Childhood Trauma and Psychological Distress During Adulthood in Children from Huntington's Disease Families: An Exploratory Retrospective Analysis

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Abstract

Background: Children of people with Huntington's disease (HD) often face a wide range of early psychological challenges which may lead to further psychological difficulties later in life.

Objective: This exploratory retrospective study aimed to investigate the relationship between childhood traumatic experiences and psychological difficulties during adulthood in individuals raised in HD families compared to matched controls.

Methods: Thirty-eight adult children of people with HD and 20 matched controls completed a demographic questionnaire, the Childhood Trauma Questionnaire-Short Form (CTQ-SF), and the Symptom Checklist-90-Revised (SCL-90-R). Mann–Whitney U Tests were used to compare groups on all measures. A multiple regression model was developed within the HD Family group to investigate which aspects of childhood trauma best predicted psychological distress in adulthood.

Results: Compared to controls, people raised in an HD family reported significantly more total childhood trauma as well emotional abuse, physical abuse, and emotional and physical neglect. Global psychological distress in adulthood, depression, and psychoticism were also observed to be significantly higher in the HD Family Group. The regression model identified childhood emotional abuse as the only significant predictor of global psychological distress in adulthood.

Conclusions: Growing up in an HD family may be significantly associated with higher levels of self-reported childhood trauma as well as psychological distress in adulthood, with emotional abuse playing a more significant role in shaping long-term mental health outcomes.

Keywords: Huntington's disease, childhood trauma, psychological distress, adverse childhood events, emotional abuse, adulthood, mental health.

Introduction

Huntington's disease (HD) is a severe rare neurodegenerative and dominantly transmitted genetic disorder.[1] It causes a wide range of motor symptoms, such as involuntary movements (chorea), muscle rigidity, and impaired coordination.[2] Cognitive and psychological difficulties are also common, and may include anxiety, low mood, compulsive behaviours, executive and memory failure, and impaired emotion processing.[3–6] Even though symptoms may present at any time in an individual's life, their onset is usually around age of 40-50 – a life time when most of people have caring responsibilities for families and children.[7] As no cure is currently available for HD, both symptomatic treatments and palliative care for the maintenance of quality of life remain the mainstays of its management, particularly at later stages of the condition, when patients typically require round the clock care.[8,9]

Due to these issues, informal caregivers of people with HD (pwHD), such as partners or children, often face a significant burden across the disease trajectory consisting of several physical, emotional, and financial challenges.[10] Major psychosocial factors contributing to caregiver's burden include loss of independence, isolation, loneliness, reversed family roles, cognitive and emotional impairments, reduced social participation, and the overall impact of HD on future life expectations.[11–13] While the experiences of partners of pwHD have received growing attention over the past three decades, [14–18] studies focusing on the challenges faced by children raised in HD families remain limited.

This represents a significant gap in the current literature, as a number of studies have reported how children of pwHD can face a wide range of challenges associated with the profound impact the condition has on family dynamics, including low cohesion, limited expressiveness, and high levels of conflict.[19,20] In addition, the above-mentioned autosomal-dominant pattern of transmission –

whereby each child of a pwHD has a 50% chance of inheriting the condition – can often lead to stigma, lack of communication, resentfulness, and survivor's guilt.[21–24]

Given the importance of early childhood for individual's cognitive and psychological development, it is not surprising that children from HD families show higher levels of attachment problems, premature adult-like responsibilities and behaviours, traumatic experiences, somatisation, depression, and anxiety,[25–29] especially when compared with their peers.[30]

Nevertheless, to our knowledge no investigation has so far focused on exploring in detail the specific types of childhood traumatic experiences of children of pwHD and their contribution in the development of psychological difficulties in adult age. Therefore, the present study aimed to explore the relationship between childhood trauma and the psychological distress developed during adulthood in individuals who grew up within HD families compared to controls from unaffected HD families. More specifically, the following research questions were addressed:

a) What are the characteristics of childhood traumatic experiences and psychological distress during adulthood in children of pwHD?
b) What is the relationship between childhood traumatic experiences and psychological distress during adulthood children of pwHD?

Methods

Design

To address the research questions above, a retrospective observational design was adopted, whereby self-reported estimates of exposure to childhood trauma were assessed retrospectively

and compared to current levels of psychological distress in adulthood in children of pwHD and matched controls.

Ethical approval

The study was approved by the Institutional Review Board of LIRH Foundation (protocol no 11.221122). Online informed consent was obtained from all participants prior to beginning the data collection.

Participants

Purposive sampling methods were adopted, whereby children of pwHD (HD Family Group) under the care of the Italian League for Research on Huntington's Disease (LIRH) Foundation in Rome were recruited consecutively between December 2022 and December 2023. Inclusion criteria for this group included having been raised within an HD family and being age 18 or older. Convenience sampling was adopted for the Control Group, whereby volunteers were recruited from an age-matched section of the general population. Inclusion criteria for this group were being between age 18 and 35 and having no history of neurodegenerative, neurogenetic, or psychiatric conditions in their parents while growing up.

Measures

Demographic Questionnaire

The demographic questionnaire consisted of questions on participants' age, gender, level of education, and occupation. For the HD Family Group, we also collected information on parents' HD, such as age at disease onset. This information was cross verified with the clinical database of the LIRH Foundation, where previous clinical information of the participants' parents were stored.

Childhood Trauma Questionnaire-Short Form (CTQ-SF)

The CTQ-SF is a questionnaire developed to assess self-reported experiences childhood abuse and neglect in adolescents and adults.[31,32] It consists of 28 questions (25 clinical and five focused on validity) evaluated on a 5-point Likert scale. The 25 clinical items yield a Total Score between 25 and 125, with higher scores indicating higher exposure to childhood trauma. The same items also yield five subscales characterised by different cut-offs: Emotional Abuse (absent = 5-8; mild = 9-12; moderate = 13-15; severe ≥ 16), Physical Abuse (absent = 5-7; mild = 8-9; moderate = 10-12; severe ≥ 13), Sexual Abuse (absent = 5; mild = 6-7; moderate = 8-12; severe ≥ 13), Emotional Neglect (none = 5-9; mild = 10-14; moderate = 15-17; severe ≥ 18), Physical Neglect (none = 5-7; mild = 8-9; moderate = 10-12; severe ≥ 13).[33] The CTQ-SF is one of the most widely adopted measures of childhood trauma and has repeatedly shown good psychometric properties across different populations and languages,[34] including its Italian validation.[35]

Symptom Checklist-90 Revised (SCL-90-R)

The SCL-90-R[36] is a 90-item self-administered questionnaire assessing psychological distress across a wide range of factors, including somatisation, obsessive-compulsive symptoms, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. Items are rated on a 5-point Likert scale and a Global Severity Index (GSI) ranging from 0 to 360 is provided as a measure of overall psychological distress, with higher scores indicating higher levels of distress. The SCL-90-R has consistently demonstrated good psychometric properties across different countries and populations,[37] including Italy.[38.]

Procedure

All the participants completed the questionnaires online via the Questionpro.com platform.

Analysis

Data were analysed using the IBM SPSS Statistics 29 software package. Correlation analyses were carried out to explore the relationship between all variables. Within-group analyses were conducted within the HD Family Group in order to investigate potential differences in UHDRS-TMS and SCL-90-R GSI scores based on genetic status (i.e., positive, negative, unknown).

Between-group analyses were performed to compare the HD Family Group and Control Group on scores of childhood trauma (CTQ-SF total score and subscales) and psychological distress in adulthood (SCL-90-R GSI and subscales). In light of the number of repeated comparisons (16), the Bonferroni correction was applied to control for family-wise error-rate (FWER) and the significance level was therefore adjusted from 0.05 to 0.003.

Results

Demographic and Clinical Characteristics

Fifty adult children of pwHD were initially invited to take part in the study. Of these, 38 eventually agreed to participate, including 15 with an HD positive genetic test, 12 with a negative test, and 11 participants whose genetic status was unknown. The mean age of the HD Family group was 28.7 (SD = 4.9, range = 20-35) and 20 (52.6%) were female. The mean age at HD onset in the affected parent was 9.6 (SD = 7.5, range = 0-25). Thirty-four of the 38 participants in this study were also enrolled in the global observational study, Enroll-HD. All 34 participants were identified as offspring of pwHD. In line with the Enroll-HD data set, we considered the most recent clinic motor assessment to investigate the potential presence of motor symptoms. The motor assessment included in Enroll-HD is the Unified Huntington's Disease Rating Scale - Total Motor Score (UHDRS-TMS), which was performed within a 3-month window from completed questionnaires and independently of the

participants' genetic status. – Thirty-three of these had a UHDRS-TMS lower than 10 and a Diagnostic Confidence Level (DCL) lower than four, while one participant had a UHDRS-TMS score of 13 and DCL of four, which is indicative of early signs of HD.[39] No HD clinical information was available for four participants (one with positive genetic test and three with unknown genetic status). A within-group one-way ANOVA showed significant differences in TMS scores within the HD Family Group ($F_{[2,31]}$ = 3.88, p = 0.031). However, the post-hoc comparisons did not show any significant differences between the three genetic statuses (i.e., positive, negative, unknown). No significant differences were also observed between genetic statuses on levels of psychological difficulties in adulthood (SCL90 GSI; $F_{[2,35]}$ = 1.25, p = ns).

The Control Group consisted of 20 participants with a mean age of 30.4 (SD = 3.9, range = 23-35). Twelve (60%) were female. Demographic and clinical information both the HD Family Group and the Control Group are summarised in Table 1.

Table 1. Sociodemographic data of participants

	HD Family Group	**Control Group**	**UHDRS-TMS N (Mean ± SD; range)**
Positive genetic test	15	--	14 (5.78±2.89; 2-13)
Negative genetic test	12	--	12 (3.58±1.31; 2-6)
Genotype unknown	11	--	8 (3.62 ±2.06; 1-6)
Total sample			34 (4.5±2.44; 1-13)
Gender F (%)	20 (52.6%)	12 (60%)	--
Age mean ± SD (range)	28.7 ± 4.9 (20-35)	30.4 ± 3.9 (23-35)	--

Age mean at the parent's onset ± SD (range)	9.6 ± 7.5 (0-25)	--	--

Note. UHDRS-TMS = Unified Huntington's Disease Rating Scale (UHDRS)-Total Motor Score (TMS); SD = Standard Deviation; F = Female

Between-Group Comparisons

Due to lack of data normality, Mann-Whitney U Tests were carried out to compare the HD Family and Control group across all indices of the CTQ-SF and SCL-90-R questionnaires. These showed significantly higher total childhood traumatic experiences in the HD Family group (U = 119.5, z = -4.284, $p < 0.001$), along with specific higher levels of emotional abuse (U = 189.5, z = -3.245, p = 0.001), physical abuse (U = 230, z = -3.189, p = 0.001), emotional neglect (U = 151, z = -3.793, $p <$ 0.001), and physical neglect (U = 93.5, z = -4.922, $p < 0.001$). Similarly, significantly higher levels of global psychological distress during adulthood were observed in the participants of the HD Family group (U = 197, z = -2.995, p = 0.003), along with specific significant differences in levels of depression (U = 153.5, z = -3.714, $p < 0.001$) and psychoticism (U = 121.5, z = -4.267, $p < 0.001$). Figure 1 illustrates the between-group comparisons on the CTQ-SF (profiles exceeding the clinical cutoff have been indicated with a red line), while Figure 2 shows the comparisons on the SCL-90-R.

[Insert Figure 1 and 2 here]

Correlation Analysis

A Spearman correlation analysis was carried out in the HD Family group to explore the relationship between age at parental onset, the CTQ-SF total score, and all the indices of the SCL-90-R (Table 2). This showed a moderate positive association between total childhood trauma and global psychological distress during adulthood (r_S = 0.467, p = 0.003). Similarly, all the subscales of the CTQ-SF were found to be moderately associated with global psychological distress during adulthood. A

moderate negative association was also found between age at parental onset and total childhood trauma (r_S = -0.418, p = 0.009), while no significant correlation was observed between age at parental onset and total psychological distress during adulthood (r_S = -0.220, p = ns). Of the SCL-90-R subscales, only levels of somatisation (r_S = -0.340, p = 0.037) and anxiety (r_S = -0.365, p = 0.024) were observed to have a weak negative correlation between age at parental onset.

Table 2. Correlation Analysis

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. CTQ_T																	
2. SCL90_T	0.467**																
3. SCL90_Somat	0.318	0.502**															
4. SCL90_OCD	0.456**	0.876**	.336*														
5. SCL90_Sensib	0.434**	0.870**	0.317	0.683**													
6. SCL90_Dep	0.380*	0.939**	0.448**	0.862**	0.779**												
7. SCL90_Anx	0.403*	0.800**	0.342*	0.783**	0.622**	0.789**											
8. SCL90_Host	0.260	0.753**	0.344*	0.622**	0.802**	0.728**	0.595**										
9. SCL90_PhobAnx	0.289	0.675**	0.337*	0.675**	0.533**	0.645**	0.835**	0.437**									
10. SCL90_Paranoid	0.628**	0.820**	0.414**	0.721**	0.781**	0.752**	0.540**	0.601**	0.457**								
11. SCL90_Psicot	0.520**	0.853**	0.623**	0.686**	0.754**	0.756**	0.560**	0.594**	0.560**	0.777**							
12. Age at PO	-0.418**	-0.220	-0.340*	-0.134	-0.186	-0.176	-0.365*	-0.189	-0.273	-0.049	-0.168						
13. CTQ_EmoAbuse	0.819**	0.506**	0.347*	0.526*	0.408*	0.467**	0.493**	0.367*	0.316	0.505**	0.453**	-0.493**					
14. CTQ_PhysAbuse	0.752**	0.223	0.344**	0.188	0.254	0.134	0.292	0.090	0.293	0.286	0.376*	-0.436**	0.559**				
15. CTQ_SexAbuse	0.441**	0.459**	0.442**	0.443**	0.439**	0.432**	0.459**	0.420**	0.429**	0.456**	0.419**	-0.269	0.475**	0.369*			
16. CTQ_EmoNeglect	0.888**	0.510**	0.284	0.466**	0.498**	0.419**	0.302	0.305	0.193	0.642**	0.538**	-0.290	0.621**	0.533**	0.331*		
17 CTQ_PhysNeglect	0.885**	0.411*	0.237	0.429**	0.370*	0.354*	0.403*	0.282	0.306	0.592**	0.444**	-0.451**	0.826**	0.577**	0.418**	0.708**	

Note. * = $p < 0.05$; ** = $p < 0.001$

Regression Analysis

A multiple regression analysis was carried out to test which of the CTQ-SF subscales observed to be significantly higher in the HD Family group (emotional abuse, physical abuse, emotional neglect, and physical neglect) was the best predictor of global psychological distress during adulthood. Bootstrapping based on 1000 samples was adopted to prevent any issues with heteroscedasticity and non-normality of residuals.[40] The regression model was significant ($F_{(4,\ 10.301)}$, $p < 0.001$) and explained 50.1% of the variance in global psychological distress during adulthood. No issues related to multicollinearity were observed (i.e., variance inflation factors below 10 and tolerance above 0.2). Among the CTQ-SF subscales, only emotional abuse was found to be a significant predictor of global psychological distress during adulthood ($b = 0.092$ [0.025, 0.139], $p = 0.011$).

Discussion

The present study aimed to explore the relationship between traumatic experiences and psychological difficulties occurred during adulthood in individuals who grew up within an HD family compared to matched controls. The results, based on 38 individuals from HD families and 20 controls, showed that people who were raised within an HD family report significantly higher levels of traumatic experiences during childhood, particularly around being exposed to emotional abuse (e.g., verbal aggression, humiliation, threatening and degrading behaviours) and physical abuse (e.g., adult physical aggressive behaviours), as well as emotional and physical neglect (e.g., lack of affection, support, sense of belonging, nutrition, safety, and health). This finding appears consistent with previous quantitative and qualitative investigations showing that being raised in an HD family is linked to considerable challenges, including adverse childhood experiences, insecure attachment,

intrafamilial conflicts, lack of communication, reduced general resilience, and increased risk of emotional and physical harm. [20,25,41–44]

In addition, participants within the HD Family group reported significantly higher levels of global psychological distress during adulthood, with depression and psychoticism representing specific issues. These findings are also consistent with previous studies highlighting increased psychological distress in relatives and adult caregivers of pwHD,[19,45,46] with evidence suggesting that approximately one-third to one-half of HD family members may develop affective and 14ehavioural difficulties.[47,48] Indeed, affective issues appear to be particularly relevant for children of people with HD, as emotional abuse emerged in our regression model as the only significant predictor of global psychological distress in adulthood.

We also found a moderate negative association between age at parental HD onset and overall levels of childhood trauma, meaning that the sooner participants were exposed to their parents' condition, the higher their self-reported childhood traumatic experiences. This is consistent with a vast body of literature highlighting how early experiences of parental illness, and particularly of mental illness, can be traumatic for children.[49,50] However, no correlation was found in this study between the age of children at the onset of their parent's HD and global psychological distress in adulthood. Since in our model the overall childhood trauma only explained 50.1% of variance in adulthood psychological distress, highlighting its significant role in shaping long-term mental health outcomes, while indicating that other factors also contribute to the complex and multifactorial nature of psychological difficulties in individuals from HD families. Considering the abovementioned pivotal role played by emotional abuse in our sample, a further explaining factor may be represented by the development of early maladaptive schemas (EMSs) – i.e., dysfunctional and distressing mental representations associated with the unfulfillment of fundamental emotional needs during childhood such as safety, connection, autonomy, competence, and self-expression.[51]

Thus, further studies involving individuals raised within HD families are warranted to explore this aspect more in depth.

Implications for Clinical Practice

Our current retrospective analysis sheds new light into the clinical management of people who are at risk of HD, irrespective of their genetic status. More specifically, the detailed examination of both the nature of traumatic experiences and their long-term psychological impact on adults who grew up within HD families provide further valuable insight into the unique challenges faced by this population. HD is a complex illness characterised by neurological symptoms and significant levels of psychological distress which often follows an unpredictable clinical trajectory, with the nuances of the relationship between psychological distress and biological changes yet to be fully understood. Although exploratory, our findings suggest that renewed attention should be given to the potential adverse childhood experiences, particularly emotional abuse, as well as physical abuse and emotional and physical neglect, as these have been shown to occur more frequently within HD families. In the absence of global consensus on HD psychological care,[5,52] and until additional evidence is accrued, clinicians may refer to psychological guidance and directions for HD, such as the document recently produced in the UK by the British Psychological Society.[9]

Finally, youth organisations (e.g., the Huntington's Disease Youth Organization initiative or NOI Huntington in Italy) may play a key role in increasing awareness and knowledge, promoting specific support programs, and developing a sense of community and comradery among young people who live within an HD family context. Given the clear genetic nature of HD, understanding the complex dynamics of intrafamilial relationships and their impact on psychological distress may help raise awareness around these issues in other genetic conditions. This could be particularly relevant for disorders that are either fully hereditary (e.g., genetic ataxias,[53,54] cystic fibrosis[54]) or characterised

by a minority of familial cases (e.g., amyotrophic lateral sclerosis[55,56]), where this topic is currently still neglected.

Limitations

A number of limitations should be considered along with the present findings. First, while appropriate for an exploratory investigation, the sample size was relatively small. Thus, further studies are needed involving larger, more representative samples of the population of children of pwHD. Secondly, the use of self-report measures in a retrospective design carries inherent limitations, such as memory biases and social desirability. In this regard, the development of prospective longitudinal investigations should be considered. Finally, future research should also aim to account for the wide variability in disease progression within HD families, which this study could not examine.

Conclusion

The findings from our study highlighted that growing up in an HD family may be significantly associated with higher levels of self-reported childhood trauma as well as psychological distress in adulthood, with emotional abuse playing a more significant role in shaping long-term mental health outcomes. Additional studies are warranted to corroborate and expand on the present results by addressing further potential psychological factors as well as to develop targeted interventions to support families affected by the disease and promote long-term mental well-being.

Statements and Declarations

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F.S. is corresponding author and member of JHD editorial board. Other authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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The data supporting the findings of this study are available upon reasonable request to the corresponding author

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Figure legends

Figure 1. Between-Group Comparison on CTQ-SF Scores

Note. * = $p < 0.003$; ** = $p \leq 0.001$. Red lines represent the cutoff for situations requiring further investigation. Error bars represent the standard error.

Figure 2. Between-Group Comparison on SCL-90-R Scores

Note. * = $p < 0.003$; ** = $p \leq 0.001$. Error bars represent the standard error.