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Stigma in Attention Deficit and Hyperactivity Disorder (ADHD) in parents and teachers residing in Porto Metropolitan Area

Inês Teixeira Maia

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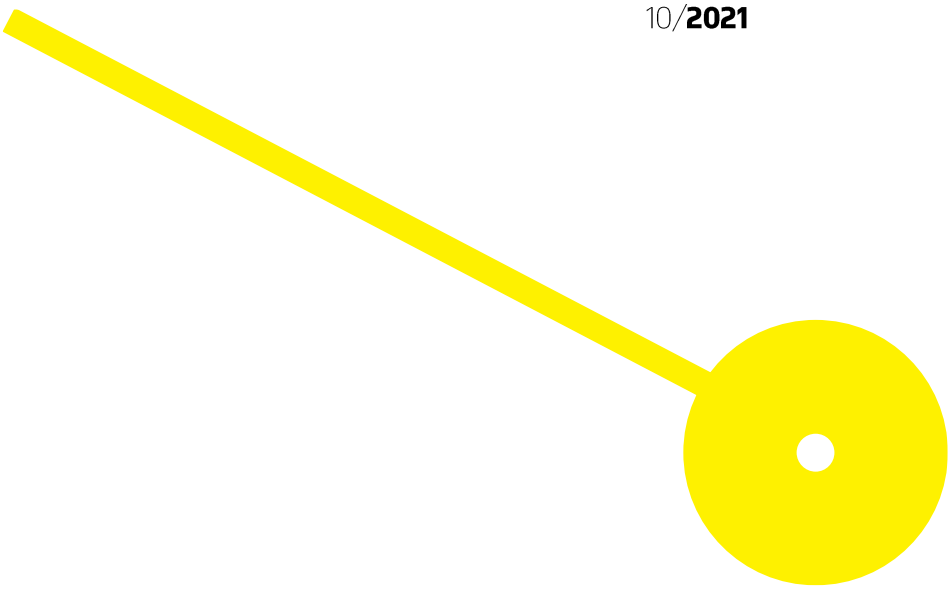

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Stigma in Attention Deficit and Hyperactivity Disorder (ADHD) in parents and teachers residing in Porto Metropolitan Area

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Abstract

Conceptualisation: People with ADHD are often victims of stigma, which later on can translate into implications for the individuals' self-esteem, well-being and quality of life. Due to the contexts in which a child is, parents and teachers assume an increased relevance for diagnosing and treating of ADHD, making it essential to understand their perceptions regarding this disorder.

Aim: To characterise the level of stigma of parents and teachers residing in Porto Metropolitan Area concerning ADHD and understand which factors influence stigma towards people with ADHD.

Methods: A mixed-method study was designed, with the quantitative study carried out using a convenience sample of 190 individuals that answered the ADHD Stigma Questionnaire online, via institutional emails. The qualitative study participants were recruited from the same sample, using non-probabilistic purposive, maximum variation sampling method, which were interviewed via Zoom-Colibri platform about stigma in ADHD. Multiple linear regression and content analysis with an inductive approach with the software WebQDA were used for data analysis.

Results: The level of stigma was, for this sample, above the average ($\bar{x}$= 62,16 ± 10,35). Stigma levels were statistically significant different regarding age (p = 0,01) and level of education (p = 0,03). The qualitative research highlights that some factors can amplify this stigma such as the "label", the knowledge that the person takes medication or goes to the psychiatrist and the type of behaviour exhibited.

Conclusion: It was identified that being older and having a higher level of education seems to function as protective factors for the probability of presenting stigma when measured by the ASQ. By opposition, stigma seems to increase when there are prevalent preconceived notions about the disorder.

Keywords: Attention Deficit and Hyperactivity Disorder (ADHD); stigma; parents; teachers; ADHD Stigma Questionnaire

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1. Conceptualisation

Attention Deficit and Hyperactivity Disorder (ADHD) is one of the most common neurodevelopmental disorders[1–3]. The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), classifies it as a persistent pattern of inattention and/or hyperactivity–impulsivity that interferes with functioning and development in at least two contexts, appearing before the age of 12.[4] ADHD manifests itself in three distinct subtypes: predominantly hyperactive/impulsive, predominantly inattentive or combined – depending on the manifestation of symptoms in each category or both, in the last six months.[4]

ADHD is intrinsically associated with significant adverse results, such as educational problems, difficulties in social relationships with peers and family, increased risky behaviours and comorbid psychiatric disorders.[5–15] Later on, difficulties in finding and maintaining employment and a reduction in salary gains compared to individuals without ADHD translate into implications for the individuals' self-esteem, well-being and quality of life.[7,8,11–13,15] ADHD has a worldwide prevalence of 3% to 7% in children and adolescents[1,16–19] and approximately 2.5% in adults.[1,17,19]In Portugal, although recent reports point to a lack of epidemiological studies in the field, the prevalence rate seems to be similar to those worldwide.[20–22]

Despite the prevalence and the commitment, it entails at social, academic, family and individual levels, available research on Mental Health Literacy (MHL) concerning ADHD has reported that society, particularly teachers and parents, have a poor understanding of the disorder.[7,23–28] The construct of MHL was conceptualised by Jorm et al.[29] and is described as the "knowledge and beliefs about mental disorders which aid their recognition, management or prevention". Research has shown that less literate individuals exhibit more discriminatory behaviour towards individuals with mental disorders and have erroneous beliefs about these disorders.[30–33] Thus, representing a significant public health challenge that needs to be tackled.[17,28] To reinforce the importance of promoting MHL, many studies highlight that although parents have been considered the primary gatekeeper of access to specialised services, they have difficulties recognising ADHD symptoms and usually only seek help when children have difficulties at school or are strongly affected by reports that they receive from the school.[34–39] However, the literature reveals that teachers usually lack knowledge of ADHD, and some demonstrate a harsh view of these students, describing them as problematic, lazy, undisciplined and violent – believing that the symptoms stem from poor parenting.[27,36–38,40,41] Hence, increasing the levels of MHL, especially in this population layer, is an essential step towards reducing stigma and negative assumptions attached to the diagnosis of ADHD.[28]

The concept of stigma was developed in the field of Social Psychology by Goffman[42] and can be described as a pejorative attribute and an attitude of social disapproval towards an individual or a specific group of people with characteristics, beliefs or behaviours that conflict with the sociocultural norm.[43–47] It can manifest itself in three distinct strands: public stigma (characterised by stereotypes, prejudices and

discrimination by society towards an individual with stigmatising characteristics)[48–53]; self-stigma (the individual internalised the stereotypes and negative attitudes maintained by society and applies them to himself)[48–53], and affiliation stigma (analogous to Goffman's courtesy stigma (1963) – involves the experience of stigma by family members or professionals who are related to the stigmatised individual).[51–54] Adverse effects of stigma such as social isolation, low self-esteem, and maladaptive coping strategies are a barrier to seeking treatment, resulting in harmful consequences on the individual's health and well-being.[44,46,50,53]

Far more than any other type of illness, individuals with ADHD may be uniquely vulnerable to stigmatisation.[50,55,56] These behaviours are present in the general population. However, due to the contexts in which a child is, parents and teachers assume an increased relevance for the diagnosis and treatment of ADHD, making it essential to know what role each plays in these children's dynamics. Extensive literature demonstrates that parents have negative perceptions about ADHD, stating that a child is "naughty" and that hyperactivity is "part of the normal developmental process", using the term "boys will be boys" as an excuse for accepting behaviours linked with ADHD.[26,36,57] An investigation has also shown that parents believe their offspring ADHD symptoms interfered with their social functioning, especially with difficulties getting along with peers.[58]

In terms of perceptions of the causes, studies reported that several parents think ADHD resulted from bad parenting practices, such as lack of discipline and overindulgence.[35,59,60] Whereas a high proportion of caregivers attributed their child's ADHD to school failure in disciplining the child and imitating their peers' improper behaviour.[60] Another research also demonstrates that parents, especially fathers, tend to believe that ADHD is caused by psychological factors such as the lack of effort from the child, attributing their high-stress levels to their child's behaviour. [58,60–62] In addition, some studies have noted that some parents consider ADHD a physical illness, caused by neurochemical imbalances and medication usage.[58,60,63] In a similar vein, parents held their own stigmatising beliefs regarding medication, based on the "horror stories" they had witnessed in the media, specifically about "zombielike" effects.[64,65]

The lack of support in the community and the negative views, such as believing that ADHD is not a "real" disease, validate the pressure felt by the parents to be at fault for the child's ADHD.[26,35,60,66,67] Research shows that parents blame themselves for causing their child's condition and, therefore, some withdraw themselves from society and develop negative emotions.[35,60,67] They found that most parents report stigma associated with medication usage and going to psychiatric appointments because they are afraid that the child will be labelled – believing that ADHD is detrimental to their child's academic performance in school and would make them outsiders.[36,61,68,69] Findings from The National Stigma Study-Children[66] suggest that adults prefer social distance from children labelled as "mentally ill" and are more reluctant to have their children interact with a child with ADHD.[53,68,70]

It is worth noting that parents also expressed concerns about society perceiving their children (and themselves) as socially isolated and rejected.[64,71] One study reported that parents disliked school policies that isolated their children from their peers, such as placing their desks away from other students.[64] In this line of thought, since children spend a significant amount of time at school and the classroom contexts often trigger ADHD symptoms when students are required to sit still, be quiet and concentrate, it is essential to understand how teachers perceive and deal with these students. [27,37,43,72]

Eisenberg and Schneider (2007)[73] found that teachers – and parents – had negative perceptions about these students' academic skills, and some studies demonstrate that teachers believe they should be placed in special education.[40,55,73–76] Presented with a diagnosis of ADHD, teachers perceived these students less favourably comparing to others, in the domains of intelligence, personality and behaviour.[74] Similarly, teachers also perceive them as needing extra instructional time and effort and may even consider them more difficult and stressful to teach, whilst others express pessimism about educating a child with ADHD in terms of discipline.[40,55,72,77–79] As stated by Richardson et al.[80] some teachers believed that removing children displaying ADHD symptoms from the classroom was sometimes preferable. According to some research, the mere ADHD label can bring adverse consequences to these children – as it separates them from the rest of the students – and teachers believe they may use it as an excuse.[40,75,78,81,82] Withal found that teachers' perception of the incidence of ADHD in their classrooms is considerably higher than the actual prevalence rate.[28,37,83]

Chi and Hinshaw (2002)[84] found that these negative perceptions affect the interactions of teachers and parents with these children, influencing their behaviour and academic success.[40,72] Moreover, their perceptions regarding ADHD can also affect and model how other children perceive and interact with those with ADHD.[27,72,75,85] The child may experience a sense of inadequacy or low self-esteem based on the belief that they cannot succeed at a high level.[82,86] Moreover, if internalised, stigma can instigate a self-fulfilling prophecy, resulting in poorer behavioural and socioemotional outcomes.[82,86]

Given these perceptions – and the consequences that they may have – combating stigma and creating public awareness is fundamental and can be done through education (presenting factual information about the stigmatised condition to correct false information or contradict myths, beliefs and negative attitudes) and through contact (the knowledge about ADHD increases with the exposure to this disorder).[37,49,53,87–90]

As far as we are aware, no studies in Portugal assess stigma perception concerning ADHD in this population layer. Hence, it becomes pertinent to develop work in this area since these groups are at the frontline in providing care and signalling children with or at risk of developing ADHD. To address this knowledge gap, this study has two main goals: 1) to characterise the level of stigma concerning ADHD of parents and teachers residing in Porto Metropolitan Area (PMA) and to determine the variables that may

influence this construct; 2) to understand the factors that influence the level of stigma towards people with ADHD.

2. Methods

In order to achieve the objectives, a mixed-method explanatory sequential study[91–94] was designed. In this type of research design, a quantitative phase[95,96] is carried out. Its data will be the basis for the qualitative phase[97–100], allowing for breadth and depth of understanding regarding the phenomena, in this case, stigma perceptions about ADHD.[91,94,101] Data analysis will be performed separately, and the results will be combined in the data interpretation stage.[91,94]

2.1 Study Participants

We used a non-probabilistic sampling method, by convenience[102,103], due to easy access to adults known to the researchers and adults that work, both teachers, non-teaching staff and guardians, at public, private and superior schools, through a protocol previously established between the institutions. Parents – with children between 11 to 17 years of age – and teachers – active and teaching from grade 5 or above, with Portuguese nationality and residency in PMA, were targeted for data collection. Individuals with communication or cognitive deficits that prevent them from understanding the questions and/or with a declared pathology, such as other neurodevelopmental and mental disorders, including autism spectrum disorder (ASD) and schizophrenia, were excluded from the study.

The qualitative study was also recruited from the same sample, using non-probabilistic purposive, maximum variation sampling method[104,105], and considering the score obtained in the ADHD Stigma Questionnaire (ASQ), which indicates the perception of stigma of the participants, finding cases that vary from each other as much as possible along these dimensions.

2.2 Data Collection

Sociodemographic data, consisting of 15 questions to collect sociodemographic data (such as age, education level, occupation) and the level of contact with individuals with ADHD (such as knowing someone with ADHD, relationship with him/her and regularity of contact) to characterise participants.

Adult ADHD Self-Report Scale V1.1 Screener (ASRS V1.1 Screener): The ASRS V1.1 Screener is a widely used screening instrument for identifying ADHD in adults.[106–108] The scale is a six-item adaptation from the 18-item original ASRS and integrates questions to assess the frequency of ADHD symptoms in individuals 18 years of age or older in the last six months.[106–108] Each question was rated on a five-point Likert scale with answers ranging from Never (0) to Very Often (4).[106–109] Each question is converted into a dichotomous scale regarding the presence or absence of symptoms compatible with ADHD.[106–109] The

final score is calculated based on the sum of the questions, using a total score of ≥4 out of 6 points as the threshold to indicate a positive screening test consistent with ADHD in adulthood.[106–109]

The developers of the ASRS Screener reported moderate sensitivity (68.7%), along with excellent specificity (99.5%) and total classification accuracy (97.9%) when assessing symptoms among a community sample.[106,107,109] Although this instrument does not present a psychometric assessment of the Portuguese version, similar values are assumed.[108] Even though there is already a version based on DSM-5[110] to recognise symptoms of ADHD, it is not validated for Portugal, so the version based on the DSM-IV criteria was used.[108]

ADHD Stigma Questionnaire (ASQ): The ASQ is a 26-item adaptation of the 40-item HIV Stigma Scale, developed by Berger et al.[111], and aims to measure perceptions of public stigma regarding ADHD.[112] As in the original scale, each question was rated on a four-point Likert scale with answers ranging from Strongly Disagree (1) to Strongly Agree (4), with higher scores indicating higher stigma perceptions in a total of 104 points.[112]

The ASQ has three subscales: Disclosure Concerns, Negative Self Image and Concerns with Public Attitudes.[112] These subscales demonstrate excellent internal consistency reliability of $\alpha = 0.83$, $\alpha = 0.81$ and $\alpha = 0.87$, respectively, with value of $\alpha = 0.93$ for the overall scale.[112] The original instrument is only validated for a population aged between 11 and 19.[112] However, the scale is currently being validated for the general Portuguese population, and its preliminary validation obtained an overall internal consistency value of α =0,93.[113]

Semi-structured Interview: For the qualitative aspect of the study, a semi-structured interview was designed due to its versatility and flexibility.[114,115] The semi-structured guide consists of two levels of questions: the main questions covering the focal content of the research objective and the follow-up questions that allow the interviewer to improvise according to the answers given by the participants.[114–117] This type of questioning provides a detailed and in-depth description of the participants' thoughts, experiences, perceptions and opinions.[114,115,117] The guide for the interview consisted of one question to collect sociodemographic data, one question regarding contact with individuals with ADHD and six open-ended questions related to stigma in ADHD: such as attitudes of prejudice or stigma towards ADHD, their negative effects and factors that may originate prejudice (use of medication, disease label, psychiatric appointments). Based on the literature, 13 interviews were carried out to achieve high degrees of saturation and provide consistent results.[118]

2.3 Procedures

The study was approved by the School of Health of Polytechnic Institute of Porto's ethics committee in February 2021 (code number CE0063A). All participants had to accept an informed consent form based on the Helsinki declaration to participate in the study and authorise the audio interview recordings.[119,120] An alphanumeric code was assigned to every participant to guarantee anonymity throughout the study.

Contact was made via e-mail with individuals known to the researchers and the educational institutions to explain the study´s specific goals and obtain authorisation by the school board to collect data. Afterwards, invitations to participate in the study were sent using the institutional emails, and those interested and meeting the eligibility criteria were selected. Self-report questionnaires were filled out using Google Forms – average response time being 15 minutes – and data was collected from March to June 2021.

Regarding the qualitative phase, a literature review was carried out to establish topics to guide the semi-structured interview to elicit perceptions, opinions, and commentaries on several topics regarding stigma in ADHD. The interview guide was reviewed by an expert panel – composed of two health professionals with experience in neurodevelopmental disorders and qualitative studies – to assess the clarity of the questions. A preliminary interview was conducted with two individuals to understand if the questions were understood and the information obtained responded to the research objectives. Using the method of spoken reflection[121,122], it was noted that modifying some of the questions was necessary to make them more intelligible; this process allowed us to obtain the final interview script. All interviews were conducted by the principal investigator and scheduled at a time convenient to the participants, using the Zoom-Colibri platform – with audio recorded – due to the epidemiological situation with COVID-19 from June to July 2021. The average duration of each interview was 40 minutes.

2.4 Data Analysis

The socio-demographic characteristics were described employing descriptive statistics, including absolute and relative frequencies for categorical variables and measures of central tendency (mean) and dispersion (standard deviation, maximum and minimum) for quantitative variables.[123,124]

The assumptions of normality were verified using the Kolmogorov-Smirnov test.[124] Since the variables did not follow a normal distribution, non-parametric tests were used (Mann-Whitney U test, Kruskal-Wallis H test and Spearman's Rank Correlation Coefficient) to evaluate the relation between the ASQ score and the variables under study. Finally, multiple linear regression with stepwise model selection was used to understand the possible predictors of stigma.[124]

Regarding the qualitative content analysis, the author transcribed the interviews verbatim, and an inductive approach with the software WebQDA was used.[125,126] The content analysis involved three distinct phases: preparation, organisation and reporting.[127–130] The preparation phase consists of

immersing in the data and obtaining a sense of the whole.[127–130] The organisation phase, also known as the data-driven approach, includes open coding and creating categories during the process (a posteriori) since information emerged from the interviews that wasn't reported in the literature, providing a more holistic analysis of the data.[126–130] Subsequently, the codes were organised into categories based on the similarities, with the categories being explored in the interpretative task.[100,128,129]

In establishing trustworthiness, Lincoln and Guba[131] created stringent criteria in qualitative research, known as credibility, reliability, confirmability and transferability.[129,132] Besides, peer review and triangulation was performed using three researchers to analyse the collected data and comprehensively understand the data.[133–135]

3. Results

3.1. Quantitative Data

The sample was composed of 190 participants, of whom 93 were parents (48,90%) and 97 school teachers (51,10%). Of the total of the sample, 147 (77,40%) were female and 43 (22,60%) male, aged between 24 and 64 years (with an average of 44,42 years of age). Further detail about participants' characteristics is provided in Table 1.

Table 1– *Survey participants characteristics*

		Absolute frequency n (%)	Minimum	Maximum	Mean ($\bar{x}$)	Standard Deviation (σ)
Age	-	190	24	64	44,42	8,23
Study Group	Parents	93 (48,90)	-	-	-	-
	Teachers	97 (51,10)	-	-	-	-
Gender	Male	43 (22,60)	-	-	-	-
	Female	147 (77,40)	-	-	-	-
Marital Status	Single	28 (14,70)	-	-	-	-
	Married	137 (72,10)	-	-	-	-
	Separated / Divorced	21 (11,10)	-	-	-	-
	Widower	4 (2,10)	-	-	-	-
Education Level	1st cycle	2 (1,10)	-	-	-	-
	2nd cycle	3 (1,60)	-	-	-	-
	3rd cycle	11 (5,80)	-	-	-	-
	High School	33 (17,40)	-	-	-	-
	Bachelor's Degree	84 (44,20)	-	-	-	-
	Master's Degree	46 (24,20)	-	-	-	-
	Doctorate (PhD)	11 (5,80)	-	-	-	-
Work status	Employed	177 (93,20)	-	-	-	-
	Unemployed	13 (6,80)	-	-	-	-

Table 1– Survey participants characteristics (continue)

		Absolute frequency n (%)	Minimum	Maximum	Mean ($\bar{x}$)	Standard Deviation (σ)
Health problems	ADHD	1 (0,50)	–	–	–	–
	Other(s)	32 (16,80)	–	–	–	–
	None	157 (82,60)	–	–	–	–
Knowing someone with ADHD	Yes	92 (48,40)	–	–	–	–
	No	98 (51,60)	–	–	–	–
Regularity of contact with ADHD*	Daily	38 (20,00)	–	–	–	–
	Weekly/Monthly	22 (11,60)	–	–	–	–
	Occasionally/ Never	32 (16,80)	–	–	–	–
Relationship with the person with ADHD*	Family/Friend	33 (17,40)	–	–	–	–
	Acquainted	59 (31,10)	–	–	–	–
ADHD symptoms (ASRS)	Unlikely to have ADHD	168 (88,40)	–	–	–	–
	Likely to have ADHD	22 (11,60)	–	–	–	–

*N = 92

According to the ASQ, it was possible to observe that there are no statistically significant differences in the level of stigma between the parents and teachers' group, socio-demographic variables, knowing someone with ADHD or presenting ADHD symptoms (Table 2). However, a higher level of stigma was found in people who contact with ADHD on a daily ($\bar{x}$= 64,21±12,15) and weekly/monthly basis ($\bar{x}$= 63,68±7,90) relatively to those who occasionally/never contact with it ($\bar{x}$= 60,41±11,50). In addition, stigma levels were higher in people who had family members/friends with ADHD ($\bar{x}$= 64,33±9,68) than those who were just acquainted ($\bar{x}$= 61,88±10,12) (Table 2).

Table 2– Differences between the collected variables in relation to stigma

		ASQ mean (σ)	Spearman Correlation (ρ)	p-value
ASQ		62,16 (10,35)	–	–
Age		–	-0,85	0,24
Study Group	Parents	62,17 (10,86)	–	0,65
	Teachers	61,81 (9,94)	–	
Gender	Male	60,07 (9,83)	–	0,17
	Female	62,55 (10,49)	–	
Marital Status	Single	60,25 (12,42)	–	0,60
	Married	62,04 (10,21)	–	
	Separated/Divorced	63,00 (7,52)	–	
	Widower	67,00 (14,83)	–	

Table 2– Differences between the collected variables in relation to stigma (continue)

		ASQ mean (σ)	Spearman Correlation (ρ)	p-value
Education Level	1st cycle	58,00 (9,90)	-	0,07
	2nd cycle	70,33 (13,58)	-	
	3rd cycle	69,18 (6,54)	-	
	High School	60,64 (11,37)	-	
	Bachelor's Degree	62,73 (10,39)	-	
	Master's Degree	60,11 (10,02)	-	
	Doctorate (PhD)	59,55 (8,26)	-	
Work Status	Employed	62,08 (10,51)	-	0,80
	Unemployed	60,77 (8,49)	-	
Health problems	ADHD	40,00 (-)	-	0,09
	Other(s)	64,31 (13,54)	-	
	None	61,66 (9,47)	-	
Knowing someone with ADHD	Yes	62,76 (11,07)	-	0,37
	No	61,27 (9,68)	-	
Regularity of contact with ADHD*	Daily	64,21 (12,15)	-	0,34
	Weekly/Monthly	63,68 (7,90)	-	
	Occasionally/Never	60,41 (11,50)	-	
Relationship with the person with ADHD*	Family/Friend	64,33 (9,68)	-	0,30
	Acquainted	61,88 (10,12)	-	
ADHD symptoms (ASRS)	Unlikely to have ADHD	61,79 (10,26)	-	0,40
	Likely to have ADHD	63,55 (11,38)	-	

*N: 92

The analysis of the stepwise model (Durbin-Watson: d=1,85) resulting from multiple linear regression shows that, when measured with the ASQ, the individual's age and education level are predictors of stigma in this sample (Table 3). Model 2, which includes the two variables described, is the one that best explains the stigma values, with a correlation coefficient, R=0.22, and a determination coefficient, R2=0.05. Thus, being older ($\beta_{younger}$= -0,21; p-value= 0,03) and have a higher education ($\beta_{lower\ education}$= -1,80; p-value= 0,01) seems to function as protective factors for the probability of presenting stigma, when measured by the ASQ.

Table 3– Results from multiple regression analysis predicting stigma

Model[a]		Non-standardized coefficients		P- value	95,0% Confidence Interval for B		VIF
		B	Error Error		Lower Limit	Upper Limit	
1	(Constant)	69,25	3,59	0,00	62,16	76,33	
	Education Level	-1,41	0,70	0,05	-2,79	-0,03	1,00
2	(Constant)	80,36	6,15	0,00	68,22	92,49	
	Education Level	-1,80	0,72	0,01	-3,21	-0,39	1,07
	Age (years)	-0,21	0,09	0,03	-0,39	-0,02	1,07

3.2. Qualitative Data

The sample was composed of 13 participants, of whom eight were parents (61,54%) and five school teachers (38,46%). All participants had Bachelors' or Master's Degree, except P2 and P8 who had: High School and thi[rd] cycle, respectively. Further detail is provided in Table 4.

***Table 4**–Participants characteristics*

Parents						Teacher's					
ID	**Gender**	**Age**	**Knowing someone with ADHD**	**ASRS score**	**ASQ score**	**ID**	**Gender**	**Age**	**Knowing someone with ADHD**	**ASRS score**	**ASQ score**
P1	F	47	Yes	0	61	**T1**	F	54	Yes	4	43
P2	F	46	Yes	1	69	**T2***	F	56	Yes	2	76
P3	F	50	Yes	1	30	**T3**	F	33	Yes	3	49
P4	F	42	No	3	47	**T4**	F	45	Yes	0	60
P5	F	48	Yes	0	87	**T5**	M	49	No	2	75
P6	F	41	Yes	0	57						
P7*	F	56	Yes	6	47						
P8*	F	51	Yes	3	79						

Label: F– Female; M– Male; *–has a kid with ADHD

From the content analysis of the interviews, three categories emerged: 1) ADHD literacy and beliefs, 2) Stigma in ADHD, and 3) Environment and importance of literacy (Table 5). Some transcript excerpts referring to the categories are presented in Appendix A – table 6.

***Table 5**– Categories characteristics*

Categories	Occurrences (n)	Occurrences (%)	Interviews (n)	Interviews (%)
1. ADHD Literacy and Beliefs	95	19,92%	13	100%
2. Stigma in ADHD	311	65,20%	13	100%
3. Environment and importance of literacy	71	14,88%	13	100%

3.2.1 ADHD Literacy and Beliefs

This category corresponds to the participants' prior knowledge regarding ADHD. It also includes the participants' perception of society's knowledge about the disorder and the misconceptions concerning the various components interrelated to ADHD, particularly in the medical field.

Most participants were aware of this disorder, naming some characteristics to describe it"(...) he cannot concentrate, he is very restless, he is never quiet"[P8]. Despite identifying the most visible symptoms, most of them considered that the manifestations vary depending on the type of ADHD and the child's personality "(...) there are children with ADHD who have more the issue of movement and intensity of agitation. Others have more of this attention deficit disorder"[P3]; "(...) then, there is also the personality of the child itself which will also influence certain types of behaviour"[P7].

Despite this knowledge on the part of the participants, most of them believe that society, in general, is not literate when it comes to the disorder "I think, quite honestly, that the general population doesn't know that hyperactivity exists as a disease (...) we talk a lot about drug addiction(...), but we don't talk about hyperactivity"[P4]. Perhaps due to the existence of low literacy, some participants show difficulties in believing ADHD diagnoses "(...) and there are also bad diagnoses of hyperactivity. You can't look and diagnose everything because you have this behaviour"[P2]; "It is very common. You go to the psychologist and it is immediately 'Hyperactivity and attention deficit', I mean. What do I think this leads to? Sometimes a person looking at determining diagnosis and saying: but is it really?"[T1]. Others even consider that there are gaps in the competence of the various medical specialities regarding the referral to the reference services and the prescription of medication: "(...) family doctors end up having extensive knowledge about many things (...), but they end up having little knowledge about particular things like this, so maybe they end up not knowing how to give the necessary response and then maybe they also have difficulty in referring them to the correct speciality"[T3]; "I think this is done a bit lightly, the issue of Ritalin"[T1].

3.2.2 Stigma in ADHD

This category corresponds to the participants' perception of the presence and manifestation of stigma in ADHD, factors that may influence it, and ways to combat such stigma.

Most participants mentioned that, in general, society is prejudiced against difference "Unfortunately with almost everything (pause). People are very prejudiced (...) just being different is already a reason for prejudice"[T5]. With regard to the stigma in ADHD, the same perception was held, with the participants resorting to describing some stigmatising behaviours and attitudes to alert to the issue, namely attitudes of education professionals and parents of other children: "[the stigma] is increasingly evident (...) especially in children (...) we talked about earlier in the school part where these children suffer from this stigma."[P5]; "(...) I have heard from several teachers: 'Now I've got that guy with hyperactivity, now he's going to ruin the class, he's going to disorientate the class"[P8]; "The children's parents themselves (...) have that kind of attitude 'X did that, stay away from him, don't deal with him, he's not a good influence on you"[P3]. Also, parents considered that the teacher's age seems to be associated with stigmatising behaviour "(...) it depends a lot on the age factor of who is dealing with the kids. The older teachers 'Oh man, the kids (pause)

I'm not even going to worry about that much'. The younger teachers (...) already have a more particularised care" [P3].

According to the participants, stigmatising attitudes also arise from peers, as one of the teachers and one of the parents interviewed testified: "When we divide the class in two and there is a captain in each team and they have to choose. Maybe they are the ones who always stay at the end"[T3];"Even the kids themselves (...) they don't want to deal with those kids [with ADHD] because they have that behaviour 'Look, I am not putting up with you, stay there' and they end up putting them aside"[P2].

Most participants consider ADHD to be a stigmatised health condition, identifying some factors that can amplify this stigma such as the "label", the knowledge that the person takes medication or goes to the psychiatrist: "(...) and the bad thing is the child being labelled, because then the adult doesn't make any effort to dismantle that label"[P5]; "(...) I think that even so a child who doesn't take any medication is capable of being less discriminated against than one who does"[T3]; "(...) society still reacts negatively when talking about psychiatrists (...) I think that maybe there is still the (...) it is not rejection, but a repulsion"[T4]. Also, the realisation that the child has special education support may be a reason to trigger the appearance of stigmatising attitudes: "(...) [when the special education teacher removes the child from the room] for the time being, it separates them from the class. In a certain way they are already creating the discriminatory factor, it is latent there (...) He was separated"[P3].

However, the participants consider that it is the type of behaviour exhibited by the child that is the primary determinant for the emergence of stigma: "Yes, there ends up being stigma (...) of course, it also depends on the degree of hyperactivity and how this hyperactivity is expressed"[T2]; "If we talk in general, there is, especially when they are hyperactive in which there is a constant difficulty in sitting in the room (...) In the case of attention deficit, who ends up being harmed is the child itself and then it goes unnoticed"[P1].

As a consequence of the stigma suffered, adverse effects will manifest themselves in the stigmatised individual, such as low confidence, association with other comorbidities, the emergence of risk behaviours and difficulty adapting to the surrounding environment, which most participants mentioned: "That self-confidence that they should have (...) that ability to go forward and react, he may not have, because he was always called attention, he was always criticised"[T5]; "Those kids end up (...) having other types of pathologies. Or because they are extremely anxious, or because they are aggressive, others may have some kind of depression"[T2]; "(...) they transfer this to impulsive and aggressive behaviours many times or self-mutilation (...) or very young consumption"[P6]; "Difficulty in finding a certain type of job (...) in children some difficulty adapting at school"[T3]. In addition to the consequences for the individual with ADHD, the family is also affected "I [mother] was traumatised, I felt the stigma, I would go to school meetings and I was already afraid of who would be there to approach me"[P7].

Although the generality of the sample considered that stigma in ADHD exists and is an inappropriate attitude, with harmful consequences, some participants consider that prejudice does not exist or, if it does, it is caused by the attitudes of people with ADHD themselves or the people who deal with them: "When I saw it [the title of the study], I thought it was exaggerated (...) because I don't think that stigma exists"[T1]; "(...) there is a certain student who doesn't get the attention he wanted at home, so he wants to get attention and then he adopts behaviours that he shouldn't"[T1]; "They [the society] blame the parents 'they talk as if they were babies; that's a lot of pampering; they set few limits and the child abuses; he has no education"[P3]; "(...) if the teacher's focus is the child with hyperactivity, then quite honestly, it will also harm the development of the others because he [teacher] won't be speaking in the same way, (...) and, therefore, the others understood the subject the first time and will have to listen to the others 9 times per supplement, that's delay"[P4].

Many participants associate stigma with lack of knowledge, identifying ways in which they could combat it: "It also comes from ignorance, and when they don't know, the first reaction is not wanting to know, it is pushing them away, it is stigmatising"[P6]; "(...) the main problem here will be to educate our society (...) to alert and to raise awareness and inform other people (...) in the classroom, the teacher has to have a different attitude and set an example and teach the kids how to treat their peer? So that there are no bad attitudes"[T4]; "Those who come with the child from a young age, from pre-school, are already used to the presence of this kids, they are already used to certain types of behaviour and accept it more easily"[P1].

3.2.3 Environment and importance of literacy

This category corresponds to the participants' perception of the influence of the environment on different aspects of the individual's with ADHD life. It also talks about the importance of society's education and the change that greater literacy can bring regarding accepting and integrating people with ADHD.

In general, participants mentioned that there is little support available for individuals with ADHD "(...) we don't have big institutions and we don't have, in terms of the government, support for this type of therapy and things that these children need"[P2], stressing that the environment plays a significant role in several aspects of these individuals lives, namely in personal development and in adopted behaviours: "(...) if they have a community that accepts them and understands them (...) this will be beneficial for their development and the development of their own personality"[T4]; "(...) it has to do with the stimuli that he receives or not, with the monitoring that he has or not. These are all factors that will define the child's behaviour"[P5]. Justifying that children learn by imitation, some participants attributed significance to the family environment and parental education "(...) many of the behaviours we see, later on, he/she has

probably seen it replicated by another classmate, by the student him/herself, in a comment by the father or the mother (...) of course, later on, they will end up replicating what they have seen"[P1].

Another aspect that participants refer to as relevant in the positive development process of people with ADHD is the supportive attitudes of society, concerning the early signalling of cases and the search for pharmacological therapy: "In the middle of the first period, she [the teacher] called me and said: Mother, if he were my son, I would take him to a psychiatrist, because I think that Z.M., if he is not, he is very close to hyperactivity"[P7]; "Parents even put a little pressure on child psychiatrists to prescribe medication (...) even teachers themselves, sometimes, when referring the student to child psychiatry, are unconsciously waiting for a medication that will keep them quieter, more concentrated"[T2]. This support, ultimately, helps people with ADHD to find and develop strategies to help deal with the disorder "M.L. [daughter] is an occupational therapist, and it helped a lot (...) because she gave him strategies and helped him find new ones"[P7].

Generally, participants agreed that the way to facilitate interaction and integration into society for individuals with ADHD is through increased literacy: "R. [son] himself used to say, 'mum, today D. [child with ADHD] hit us and ran away, but then we went to see him, and he calmed down, and we all played again'. So, they knew that if they gave him a bit of time and space, things would go well, all because of the training the teacher gave them" [P6]. Furthermore, some participants referred that this knowledge facilitates the design of strategies that help the integration and success in the school environment of these children "Using all those measures that we know to try to minimise the problems arising in terms of learning" [T1].

As a consequence of greater literacy and a change in behaviour on the part of society, positive results will arise, according to the interviewees' perspective, at various levels, such as in self-esteem, school success and the development of self-control strategies in the person with ADHD: "(...) create a good self-esteem in the child which is essential because if they have a good self-esteem, they can also have a totally different path and end up liking school more" [P8]; "The children, all of them, had excellent grades, were excellent students, had a spectacular school path (...) because the teachers always made a more intensive investment with these children and believed in them" [P3]; "(...) the classmates will start to use these strategies. Moreover, that even helps the child [with ADHD] improve because it gives an incentive like 'Ok, if I stay here quiet, my classmates will even let me play ball with them', and maybe he will have a little bit of self-control [P2].

4. Discussion

This study aimed to characterise the level of stigma concerning ADHD of parents and teachers residing in PMA and understand the factors that influence the level of stigma towards people with ADHD. According to the results, it shows to be a positive contribution to this issue.

Concerning the characterisation of the levels of stigma in parents and teachers, although the ASQ scale has no cut-off point[112], it was possible to say that the sample shows stigma values above the mean score, which, although not very high, indicate a tendency towards a moderate stigma. These data seem to confirm the results obtained in a study in Korea, which used the same scale and also obtained stigma values above the mean ($\bar{x}$=70,90), reporting that stigma appears in childhood and continues into adulthood.[136] However, the sample of that study was extended to the general population and the sociocultural reality of Asian and European countries is different.[137] This means that the similarity between the results should be considered with some caution. Nevertheless, according to a study by Masuch et al.[138], developed with the British population, society still believes that ADHD is a consequence of bad parenting, presenting difficulties in accepting it as a disorder. Another hypothesis may be that these preconceived ideas that what these individuals need are parental education and social rules translate into stigmatising behaviours and attitudes that may condition the amount and form of interaction with people with ADHD, which is in line with the content found in the interviews of this study.

Regarding parental stigma, the literature found that one in five parents of children without ADHD reported being unwilling to have their children in a class with other children with ADHD or for their child to be a friend to a child with ADHD.[139] Another study reported that the desire to withdraw from children exhibiting ADHD behaviours in a play environment appeared to form within 30 minutes of contact.[53]

Despite the scarcity of studies evaluating the level of stigma of parents and teachers concerning ADHD, some have reported that these two groups have insufficient knowledge about the disorder and that this low literacy was intrinsically linked to the presence of stigmatising behaviour.[27,28,30]

Low literacy may also influence the perception of the disorder to the extent that people know the "label" or typical ADHD symptoms and associate them with negative perceptions.[30,140,141] This is supported by the literature which reported that the label, although it may aid understanding and access to support, had several negative aspects, as it increased the risk of being separated from society and becoming a victim of public stigma, with peers interpreting them as "stupid".[50,55,81] However, some studies have reported that the level of disapproval of these individuals could be more related to the type of behaviour exhibited and not necessarily to the label.[50,55,142] Meza et al.[50] suggested that the most negative attitudes seemed to be interconnected with the stigma associated with individuals manifesting active symptoms of ADHD. The perception that the behaviour of the individual with ADHD was a threat elicited stigma from peers.[55]

Also, knowing that the individual was seeking psychiatric help and taking medication for ADHD seemed, in individuals with lower literacy,[143,144] to also trigger stigma, as verbalised by the interviewees. This belief was supported by the literature which reported that parents of children with ADHD often did not seek help due to the stigma associated with going to the psychiatrist, with society rejecting or avoiding these people for fear of their illness.[68,145] Anand et al.[36] confirmed that there is a stigma regarding seeking

psychiatric help and this causes a delay from the onset of symptoms to contact with the specialised professional, delaying diagnosis and treatment. In contrast, regarding pharmacological therapy, the literature showed that people believed that doctors overmedicate children with behavioural problems.[64] Society also seemed to attribute significant risks to medication and expressed concerns about the immediate and future side effects of taking it.[65,146]

In this study, there was a significant correlation between ASQ score and age, with older individuals exhibiting lower levels of stigma. In the literature, it was found that some studies indicated that, although weak, there was a negative correlation between age and the level of stigma, that is, increasing age co-occurred with a decrease in the level of stigma.[147] Younger individuals expressed more stigmatising attitudes towards social functioning and medication misuse choosing negative adjectives to characterise these people.[148] In contrast, older individuals seemed to have a greater variety of life experiences, which led them to be more accepting of differences and more tolerant towards mental illness.[147,149] These perceptions may justify, in part, the results obtained in this study, to the extent that older individuals possibly had more opportunity for contact with individuals with ADHD, either in the family or school context, which allowed them to deconstruct some myths and, consequently, decrease stigmatising attitudes. On the other hand, other studies showed that older individuals showed more stigmatising attitudes towards the ability of individuals to take responsibility and had a strong belief that the problem is "abnormal", expressing feelings of social withdrawal.[148,150] Nonetheless, and despite the controversy that emerged from the various studies, in general, the interviews in the present study did not show that there was a difference in the discourses of older and younger people regarding stigma towards people with ADHD. One of the reasons that may underlie this discrepancy is the fact that, when selecting the qualitative sample from the scores obtained in the ASQ, we ended up obtaining only participants mostly aged between 40 and 50 years, i.e., with a relatively homogeneous age range, which could have led to the dissipation of the differences found in the quantitative sample, which had a much more comprehensive age range.

Although not significant, there was also a correlation between the ASQ score and gender in this study, with women tending to have higher levels of stigma. A study that focused on stigma in mental disorders, although not directed to ADHD, reported that women showed more stigma, exhibiting social withdrawal behaviours towards individuals with mental illness.[149] On the other hand, another study argued that men exhibited more stigmatising attitudes, voicing objections to ADHD individuals being in jobs with increased responsibility, as well as doubts regarding the existence of ADHD as an illness and conventional treatment.[148] Other studies corroborated this position, stating that women had a lower belief that the problem is "abnormal", being less susceptible to stigmatisation and exclusion of these individuals.[150,151] Given these results, the existence of a relationship between the presence of stigma and gender still seems to be an issue under discussion.

Unlike age and gender, the role of education level was less controversial. The present study showed a significant correlation between ASQ score and education, with individuals with higher levels of education exhibiting less stigma. These results were corroborated by the findings of the qualitative component, which showed that individuals with higher educational levels had, in general, more knowledge about the disorder and typical characteristics, which may justify the lower negative attitudes towards these individuals. These results were in line with the literature, which reported that individuals with higher levels of education were more likely to have heard of ADHD and to be able to identify it and, consequently, demonstrate more positive attitudes towards these individuals.[60,147] This showed that individuals with more education tended to have lower levels of stigma as well as a lower likelihood of seeking to distance themselves from people with mental health problems.[152–154]

Although not significant, in this study, there was a tendency towards a higher level of stigma in people with ADHD symptomatology and in individuals who had contact with people with ADHD. The interviews, especially those of participants who had children with ADHD, corroborated these results as the participants presented a more detailed view of moments where they felt the stigma by society, especially in school context and the consequences that had in their lives, such as fear and stress when engaging in these situations. The experience of these stigmatising situations can lead to an internalisation of this stigma and causing them to exhibit higher levels of stigma. The tendency for this type of reaction was supported by the literature that recognised that, regardless of having a formal diagnosis, individuals with ADHD symptoms were stereotyped by their peers as "stupid".[50] Thus, if others stigmatised the person, he or she could experience self-stigma, reinforcing the experience of being "different".[155] In turn, according to Chang et al.[54], people who come into contact with individuals with ADHD have greater affiliation stigma through the perception and internalisation of public stigma about the person with ADHD. The same study reported that mothers of children with ADHD generally had more opportunities to interact with parents of other children, for example in the school environment, which is the main source of stigma, which led to an increase in the caregiver's psychological suffering.[54] Additionally, studies conducted with parents of children with ADHD showed that affiliation stigma was directly associated with higher levels of stress in parents.[62,156] In general, these factors contributed to a negative impact on the well-being of families and, consequently, in their children with ADHD, which can affect their personal development.

The awareness that exposure to stigmatising behaviours entailed negative consequences in individuals with ADHD was highly explored by the various interviewees, mentioning that they had a significant impact on well-being and quality of life. Although it is still an under-researched topic, these results are supported by the literature which reported that experiencing stigma at any level had repercussions on social relationships, psychological and behavioural responses, worsening the individuals' health status.[157] Thus, it was mentioned in the interviews that the way to combat stigma was through access to information and contact with the disorder. These results were also supported by the

literature, which highlights that presenting factual information about the disorder helped to correct misconceptions and contradict negative beliefs, decreasing public stigma and self-stigma.[158,159] Furthermore, contact-based education has shown positive results, with the ability to reduce prejudiced attitudes and improve the social acceptance of people with mental illness in different target groups and sectors.[49,159,160]

This study, like any other, had some limitations, the first being the representativeness of the sample, which shows a large proportion of women [young adults] and individuals with a high level of education, data that do not correspond to the reality of the Portuguese population and that, in the qualitative component, did not allow the collection of opinions from different socio-cultural strata, with different experiences.[161,162] Another limitation resulted from the way qualitative data were collected, through online interviews. Despite being a viable alternative to face-to-face interviews, these were subject to internet failures that conditioned information collection. In addition, some of the participants have chosen to have the video turned off which prevented the collection of non-verbal information such as facial expressions that could have enriched the study.[163,164]

On the positive side, a large sample was obtained, facilitated by the online application of the assessment instruments. It is noteworthy that data collection in this format provided data as valid as those collected in traditional methods and had the potential to reduce data loss.[165,166] In addition, it increased participants' privacy when filling out the tests and decreased the social desirability effect, both important features in studies that aimed to characterise the levels of stigma in the population.[167]

In future research, it is considered essential to characterise the levels of ADHD stigma in individuals with this disorder (self-stigma) or their relatives (affiliation stigma). It is also considered important to characterise the contact of individuals without ADHD with others with ADHD, in school and social contexts, and investigate the impact of this contact on stigma levels. Longitudinal studies are also suggested through the development and implementation of literacy programmes in this area, followed by characterisation studies of stigma in the population. Finally, it is recommended to obtain a more heterogeneous sample to collect information that more adequately represents the population.

5. Conclusion

Given the prevalence of ADHD worldwide and the fact that individuals with this disorder are vulnerable to stigmatisation, it is essential to understand the levels of stigma in the population, especially in groups that are on the frontline of healthcare provision, so that effective solutions to curb this problem can be found.

This paper identified that being older and having a higher level of education seems to function as protective factors for the probability of presenting stigma when measured by the ASQ. By opposition, stigma seems to increase when there is low literacy and prevalent pre-conceived notions about the

disorder. In addition, it was highlight that a set of factors seems to trigger and amplify stigma, such as the disease "label", the knowledge that the person takes medication or goes to the psychiatrist and the type of behaviour exhibited. Furthermore, the results confirm that stigma appears to be socially rooted, and society is often unaware of it, with expressions of “being stupid” or “being rude” used to describe these individuals. This information allows to realize that is the core of the problem that should be first addressed, in order to combat stigma efficiently.

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Appendix A

Table 6- Categories and Participants' transcripts

Categories	Transcripts
ADHD Literacy and Beliefs	**P1:** "(...) the difficulty in being concentrated. Someone who can be still, quiet in his place, very well-mannered, but there are moments when he has a lot of difficulty being attentive." **P2:** "The behaviour already goes according to the personality of each one"; **P6:** "I honestly believe that many [diagnosis] are well done, but others are also a lack of time and patience for the children"; **P7:** "Each individual is one and each hyperactivity will be different. It is logical that a hyperactive person who has movement, who has a lot of physical interaction calls more attention (...) than a hyperactive person, but who is physically calm. He has more of that attention deficit component." **T1:** "Unfortunately, I would go so far as to say that the diagnosis is becoming commonplace"; **T4:** "[the symptoms] It depends a lot also on the type and degree of hyperactivity they have. Some are a milder thing than others";
Stigma in ADHD	**P1:** "A young person who is born with a disability but ends up having no behavioural problems is more easily accepted than another who has difficulty sitting still, being quiet, following rules. Because it ends up destabilising the norm and everything that affects the norm is a problem." **P2:** "(...) they are already putting a label on him and automatically putting him aside"; **P3:** "I walked into the room I already knew who the kids who had ADHD were. They were always at the back of the room"; **P4:** "So in general, they say 'Ah, this child is hyperactive', they don't see it as a disease, they see it as a child who has to have rules at home and who has to be educated"; "(...) they want to keep their children away from that child [with ADHD], because they will think that he/she will be a bad influence"; **P5:** "The fact that, whether it's a child or an adult going to a psychologist "is crazy". Nobody sees it as going to the dentist (...) most people, even if they need help in the mental health field, try to hide so that they don't suffer the stigma of society"; **P6:** "Because what we have come to realize is that when we explain things to them, right? From beginning to end and when we try to describe it, whether it's a disease, a behaviour, anything, people understand and become more receptive"; **P7:** "(...) [the stigma] is even felt by people who are very close to us, for example, friends, relatives, who often in front of us say 'OK, don't mind' and when they leave our side they say 'If it were my son, two slaps in the face and he would behave properly'; "They [children with ADHD] get anxious themselves, 'tomorrow I'm going to school and I already have a disciplinary fault"; **P8:** "(...) these people are not understood and often end up becoming even more rebellious (...) they become more agitated"; **T1:** "At the time I was like 'Take medication...but she's so small. No, no way'. (...) Children are by nature restless"; **T2:** "Now if we think about a child who really has those characteristics of a hyperactive person – he's never quiet, he's never still, he's not attentive, he doesn't stop moving – yes, this kid probably won't have many friends, because his friends don't have the patience to listen to him"; **T3:** "They're different [people with ADHD] and so they're always afraid of 'is he going to have some behaviour that I am not expecting and that it's going to harm me in some way"; **T4:** "(...) they end up isolating themselves, not wanting to socialise and not wanting to go out, because they don't feel integrated into a group of friends, unless they are with people with whom they normally socialise or within a group of people who have the same difficulties that they have"; **T5:** "I think that maybe even at the level of employment, right? Or at the level of working on a project and maybe if people know that that person has that problem, maybe they will choose someone else to do the project"; "(...) maybe we need to work a little bit in this sense. Educating people [to reduce stigma]";

Table 6– Categories and Participants' transcripts (continue)

Categories	Transcripts
Environment and Importance of literacy	**P1:** "(...) in a physical education class they will have a behaviour that they won't have, for example, in a maths or portuguese class, right? Especially a more theoretical class that requires so much time sitting in the same place"; **P3:** "Parental education is also very necessary to deconstruct these myths"; **P4:** "(...) it also depends a lot on the resources you have and the people you have next to you to turn it around and overcome"; **P6:** "Children function by example, don't they? By repetition and, therefore, if they have a teacher who speaks calmly and who has more patience to help that boy and who will spend more time with him, the class will realise that they have to have [other attitudes] in play too"; **T1:** "This context [school] ends up being much more evident [the symptoms] than at home"; **T4:** "The environment in which they are and the way in which we interact also has a great influence on the child's behaviour later on"; "I believe that in a school context, a teacher with large classes (...) ends up not being able to give all the necessary attention...and there it is necessary for them to have their behaviour a little more under control and they need medication, so I believe that teachers would encourage parents to give medication";