsh's concept (2016) of family resilience, which is the result of interaction within family dynamics and the integration of ecological, evolutionary and relational factors. Therefore, children and adolescents with parents who are sick with Huntington's disease and in poverty may develop tools to cope with adversity, as do children and adolescents in vulnerable circumstances.

González Arratia (2011) defined internal protective factors as functions that relate to problem-solving skills. In the present study, scores were high in both groups though the control group's scores were higher. Data obtained from the study population suggest that resilience levels do not increase in the face of overexposure to adversity. It should be borne in mind that prolonged adversity over time constitutes a psychological risk factor (Hoppen & Chalder, 2018; You et al., 2019). There may also be a resilience threshold for stressful or conflictive situations in life (McAdam-Crisp, 2006; Tol et al., 2013).

The children and adolescents in the study population all had one parent suffering from Huntington's disease, a risk factor for development because of its genetic fingerprint and its impact on the well-being and quality of life of their relatives (see Pino et al. 2017). Unlike other genetic diseases, Huntington's disease brings about neurobiological and behavioural changes that have a significant impact on patients and their families. This study on resilience changes the perspective by pointing out that it can be positive for the development of the child. Huntington's disease is considered a rare disease in Colombia, and it is estimated that in 2017 there were about 1,000 cases.

The study of resilience in children and adolescents has acquired increasing interest because of its practical implications, the application of results in educational contexts and their impact on society and community. Melillo, Rubbo and Morato (2004) consider education central to fostering the resilience of children and adolescents, and to preparing them for growth and social integration.

Declaration of interest statement: The authors declare that they have no conflict of interest.

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