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► **To cite this version:**

Sylvie Couderc, Florence Cousson-Gélie, Eric Pernon, Bertrand Porro, Stéphanie Miot, et al.. Burnout among direct support workers of adults with autism spectrum disorder and intellectual disability. *Scandinavian Journal of Caring Sciences*, 2023, 37 (1), pp.131-140. 10.1111/scs.13008 . hal-03280817

HAL Id: hal-03280817

<https://hal.science/hal-03280817v1>

Submitted on 26 Sep 2023

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EMPIRICAL STUDIES

Burnout among direct support workers of adults with autism spectrum disorder and intellectual disability

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Funding information

Institut de la Recherche En Santé Publique (IRESP)

Abstract

Background: Direct support workers (DSWs) accompany adults with autism spectrum disorder (ASD) and intellectual disability (ID) in residential care homes. Such DSWs, without specialised ASD training, are exposed to chronic stress linked to supporting ASD-ID clients and must adjust by coping strategies adapted to the needs of the residents. Nevertheless, difficulties adjusting constitute a burnout risk for DSWs, characterised by high levels of emotional exhaustion, depersonalisation and loss of a sense of personal accomplishment. We aimed to describe the burnout of DSWs who support adults with ASD-ID and to identify personal variables (experience and specialised training for ASD) and transactional variables (perceived stress and coping strategies) that could predict and mediate burnout.

Method: In total, 125 DSWs accompanying ASD-ID adults on a daily basis were included. Each participant answered four questionnaires measuring burnout, sociodemographic and professional variables, coping strategies and perceived stress.

Results: Five per cent of DSWs were in a state of burnout. Eighteen, six and fifty-nine per cent showed high average scores of emotional exhaustion, depersonalisation and loss of a sense of personal accomplishment, respectively. Being older, specialised training in ASD, stress perceived as a challenge and problem-focused coping strategies were associated with low levels of depersonalisation and loss of a sense of personal accomplishment.

Conclusions: Understanding the burnout process of ASD-ID DSWs may require the assessment of the organisational characteristics linked to the quality of life of the DSWs and the recognition of their specific needs when facing difficulties. The necessary ASD-focused training and support depends on an appraisal that would be individualised to adult ASD-ID DSWs.

KEYWORDS

autism spectrum disorder, burnout, direct support workers, intellectual disability, predictor and transactional factors

INTRODUCTION

Autism spectrum disorder (ASD) is defined in DSM-5 [1] as the association between persistent deficits in social communication and stereotypical behaviour and restricted interests. ASD manifests in various clinical forms, the severity of which is represented by three levels of required assistance (DSM-5 [1]). ASD is often associated with other disorders, such as intellectual disability (ID) [2], psychiatric [3], neurological [4, 5] and somatic disorders [6–8]. The adaptive prognosis of adults with ASD-ID is poor [9] and their need of assistance is significant, persisting throughout their lives and mobilising medical resources that are still insufficient [10]. Some adults with ASD-ID live in residential care homes, whose mission is to care for them until the end of their lives. Support in all acts of daily life for residents is provided by direct support workers (DSW) who were not trained in ASD during their initial general educational background. However, these workers must provide quality support, as defined in the good practice recommendations [11–15]. In this context, characterised by high job demands and low specialised resources, the quality of the DSWs' work life depends on their ability to adapt and on the health consequences related to burnout.

Burnout is both a response to professional and chronic stressors [16] and the process of physical, psychological and social wear, which alters the adaptability of workers [17]. Burnout affects workers in personal services and therefore the quality of care and service [18]. It is characterised by three dimensions that evolve by stage [18]: emotional exhaustion, depersonalisation and a loss of a sense of personal accomplishment. First, workers suffer from emotional exhaustion regarding the emotional demands to which they are exposed. It is characterised by exhaustion of their emotional and physical resources. Emotional exhaustion represents the dimension of individual stress in burnout. To remain efficient at work, workers then seek to reduce and control their emotional exhaustion, leading them, in a second step, to use strategies of distancing and disengagement towards the clients, which characterises the depersonalisation stage. Then, emotional exhaustion and depersonalisation evolve towards a personal and painful attack on the sense of efficiency of the worker, loss of personal accomplishment, which is the third dimension of burnout [16]. In its complete form, burnout corresponds to a high level of severity in each of the three dimensions [19]. It is not the subject of a dichotomous clinical diagnosis [20, 21] and is not considered to be a disease in diagnostic classifications. The prevalence of burnout concerns from 1 to 5% of French caregivers and 4% of community teams in the East of England supporting adults with ID [15, 22, 23].

There are several risk factors for burnout. Some are related to stressors experienced by workers, such as organisational or contextual factors related to working conditions

[24–26], and/or personal factors related to the individual characteristics of workers [27–29]. Other risk factors are subjective stressors, such as transactional factors [30, 31], which reflect the activity of the individual to deal with a stressful situation. Perceived stress and coping strategies are specific transactions that can have a dysfunctional effect when the perceived stress is intense and threatening and the coping strategies used are not focused on problem-solving [31–34]. These various risk factors are organised into a theoretical model that can allow better understanding of the psychological processes involved in the burnout of DSWs caring for adults with ASD-ID.

The transactional conception of stress and coping studied by Lazarus and Folkman [35] defines stress as 'a special relationship between the person and the environment, which is assessed by individuals as exceeding their resources and threatening their well-being'. According to this conception, perceived stress may be an experience of either threat, loss or challenge, regardless of the objective characteristics of the stressor that predate the transaction. Faced with a perceived stressful situation, individuals use coping strategies, that is to say 'all cognitive and behavioural efforts intended to control, reduce or tolerate the internal or external demands which threaten or exceed the resources of an individual' [35]. Thus, perceived stress and coping strategies are transactional processes that change, according to the period of life and situation, in the same individual [30]. They are characterised by a cognitive effort that can have a functional or dysfunctional effect on the individual's adjustment [36] and, in the event of a dysfunctional effect, can lead to burnout.

DIRECT SUPPORT WORKERS CARING FOR ADULTS WITH AUTISM SPECTRUM DISORDER AND INTELLECTUAL DISABILITY

There are no studies on the specific burnout of DSWs who accompany adults with an ASD-ID in all acts of daily life. However, many studies examined the burnout of various workers working in adult services with individuals with an ID [28, 37–39]. These studies revealed that workers, more specifically DSWs of adults with an ID housed in institutions, did not have an increased risk of burnout compared with workers in other personal services, even if there was a higher tendency for loss of personal accomplishment [40].

The risk factors studied showed that those linked to an organisation had a significantly greater effect on burnout than those linked to the severity of the characteristics of the residents [40]. More specifically, although the frequency of hetero-aggressiveness of residents increased emotional

exhaustion and depersonalisation, the severity of the attacks led to an increase in personal accomplishment [41] and the fear of violence decreased with exposure to violence [42]. DSWs in a state of burnout were workers who were invested in their work [40]. Establishing a link between the factors associated with the severity of the characteristics of adults with ID and burnout is complex due to contradictory results in the literature [40]. Concerning transactional factors, the stress perceived as a threat or a loss and emotion-focused coping strategies contribute to the vulnerability of special-education workers who work with children with ASD to emotional exhaustion [43]. DSWs use more often appropriate coping strategies, rather than inappropriate coping strategies [28].

Our principal aim was to describe the burnout process of DSWs caring for adults with an ASD-ID and to study the factors associated with this process. We hypothesise that the level of these workers is high for all three dimensions of burnout. Our second hypothesis is that certain predictors – such as age, significant professional experience with adults with an ASD-ID and specialised continuing training in ASD – and certain transactional factors – such as stress perceived as a challenge, problem-focused coping strategies and seeking social support – are protective factors for the three dimensions of burnout. Stress perceived as a threat or a loss and emotion-focused coping strategies are risk factors for the dimensions of burnout.

METHODS

Participants

This cross-sectional study was part of a prospective and multicenter study on frailty assessment in ageing adults with autism spectrum and intellectual disabilities [10]. The recruitment of DSWs was carried out from eight residential care homes in the south of France participating in the EFAAR study, providing services for adults with multiple disabilities, including ASD-ID. To be included, these workers had to assist directly (and therefore DSWs) in all of the daily activities of at least one of the adults with ASD-ID participating in EFAAR. The exclusion criteria were being health professionals (doctors, nurses, psychologists), social workers or managers who do not work directly with adults with an ASD-ID. Managers have listed the DSWs who met the inclusion criteria.

Variables and measures

The three dimensions of burnout were measured with the Maslach Burnout Inventory (MBI), the predictors with

the Predictor Questionnaire, the transactional processes with the Appraisal of Life Events Scale (ALES.vf) and the Ways of Coping Checklist-Revised (WCC-R). Each of these measurement tools was self-administered questionnaires, adapted and validated in French with a population of workers who support people with ASD [43]. The adaptation of the instructions was carried out in this study to assess specifically experiences of the DSWs with ASD-ID adults.

The MBI of Maslach, Jackson and Leiter [19], translated into French [44], consists of 22 items grouped into three scales, giving three scores: 1 – emotional exhaustion, 2 – depersonalisation and 3 – personal accomplishment. The MBI measures personal accomplishment, which is interpreted in terms of loss of personal accomplishment: a low personal accomplishment corresponds to a high loss of personal accomplishment. Each item is evaluated on a Likert-type frequency scale from 0 (never) to 6 (every day). To establish the scores, the absence of French standards led us to consider the symptomatology levels (low, moderate and high) stemming from American standards [19]. High scores for the emotional exhaustion (>29) and depersonalisation (>11) scales and low scores for the personal accomplishment (<34) scale are signs of burnout. Emotional exhaustion obtained a Cronbach's alpha score of 0.85, depersonalisation a score of 0.61 and personal accomplishment a score of 0.71.

Sociodemographic and professional were collected by an interview and questionnaire inspired by previous French research based on this population [43]. The interview grid contained 11 items: gender, age, married or in partnership, parental status, qualification and seniority of diploma, experience in residential care homes for adults and ASD training.

The Appraisal of Life Events Scale (ALES) is a scale created by Ferguson, Matthews and Cox [45] that measures perceived stress. Adapted and validated in French, the ALES-vf [46] is based on the original three-factor model and provides three scores of perceived stress: 1 – threat is the feeling of risking harm, 2 – loss corresponds to harm, and 3 – challenge reflects a challenge of gain. Participants must estimate their current experience with ASD-ID residents from 16 adjectives offered to them using a 6-point Likert scale. The Cronbach's alpha score was 0.85 for stress perceived as threat but also for stress perceived as loss and 0.83 for stress perceived as challenge.

The Ways of Coping Checklist-Revised (WCC-R) by Vitaliano et al. [47] consists of the revised scale of coping strategies by Folkman and Lazarus [48], validated in French by Cousson et al. [49]. The scale includes 27 items that assesses three types/styles of coping strategies used to cope with a stressful event: 1 – problem-focused coping, 2 – emotion-focused coping and 3 – social support-seeking. Participants must indicate which coping strategies they had

used on a 4-point graduated scale. Cronbach's alpha scores were 0.68, 0.72 and 0.64, respectively.

Procedure

Our survey received, in early 2017, a favourable opinion from the French Ethical Research Committee (Comité de Protection de Personnes, identification number 2016-A00166-45) and registered in the international clinical trials register (number NCT02791321). The study was then presented orally and in writing to the DSWs, who were informed of the anonymous nature of the study and their freedom not to participate. The data were collected by the study investigators from June 2017 to June 2018 on site. Without making an appointment, the DSWs who wished to participate came in a room made available for the survey. The room was away from institutional life. The average duration of the paper questionnaires was one hour. Someone was physically available throughout the entire procedure to help the participants who could not answer the questionnaires for material reasons, had difficulties in writing or had difficulties in understanding the instructions.

Statistical analyses

Descriptive and inferential statistics were calculated using Statistical Package for the Social Sciences (SPSS) Version 18. Univariate analysis permitted to identify variables significantly related to burnout scores. Hierarchical linear regression analyses were performed to examine the determinants of the dimensions of the burnout and to explain the impact of the predictors and transactional variables on the three dimensions. The first block included the sociodemographic and professional variables that significantly predict the dependent variable. The second block included the transactional variables (perceived stress and coping strategies). In order to assess coping as a mediator between stress and burnout, we used the Model 4 into the Hayes PROCESS Macro for SPSS (v 3.5) [50]. A sample size estimation, using G Power 3.1 software, identified a number of inclusions required for 81 participants (alpha (α) error probability = 0.20; 1-beta (β) error probability = 0.80; number of predictors = 12).

RESULTS

Descriptive analyses

Participants

Out of the 130 eligible DSWs, 125 have participated in the study and five declined. The DSWs were mainly women

TABLE 1 Sociodemographic and professional characteristics of participants (N = 125)

Predictors questionnaire	Participants (N)	%
Women	94	75
Men	31	25
Married or in partnership	77	62
Parental status	76	62
Qualifications		
• Nursing auxiliary	31	25
• Special-education professional	88	70
• Other or unqualified	6	5
Seniority of diploma ≤ 10 years	74	60
Experience in residential care homes for adults ≤ 10 years	78	63
Specialised continuing ASD training	84	74
Without specialised continuing ASD training	30	26
Supervision/practice analysis meetings	113	91
	Means	SD
Age (years)	38.44	10.08
Number of children	1.18	1.11
Seniority of diploma (years)	8.87	7.66
Experience in current residential care home for adults (years)	6.98	7.24
Experience in residential care homes for adults (years)	9.28	7.92
Specialised continuing ASD training (hours)	36.63	51.82
Supervision/practice analysis meetings (hours)	2	0.47
Frequency of supervision/practice analysis meetings (N/year)	7	3.40

(75%), aged 38.44 (± 10.08) years. The sociodemographic and professional characteristics of the 125 DSWs included in the study are presented in [Table 1](#).

Burnout

The results obtained with the MBI by dimension and severity level by USA reference standards [19] are presented in [Table 2](#). For the three dimensions, 18% of the DSWs had a high and 29% a moderate level of emotional exhaustion, 6% had a high and 16% a moderate level of depersonalisation, and 59% had a high and 26% a moderate level of loss of personal accomplishment. The burnout profile is presented in [Table 3](#). Although 37% of the DSWs had no high burnout dimensions, 58% were at risk of burnout, with one

TABLE 2 Means and distribution of scores on each dimension of the Maslach Burnout Inventory (MBI)

Health criteria			Low		Moderate			High			
Measure	Dimensions (N)	M (SD)	N	%	Range	N	%	Range	N	%	Range
MBI	EE (120)	18.09 (9.89)	64	53	0–17	35	29	18–29	21	18	30–54
	DEP (121)	3.51 (4.14)	94	78	0–5	19	16	6–11	8	6	12–30
	LPA (119)	31.45 (7.69)	18	15	40–48	31	26	34–39	70	59	0–33

Abbreviations: EE, Emotional Exhaustion; DEP, Depersonalisation; LPA, Loss of Personal Accomplishment.

TABLE 3 Description of the burnout process (low profile, moderate profile, risk profile, burnout)

Burnout Profile N (%)	Low and moderate profile: No high dimension N (%)		Risk profile: 1 high dimension N (%)		Risk profile: 2 high dimensions N (%)		Burnout: 3 high dimensions N (%)	
122 (100)	45 (37)		61 (50)		10 (8)		6 (5)	
	Low profiles* 34 (28)	Moderate profiles† 11 (9)	EE	6 (5)	EE + DEP	1 (1)	EE + DEP + LPA	
			DEP	0 (0)	EE + PAP	8 (6)		
			LPA	55 (45)	DEP + LPA	1 (1)		

Abbreviations: EE, Emotional Exhaustion; DEP, Depersonalisation; LPA, Loss of Personal Accomplishment.

*Majority of low scores.

†Majority of moderate scores.

TABLE 4 Means and distribution of scores for each dimension of the Appraisal of Life Events Scale (ALES.vf) and the Ways of Coping Checklist-Revised (WCC-R)

Transactional processes			Low		Moderate			High			
Measure	Dimensions (N)	M (SD)	N	%	Range	N	%	Range	N	%	Range
ALES.vf	Perceived stress										
	.Challenge (124)	19.67 (6.10)	22	18	0–13	84	68	14–26	18	14	27–30
	.Threat (124)	7.75 (6.35)	19	15	<2	86	70	2–14	19	15	15–30
	.Loss (124)	4.04 (4.34)	--	--	--	106	85	0–8	19	15	9–20
WCC-R	Coping strategies										
	.Problem-focused (113)	27.79 (4.98)	16	14	0–21	88	78	22–33	10	8	34–40
	.Emotion-focused (120)	20.40 (5.09)	14	12	0–15	96	80	16–27	10	8	28–36
	.Social support-seeking (119)	23.74 (4.40)	6	5	0–15	63	53	16–25	50	42	26–32

(50%) to two (8%) high dimensions, and 5% were in a state of complete burnout (three high dimensions). Loss of personal accomplishment was the dimension that was most often high, whether alone (45%) or in combination with emotional exhaustion and depersonalisation (6% and 1%).

The validation studies of the ALES.vf and WCC-R did not establish a 'low', 'moderate' or 'high' cut-off for each of the dimensions. However, these values are useful in describing and understanding the reactions of the DSWs. We therefore determined the moderate levels from the averages and the standard deviations of the dimensions of our sample. Thus, the cut-off of the moderate interval was the

low average (Mean -1 SD) and the high average (Mean $+1$ SD). The results obtained for the ALES.vf and WCC-R, by dimension and level of severity, are presented in Table 4.

Perceived stress

The experience of stress perceived as a challenge was high for 14% and moderate for 68% of the DSWs. The experience of stress perceived as a threat was high for 15% and moderate for 70%, and the experience of stress perceived as a loss was high for 15% and moderate for 85%.

Coping strategies

To cope with caring for adults with ASD-ID, the use of coping strategies focused on the problem was high for 8% of the DSWs and moderate for 78%, the use of coping strategies focused on emotions was high for 8% and moderate for 80%, and the use of coping strategies focused on seeking social support was high for 42% and moderate for 53%.

Inferential analyses

Table 5 presents the Spearman correlations of the different variables. Low to moderate correlations were obtained between measures of perceived stress, coping strategies and burnout. Perceived stress as challenge was significantly and positively correlated to social support-seeking ($r = 0.18$), personal accomplishment ($r = 0.30$) and negatively correlated to emotional exhaustion ($r = -0.20$). Perceived stress as threat was significantly and positively correlated to emotion-focused coping strategies ($r = 0.36$) and emotional exhaustion ($r = 0.38$). Perceived stress as loss was significantly and positively correlated to emotion-focused coping strategies ($r = 0.23$), emotion exhaustion ($r = 0.54$) and negatively correlated to personal accomplishment ($r = -0.20$). Problem-focused coping strategies were no significantly correlated to perceived stress and burnout. Emotion-focused coping strategies were significantly and positively correlated to emotional exhaustion ($r = 0.27$). Social support-seeking was significantly and negatively correlated to depersonalisation ($r = -0.19$).

The results of the analysis of multiple linear regressions are presented in Table 6. Both explored models had the following quality of prediction: emotional exhaustion ($R^2 = 0.338$, $p < 0.001$), depersonalisation ($R^2 = 0.281$, $p < 0.001$) and loss of personal accomplishment ($R^2 = 0.238$, $p < 0.001$).

Age ($\beta = 0.286$, $p < 0.05$) and specialised ASD training ($\beta = 0.209$, $p < 0.05$) predicted a high level of personal accomplishment, whereas level of experience ($\beta = -0.242$, $p < 0.05$) predicted a low level of personal accomplishment (or high level of loss of personal accomplishment), with these variables explaining 13.3% of the variance of personal accomplishment. Stress perceived as a loss ($\beta = 0.415$, $p < 0.01$) and the use of emotion-focused coping strategies ($\beta = 0.218$, $p < 0.05$) predicted a high level of emotional exhaustion, with these variables explaining 32.7% of the variance of emotional exhaustion. Stress perceived as a loss ($\beta = 0.376$, $p < 0.05$) and the use of emotion-focused coping strategies ($\beta = 0.231$, $p < 0.05$) also predicted a high level of depersonalisation, whereas the use of problem-focused coping strategies ($\beta = -0.212$, $p < 0.05$) predicted a low level of depersonalisation, with these variables explaining 23.1% of the variance of depersonalisation. Stress

TABLE 5 Correlations: independent and dependent variables

	1	2	3	4	5	6	7	8	9	10	11	12
1. Age	--											
1. Current experience	0.43 ^{***}	--										
1. Specialised ASD training	0.19 *	0.36 ^{***}	--									
1. Perceived stress as challenge	-0.14	-0.23 ^{***}	.02	--								
1. Perceived stress as threat	0.08	0.16	-0.10	-0.04	--							
1. Perceived stress as loss	0.13	0.24 ^{***}	0.00	-0.25 ^{***}	0.72 ^{***}	--						
1. Problem-focused coping strategies	-0.10	-0.17	-0.01	0.18	0.08	-0.09	--					
1. Emotion-focused coping strategies	-0.22 *	-0.04	0.09	0.07	0.36 ^{***}	0.23 *	0.28 ^{**}	--				
1. Social support-seeking	-0.14	-0.15	-0.08	0.18 *	0.13	-0.02	0.37 ^{***}	0.31 ^{**}	--			
1. Emotional exhaustion	-0.01	0.12	0.09	-0.20 *	0.38 ^{***}	0.54 ^{***}	-0.15	0.27 ^{**}	-0.03	--		
1. Depersonalisation	-0.21 *	-0.16	-0.00	-0.12	0.06	0.17	-0.16	0.09	-0.19 [*]	0.32 ^{***}	--	
1. Personal accomplishment	0.19 *	-0.08	0.04	0.30 ^{**}	-0.10	-0.20 [*]	0.18	-0.09	0.02	-0.11	-0.17	--

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

TABLE 6 Hierarchical multiple linear regressions on the three dimensions of burnout: Emotional Exhaustion (EE), Depersonalisation (DEP) and Personal Accomplishment (PA)

	EE		DEP		PA	
	R ² Δ	β	R ² Δ	β	R ² Δ	β
Block 1	0.011		0.050		0.133**	
Age		0.034		-0.209		0.286*
Current experience		-0.109		-0.033		-0.242*
Specialised continuing ASD training		-0.038		0.075		0.209*
Block 2	0.327***		0.231***		0.106	
Perceived stress						
.as a challenge		-0.150		-0.186		0.261*
.as a threat		-0.020		-0.250		0.137
.as a loss		0.415**		0.376*		-0.107
Coping strategies						
.Problem-focused		-0.123		-0.212*		0.129
.Emotion-focused		0.218*		0.231*		-0.118
.Social support-seeking		-0.076		-0.091		0.047
Total R ²	0.338***		0.281***		0.238**	

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

perceived as a challenge ($\beta = 0.261$, $p < 0.05$) predicted a high level of personal accomplishment, explaining 10.6% of the variance of personal accomplishment.

The results of mediation analyses showed no significant mediating effect of the three types/styles of coping strategies (problem, emotion and social support-seeking) between the three dimensions of perceived stress (as a threat, a loss and a challenge) and emotional exhaustion, depersonalisation and personal accomplishment (Table S1).

DISCUSSION

The aims of this study were to describe the burnout of DSWs supporting adults with ASD-ID and to study its determinants. First, the estimated prevalence of burnout was 5% for our population, which is close to that of other studies on health worker burnout [22, 23]. Second, most of the DSWs had a burnout profile consisting of a considerable loss of personal accomplishment (59%), whereas the emotional exhaustion (53%) and depersonalisation (78%) towards the residents were less altered. Levels of burnout dimensions are consistent with the data from studies of burnout of DSWs performing with adults with ID [41, 51–53]. Third, loss of personal accomplishment was a central dimension in the burnout of DSWs because it was high (52%) for most at-risk DSWs (58%). Contrary to the burnout-by-stage concept, in which emotional exhaustion and depersonalisation are the primary symptoms of burnout, we observed 1% of DSWs with a high level of emotional exhaustion associated with a high level of depersonalisation.

Our results partially verify our assumptions about the effects of the predictors of burnout, as certain sociodemographic predictors and job characteristics were associated with emotional exhaustion and depersonalisation. Age, level of experience and specialised training in ASD did not reduce emotional exhaustion or depersonalisation. Most of the DSWs received specialised training in ASD in their recognised career path to reduce emotional demands. This result can be interpreted by the low average duration of training (37 h for 9 years of experience) and insufficient training and/or training that did not meet the needs of DSWs to cope with stressful situations. Age and specialised training in ASD had a protective effect concerning loss of personal accomplishment, whereas the level of experience predicted a high loss of personal accomplishment. The DSWs who were the most highly accomplished in their work with adults with ASD-ID were the oldest and the most highly trained in ASD. Our results partially agree with those in the literature, which suggest that preparing and training DSWs to manage challenging behaviours reduces their burnout [42]. By contrast, the older the DSWs in the institution, the less they are accomplished in their work, which is contrary to results showing that learning by experiencing challenging behaviours of adults with ID reduces the loss of personal accomplishment [41]. This result may suggest that seniority is not a variable specific to the knowledge and skills acquired in the field of ASD. Seniority covers other predictors of burnout, such as poor relationships between colleagues, leadership that does not guarantee the well-being of DSWs, and a lack of recognition of the work,

which may pose a risk of burnout [54]. Indeed, adults with ASD-ID have few social skills with which to show DSWs their satisfaction and recognition. As a result, the promotion of DSWs passes through other people, such as professional managers and families of residents and colleagues, although 26% of DSWs received no training in ASD, which may affect team cohesion. It can also be assumed that the low income of DSWs is a factor that can encourage turnover and professional reorientation [55]. Our results show that most (63%) DSWs worked for less than 10 years with adults with ID, including those with ASD, and graduated less than 10 years before, suggesting that they leave the adult medical and social sector after 10 years of experience for reasons perhaps related to the loss of personal accomplishment or variables associated with seniority, such as the lack of status and higher salary.

Our hypothesis on the effects of transactional processes in burnout was partially verified. The experience of stress perceived as a loss and emotion-focused coping strategies were risk factors for emotional exhaustion and depersonalisation, whereas experience of stress perceived as a threat had no effect on emotional exhaustion or depersonalisation. According to our results, it is not fear of a threat but exposure to threatening experiences that has dysfunctional consequences on the well-being of DSWs, in accordance with the literature [41, 42]. In the context of low seniority and high turnover, the major difficulty faced by DSWs is the repetition of such threatening experiences while caring for adults with ASD-ID. In addition, experiences of stress as a challenge had a protective effect against loss of personal accomplishment and thus contributed to a better sense of effectiveness as defined by personal accomplishment [16]. Similarly, when they used problem-focused coping strategies and sought to resolve the difficulties encountered, the interpersonal link between DSWs and adults with ASD-ID was protected (low depersonalisation), but coping has no effect on personal accomplishment, which is high in DSWs. They have no functional coping to protect their personal accomplishment, which could lead them to leave their job earlier and explain the negative effect of current experience on their personal accomplishment. These results allow us to interpret the *malaise* of DSWs in terms of burnout as a consequence of acute and chronic stress experiences, which DSWs manage by their emotions, due to the lack of solutions to the difficulties encountered. This suggests that professionals develop a style of coping that influences stressful transactions with residents, instead of being influenced by perceived stress [56]. The lack of mediating effect of coping between stress and burnout confirms this suggestion. Emotional support of DSWs is necessary but insufficient. DSWs need to use more functional coping strategies organised according to the type of prevention targeted (primary, secondary or tertiary): prior training, information and

research are useful resources for solution-finding strategies; individual or collective psychological support in crisis or post-operational situations reduces the effects of negative stress on health; and stress and challenging-behaviour management improve the use of strategies to reduce emotional stress. DSWs need to understand the challenging behaviours of adults with ASD-ID to adapt to them, and this may create an additional stressor for the well-being of all residents and professionals. Parents of children with ASD experience the burden of challenging behaviours on family quality of life, and research has developed specific interventions to support them [57, 58]. Design of parents' quality-of-life research could promote research on that of caregivers of adults with ASD-ID and therefore DSWs [55].

Study limitations

The interpretation of our results shows certain limitations. The first is that we did not take into account the organisational determinants, whose effect on burnout was proved [38, 40]. The second is that we did not consider the political factors linked to health and disability. These social determinants of health, defined by the World Health Organization (WHO, [59]), have consequences on the working conditions and could have improved the interpretation of our results relative to those collected in other countries. A third limitation was that we included voluntary establishments, with dynamic institutional working cultures, which may have constituted a recruitment bias. Finally, our study was cross-sectional, and the self-assessment of perceived stress levels and coping strategies used may have been influenced by the burnout level of the DSWs.

CONCLUSION

Burnout is a common occurrence among DSWs caring for adults with ASD associated with an ID, as 5% of the DSWs in our study were in a state of burnout and 58% at risk of being so. DSWs were affected by significant loss of a sense of personal accomplishment, and they faced high emotional demands. When subjected to emotional exhaustion and depersonalisation, only the use of problem-focused coping strategies had a protective effect. When they had lost a sense of personal accomplishment, specialised ASD training and experiences perceived as a challenge had a protective effect. In this context, the training and support offered to DSWs to cope with the challenges of their profession must be developed and better meet their needs. Future research should use a longitudinal approach to the quality of life in residential care homes, focusing on the interactions between the quality of life of all professional actors, including that of the DSWs,

and the quality of life of adults with an ID, including those with ASD-ID.

ACKNOWLEDGEMENT

We thank the workers who took part in the study as well as the residential care homes, which welcomed us.

CONFLICTS OF INTEREST

The authors have no conflicts of interest to declare.

ETHICAL APPROVAL

Authorisation for handling personal data was granted by the French Data Protection Authority (CNIL: Commission Nationale de l'Informatique et Libertés). The initial project was approved by the French Ethical Research Committee (Comité de Protection de Personnes (CPP), identification number 2016-A00166-45) and registered in the international clinical trials register (number NCT02791321). All subjects gave written informed consent in accordance with the Declaration of Helsinki.

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REFERENCES

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5®). Washington, DC: American Psychiatric Publishing; 2013.
- Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord*. 2003;33(4):365–82.
- Cervantes PE, Matson JL. Comorbid symptomology in adults with autism spectrum disorder and intellectual disability. *J Autism Dev Disord*. 2015;45(12):3961–70.
- Amiet C, Gourfinkel-An I, Bouzamondo A, Tordjman S, Baulac M, Lechat P, et al. Epilepsy in autism is associated with intellectual disability and gender: evidence from a meta-analysis. *Biol Psychiatry*. 2008;64(7):577–82.
- Fortuna RJ, Robinson L, Smith TH, Meccarello J, Bullen B, Nobis K, et al. Health conditions and functional status in adults with autism: a cross-sectional evaluation. *J Gen Intern Med*. 2016;31(1):77–84.
- Wang LW, Tancredi DJ, Thomas DW. The prevalence of gastrointestinal problems in children across the United States with autism spectrum disorders from families with multiple affected members. *J Dev Behav Pediatrics*. 2011;32(5):351–60.
- Zerbo O, Leong A, Barcellos L, Bernal P, Fireman B, Croen LA. Immune mediated conditions in autism spectrum disorders. *Brain Behav Immun*. 2015;46:232–6.
- Zimmer MH, Hart LC, Manning-Courtney P, Murray DS, Bing NM, Summer S. Food variety as a predictor of nutritional status among children with autism. *J Autism Dev Disord*. 2012;42(4):549–56.
- Baghdadi A, Michelon C, Pernon E, Picot MC, Miot S, Sonie S, et al. Adaptive trajectories and early risk factors in the autism spectrum: A 15-year prospective study. *Autism Res*. 2018;11(11):1455–67.
- Miot S, Akbaraly T, Michelon C, Couderc S, Crepiat S, Loubersac J, et al. Comorbidity burden in adults with autism spectrum disorders and intellectual disabilities-A report from the EFAAR (Frailty assessment in ageing adults with autism spectrum and intellectual disabilities) study. *Front Psychiatry*. 2019;10:617.
- ANESM. Qualité de Vie En MAS-FAM (Volet 1) : Expression, Communication, Participation et Exercice de La Citoyenneté. Saint-Denis La Plaine [France] : ANESM - Agence nationale de l'évaluation et de la qualité des établissements et des services sociaux et médico-sociaux.; 2013.
- ANESM. Qualité de Vie En MAS-FAM (Volet 2) : Vie Quotidienne, Sociale, Culture et Loisirs. Saint-Denis La Plaine [France] : ANESM - Agence nationale de l'évaluation et de la qualité des établissements et des services sociaux et médico-sociaux.; 2013.
- ANESM. Qualité de Vie En MAS-FAM (Volet 3) : Le Parcours et Les Formes Souples d'accueil et d'hébergement. Saint-Denis La Plaine [France] : ANESM - Agence nationale de l'évaluation et de la qualité des établissements et des services sociaux et médico-sociaux.; 2014.
- Haute Autorité de Santé HAS. Autisme et autres TED diagnostic et évaluation chez l'adulte. Saint-Denis La Plaine: Recommandation de Bonne Pratique; 2011.
- Haute Autorité de Santé HAS. Repérage et prise en charge cliniques du syndrome d'épuisement professionnel ou burnout. Saint-Denis La Plaine: Recommandation de Bonne Pratique; 2017.
- Maslach C, Schaufeli WB, Leiter MP. Job burnout. *Annu Rev Psychol*. 2001;52:397–422.
- Innstrand ST, Espnes GA, Mykletun R. Job stress, burnout and job satisfaction: an intervention study for staff working with people with intellectual disabilities. *J Appl Res Intellect Dis*. 2004;17(2):119–26.
- Maslach C, Jackson SE. The measurement of experienced burnout. *J Organ Behav*. 1981;2(2):99–113.
- Maslach C, Jackson SE, Leiter MP. The Maslach burnout inventory-test manual. Palo Alto, CA: Consulting Psychologists Press; 1996.
- Truchot D. Epuisement Professionnel Et Burnout-Concepts. Modèles, Interventions, Dunod, Collection: Psycho Sup; 2004.
- Vincent L, Brindley PG, Highfield J, Innes R, Greig P, Suntharalingam G. Burnout Syndrome in UK Intensive Care Unit staff: Data from all three Burnout Syndrome domains and across professional groups, genders and ages. *J Intens Care Soc*. 2019;20(4):363–9.
- Clare IC, Madden EM, Holland AJ, Farrington CJ, Whitson S, Broughton S, et al. 'What vision?': experiences of Team members in a community service for adults with intellectual disabilities. *J Intellect Dis Res*. 2017;61(3):197–209.
- Dusmesnil H, Serre BS, Régi JC, Leopold Y, Verger P. Professional burn-out of general practitioners in urban areas: prevalence and determinants. *Sante Publique (Vandoeuvre-les-Nancy, France)*. 2009;21(4):355–64.
- Mascha K. Staff morale in day care centres for adults with intellectual disabilities. *J Appl Res Intellect Dis*. 2007;20(3):191–9.
- Maslach C, Leiter MP, Leiter MP. Burn-out: des solutions pour se préserver et pour agir: Les Arènes. 2016.
- O'Connor K, Muller Neff D, Pitman S. Burnout in mental health professionals: A systematic review and meta-analysis of prevalence and determinants. *Eur Psychiatry*. 2018;53:74–99.
- Ahola K, Honkonen T, Virtanen M, Aromaa A, Lönnqvist J. Burnout in relation to age in the adult working population. *J Occup Health*. 2008;50(4):362–5.

28. Mitchell G, Hastings RP. Coping, burnout, and emotion in staff working in community services for people with challenging behaviors. *Am J Mental Retardation*. 2001;106(5):448–59.
29. Papineau M, Plante N, Desjardins S, Aubin-Cantin C, Vachon M. Facteurs de risque individuels de l'épuisement professionnel: Construction et validation du questionnaire style personnel au travail. *Can J Behav Sci Revue Can Sci Comportement*. 2018;50(2):77.
30. Bruchon-Schweitzer M, Boujut E. *Psychologie de la santé-2e éd: Modèles, concepts et méthodes*: Dunod. 2014.
31. Laugaa D, Rasclé N, Bruchon-Schweitzer M. Stress and burnout among French elementary school teachers: A transactional approach. *Eur Rev Appl Psychol*. 2008;58(4):241–51.
32. Devereux JM, Hastings RP, Noone SJ, Firth A, Totsika V. Social support and coping as mediators or moderators of the impact of work stressors on burnout in intellectual disability support staff. *Res Dev Dis*. 2009;30(2):367–77.
33. Laugaa D, Bruchon-Schweitzer M. L'ajustement au stress professionnel chez les enseignants français du premier degré. *L'orientation Scolaire et Professionnelle*. 2005;34(4):499–519.
34. Rasclé N, Bergugnat L. *Les déterminants et les conséquences de l'épuisement professionnel des enseignants débutants*. 2013.
35. Lazarus RF, Folkman SCS. *Stress, appraisal, and coping*. New York: Springer Publishing Company; 1984.
36. Rasclé N. Testing the mediating role of appraised stress and coping strategies on employee adjustment in a context of job mobility. *Eur Rev Appl Psychol Rev Eur Psychol Appl*. 2000;50(3):301–7.
37. Aitken CJ, Schloss JA. Occupational stress and burnout amongst staff working with people with an intellectual disability. *Behav Intervent*. 1994;9(4):225–34.
38. Chung MC, Corbett J. The burnout of nursing staff working with challenging behaviour clients in hospital-based bungalows and a community unit. *Int J Nurs Stud*. 1998;35(1–2):56–64.
39. Shaddock A, Hill M, Van Limbeek C. Factors associated with burnout in workers in residential facilities for people with an intellectual disability. *J Intellect Dev Dis*. 1998;23(4):309–18.
40. Skirrow P, Hatton C. 'Burnout' amongst direct care workers in services for adults with intellectual disabilities: a systematic review of research findings and initial normative data. *J Appl Res Intellect Dis*. 2007;20(2):131–44.
41. Hensel JM, Lunskey Y, Dewa CS. Exposure to client aggression and burnout among community staff who support adults with intellectual disabilities in Ontario, Canada. *J Intellect Dis Res*. 2012;56(9):910–5.
42. Howard R, Rose J, Levenson V. The psychological impact of violence on staff working with adults with intellectual disabilities. *J Appl Res Intellect Dis*. 2009;22(6):538–48.
43. Cappe E, Rougé M-C, Boujut E. Burnout des professionnels de l'éducation spécialisée intervenant auprès d'individus ayant un trouble du spectre de l'autisme: rôle des antécédents psychosociaux et des processus transactionnels. *Psychol Travail Organ*. 2015;21(2):125–48.
44. Dion G, Tessier R. Validation de la traduction de l'Inventaire d'épuisement professionnel de Maslach et Jackson. *Can J Behav Sci Rev Can Sci Comportement*. 1994;26(2):210.
45. Ferguson E, Matthews G, Cox T. The appraisal of life events (ALE) scale: Reliability and validity. *Br J Health Psychol*. 1999;4(2):97–116.
46. Cappe E, Poirier N, Boujut E, Nader-Grosbois N, Dionne C, Boulard A. Autism spectrum disorder and evaluation of perceived stress parents and professionals: Study of the psychometric properties of a French adaptation of the Appraisal of Life Event Scale (ALES-vf). *Encephale*. 2017;43(4):321–5.
47. Vitaliano PP, Russo J, Carr JE, Maiuro RD, Becker J. The ways of coping checklist: revision and psychometric properties. *Multivariate Behav Res*. 1985;20(1):3–26.
48. Folkman S, Lazarus RS. An analysis of coping in a middle-aged community sample. *J Health Soc Behav*. 1980;21(3):219–39.
49. Cousson F, Bruchon-Schweitzer M, Quintard B, Nuissier J, Rasclé N. Analyse multidimensionnelle d'une échelle de coping: validation française de la WCC (Ways of Coping Checklist). *Psychol Française*. 1996;41(2):155–64.
50. Hayes AF. *Introduction to mediation, moderation, and conditional process analysis: A regression-based approach*. New York, NY, US: Guilford Press; 2013. xvii, 507-xvii, p.
51. Chung MC, Harding C. Investigating burnout and psychological well-being of staff working with people with intellectual disabilities and challenging behaviour: The role of personality. *J Appl Res Intellect Dis*. 2009;22(6):549–60.
52. Mutkins E, Brown RF, Thorsteinsson EB. Stress, depression, workplace and social supports and burnout in intellectual disability support staff. *J Intellect Dis Res*. 2011;55(5):500–10.
53. Rose J, Mills S, Silva D, Thompson L. Client characteristics, organizational variables and burnout in care staff: the mediating role of fear of assault. *Res Dev Dis*. 2013;34(3):940–7.
54. Kozak A, Kersten M, Schillmöller Z, Nienhaus A. Psychosocial work-related predictors and consequences of personal burnout among staff working with people with intellectual disabilities. *Res Dev Dis*. 2013;34(1):102–15.
55. Hastings RP. Support staff working in intellectual disability services: the importance of relationships and positive experiences. *J Intellect Dev Dis*. 2010;35(3):207–10.
56. Lazarus RS. *Stress and emotion: A new synthesis*. 1999.
57. Cappe E, Wolff M, Bobet R, Adrien JL. Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Qual Life Res*. 2011;20(8):1279–94.
58. Rattaz C, Michelon C, Roeyers H, Baghdadli A. Quality of life in parents of young adults with ASD: EpiTED cohort. *J Autism Dev Disord*. 2017;47(9):2826–37.
59. World Health Organization. *World conference on social determinants of health: meeting report, Rio de Janeiro, Brazil, 19-21 October 2011*. 2012.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Couderc S, Cousson-Gélie F, Pernon E, Porro B, Miot S, Baghdadli A. Burnout among direct support workers of adults with autism spectrum disorder and intellectual disability. *Scand J Caring Sci*. 2023;37:131–140. <https://doi.org/10.1111/scs.13008>