Ann Ist Super Sanità 2020 | Vol. 56, No. 2: 215-221
DOI: 10.4415/ANN_20_02_11

Stress and wellbeing among professionals working with people with neurodevelopmental disorders. Review and intervention perspectives

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Abstract
Supporting individuals with NDD is extremely demanding, with significant exposure to critical contexts and events, and painful ongoing experiences. Stress and burnout condition is a main concern with growing interest in research, despite the lack of consensus on theoretical explanatory models and modification standards.
The paper provides an up-to-date review of risk factors and involved processes, and presents evidence-based procedures and protocols to implement effective preventive actions addressing both organizational and individual factors. The aim is to offer a global understanding of the subject and offer examples of practical plans to increase the impact on the quality of life of clients and staff members.

Key words
- staff
- stress
- neurodevelopmental disorders
- autism spectrum disorder
- applied behavior analysis

INTRODUCTION

Psychological stress and associated medical illnesses are significant problems amongst those working with individuals with neurodevelopmental disorders (NDD). Potential implications on the quality of life of clients and staff members are significant: psychological condition of professionals is always (to some extent) impacting the quality and quantity of given supports and human interactions. Furthermore, organizations have a moral and legal duty to ensure the welfare of their employees [1].

The present paper is presenting an up-to-date overview of the above topics, and describe the main intervention perspectives.

STRESS CONDITION IN STAFF WORKING WITH NEURODEVELOPMENTAL DISORDERS

Burnout is a job-related illness, considered a consequence of chronic work-related stress related to factors related to work and private events.

Maslach and Jackson [2] original definition of burnout included three distinct elements: feelings of being exhausted emotionally, loss of feelings of accomplishment on the job, and negative, cynical and depersonalizing attitudes towards service users. It is nowadays considered a label for a broader set of psychological processes, where initial feelings of stress lead to a longer-term sensation of exhaustion and ultimately to a more stable change in behavioral patterns. This change is often described as "coping style", and is associated with negative attitudes towards people with NDD (e.g. treating clients in a mechanical or detached way).

These models have been widely studied and applied, since they allow to make specific predictions about emotional, behavioral and attitudinal change, and to make modifications both from the individual and organizational points of view.

Empirical and theoretical research on stress and burnout among professionals working with people with NDD is limited, but the interest is growing [3]: their impact on staff and clients' wellbeing is acknowledged and review and clinical papers are retrievable, although there still is no consensus on the dimensions of these topics and how to deal with them appropriately (e.g. lack of reliable assessment tools, longitudinal and controlled studies, standardized intervention protocols, etc.).

Staff members working with persons with NDD (including, for instance, intellectual disabilities and autism

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spectrum disorders, often in comorbidity with psychiatric disorders) usually faces in their daily job emotionally and physically challenging situations [4, 5]. Significant levels, between 25 and 32 percent, of work-related stress and burnout, is reported in the literature [1, 6] even if the level of burnout among workers in the field of NDD is not necessarily higher than in other helping professional groups [6].

REACTION TO STRESS AND IMPACT OF WELLBEING

Supporting a person with NDD is extremely demanding. Both professionals and caregivers are exposed to critical contexts and events, and live painful experiences extended on time.

Studies exploring the consequences of stress and burnout in professionals working with NDD report a variety of outcomes [5, 7] including: lower levels of production, lower quality of direct support and interaction [8]; higher absenteeism and turnover [9]; negative emotional reactions [10]; unhealthy lifestyle [11], mental health problems, physical issues and chronic diseases [12]; higher risk of physical and mental abuse towards clients [13]. Burnout has been specifically associated with increased job turnover and lower level of direct support and interactions [14]: a recent survey of 21 US states reported an average annual turnover rate of 46% in 2016 [15].

Panicker and Ramesh [16] recently studied the psychological status of caregivers of individuals with intellectual disability and psychiatric illness. All the participants (N = 120) experienced depression, anxiety and stress symptoms. These symptoms were found to be significantly higher among caregivers of individuals with intellectual disabilities than those with psychiatric illness.

RISK FACTORS

The common understanding of stress and burnout are usually based on a supposed causal relationship between the complexity of the job (particularly challenging behaviors of clients) and staff well-being, and the implication that these kinds of job are "burning" professionals over time. There is no empirical support for these hypotheses. A deeper examination of the interaction between multiple factors is needed.

Risks factors have been studied and reviewed (e.g. [7]). Considering specific literature [4, 10, 17-20], these could be summarized and clustered as follows: a) client factors (poor functioning, challenging behaviors, frequency and chronicity of problems; atypical attitudes); b) job factors (work load, work shifts, perception of relationships and received support, low salary, injuries risk); c) organizational factors (low occupational status, role ambiguity and limited job autonomy); individual (staff) factors (psychological).

Finkelstein *et al.* [3] in a sample of 199 professionals, found no significant differences in burnout levels when related to socio-demographic factors and to professional characteristics. Most of the predictors (46.8% of the variance) were indeed organizational measures: role ambiguity, perceived overload, care-recipient group and job involvement.

Emotion-focused coping has been associated with greater burnout and work stress [21, 22]. Michelini *et al.* [23] found burnout as significantly depending on both organizational and individual factors (specifically "psychological flexibility"), with strong independence of those variables.

As a consequence of the above data, interventions aimed to promote stress reduction and wellbeing should be provided at two levels: organizational and individual. The following sections present a summary of the emerging evidence from the two perspectives with examples aimed to support clinicians and managers to introduce supported interventions in their organization.

INTERVENTIONS AT THE ORGANIZATIONAL LEVEL

As said, challenging behaviors probably are the most impacting factor associated with stress and burnout, with an extremely high prevalence within the population of individuals with NDD (e.g. rates over 60% in children [24]; in adults average estimates of 18.1-18.7% or 50-80% in studies looking at specific settings, subpopulations, or behaviors [25]).

Applied behavior analysis, with a variety of treatment models, has the solidest evidence in terms of efficacy and cost-effectiveness [26-28] for the treatments of challenging behaviors. We must actually consider that applying evidence-based treatment procedures presents significant difficulties in terms of willingness, consistency, accuracy, alignment with changing needs, etc. This concern has been explored by behavior analysis itself: training and management of the treatment-related performance of human service personnel represent one of the core areas of applied behavior analysis named organizational behavior management (OBM) [29]. Therefore, OBM procedures are considered the current standard to change contextual factors impacting on stress and burnout.

Accordingly to OBM, when professionals don't apply behavioral interventions correctly, it means they are not addressing challenging behaviors as required. This could increase the frequency and severity of challenging behaviors, and consequently the exposure to stressful conditions and the risk to develop burnout [30]. Usually, this happens for two main reasons [31]: 1) lack of specific skills; and 2) lack of motivation. OBM indicates two areas of intervention to address these variables: one dimension dedicated to the organizational factors, and one dimension focused on the professionals as individuals.

In order to impact on the organization, research points out the main core tasks to address [32]:

a) clarify roles, responsibility, and duties with a precise schedule;
b) train (and refresh) all staff members on:
   - general rationale;
   - protocols;
   - specific skills *in vivo* (i.e. behavioral skills training);
   - direct modeling and feedback;
c) observe, measure, and analyze data;
d) provide feedback:
   - on the required skills;

- on the personal attitude and performance using collected data;

e) give direct support to professionals:
- corrective actions (make professionals aware of errors and provide ethical and approved forms of punishment);
- reinforcement processes (related to skills and attitudes).

The best prevention for stress and burnout can be provided when implementing the above tasks using a precise behavioral methodology. In *Figure 1* the core tasks are summarized and referred to basic behavioral procedures.

Motivation is usually considered [31] defined by two factors: a) the willingness to apply the required skills; b) the satisfaction in doing a specific activity. The former has a higher risk of failure, is strongly related to the job environment, and it is always fluctuating. The satisfaction in doing a specific activity constitutes an essential factor and should always be addressed since punishment by itself is not effective in a long term perspective. Increasing the access to positive consequences of job activity means reinforcing positive behaviors: staff is progressively less involved in avoiding efforts and more committed to an active search for positive/preferred consequences.

The procedures summarized above stimulate changes in learning processes used by staff members and constitute the base for implementing interventions at the individual level.

INTERVENTIONS AT THE INDIVIDUAL LEVEL

Accordingly with literature, an intervention at the individual level should be provided and combined with those at the organizational level [5].

Richardson and Rothstein [33] showed how classical interventions for work-related stress were based on psychoeducational training with elements of cognitive behavior therapy (CBT) or cognitive therapy (CT) emphasizing problem-solving. Beyond the usefulness of these approaches and treatment, the limitations are known: the nature itself of challenging behaviors (i.e. cognitive limitations, behavioral deficits, learning history, the inadequacy of environment) make changes and predictability poorly effective or short-lasting.

As a consequence, carers of individuals with NDD develop ineffective emotion-focused coping strategies (avoidance of negative perceptions and thought suppression), increasing paradoxically their risk of experiencing burnout and stress [21, 34, 35]. The importance of individual's responses (i.e. coping resources) associated with the permanency of stressors related to NDD, increased the interest of psychological approaches to treatments aimed to increase resilience [36]. Within these, the third wave of behavior therapies (for a review see [37]) applied to carers of individuals with NDD is growing rapidly [7, 20]. Mindfulness and acceptance are key constructs of 3rd generation behavioral approaches, describing psychological processes confirmed to be effective at reducing occupational stress responses and increasing psychological resilience [20, 38, 39].

Mindfulness-based interventions (MBI) and acceptance and commitment therapy (ACT) can produce positive outcomes for individuals with ID and challenging behaviors [40, 41], and increase the wellbeing of support staff [22, 35, 42]. Protocols based on these processes reduce the efficacy of ineffective coping strategies, and increase the willingness to experience difficult thoughts and feelings ("avoiding the avoidance"), reducing the stressful impact of uncomfortable thoughts and sensations and increasing flexible attitudes towards the events and awareness on individual reactions and responses [5]. A recent study [36] on ninety-seven direct support professionals, confirms Noone and Hast-

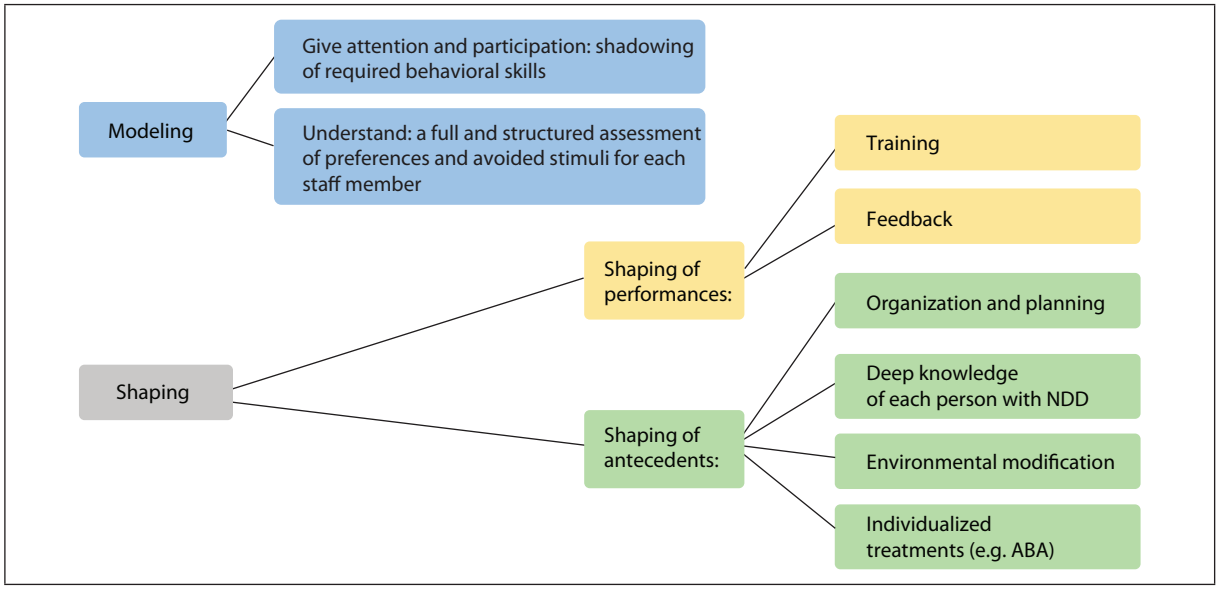

Figure 1
Behavioral procedures used in the core organizational behavior management (OBM) tasks for increasing skills as prevention of stress and burnout.

ings findings on the importance of mindfulness as a cognitive mechanism in protecting against negative outcomes. Mindfulness practices operate as a protective factor against burnout and emotional discomfort (e.g. psychiatric symptoms and neuroticism), and associates with adaptive attitudes.

Mindfulness-based and ACT interventions recognize the reality of the challenge that professionals and caregivers of individuals with NDD face day by day. The psychological processes involved help to overcome the limitations of classical CBT and problem-solving approaches: they support learning processes in professionals and caregivers, increase being present in one's discomfort, and foster acceptance and values-oriented behaviors. These approaches will play an important role in disability services as a whole [43]: clinicians and service leaders should explore these opportunities and plan training and implementation in their own work context.

An example of these training is the promotion of acceptance in carers and teachers (PACT) [22], the first treatment protocol based on mindfulness and ACT (acceptance, mindfulness, and values), designed to help

Table 1
Workshop modules with descriptions

Day	Module	Description
Day 1	Introduction	Overview, introduction, schedule and expectations Discuss how people react to challenging behaviors Stress and burnout processes and prevalence Introduce "psychological flexibility": ACT matrix and mindfulness practices
	Thoughts and reality	Video metaphors (e.g. Russ Harris, Happiness Myth) Exercises (break into pairs) to describe unpleasant thoughts and feelings and important things we care into our lives
	Introduction to the Matrix	Clinical examples assessed using a simplified Hexaflex model (e.g. Polk's Matrix)
	Mindfulness	Guided experience (plus homework)
Day 2	Mindfulness	Group members are leading the guided experience
	Processes awareness	Clinical examples with video of ACT and mindfulness applied to individuals with NDD (high and low functioning)
	Matrix	Break into groups and apply to their stressful experiences
	Sharing	Each group presents their case Combining ABA (functional approach) to the matrix People describe experiences
	Values	Introduction and assessment (VLQ and VQ) [47][48] Feedback on the individual scoring Eye contact exercise
	Mindfulness	Homework
Day 3	Mindfulness	Group members are leading the guided experience
	Processes awareness	Clinical examples with video of ACT and mindfulness applied to individuals with NDD (high and low functioning)
	Defusion	Metaphors and exercises (e.g. chessboard, observer self) to help people get a sense of the part of them that just observes
	Committed action	Individual use of the Matrix Mindful exercise to visualize values-oriented actions
	Matrix	Break into groups and implement their cases with left-to-right and up-to-down processes (e.g. making lists of contents, observing and linking factors to experiences) People describe experiences
	Mindfulness	Homework
Day 4	Mindfulness	Group members are leading the guided experience
	Processes awareness	Clinical examples with video of ACT and mindfulness applied to individuals with NDD (high and low functioning)
	Matrix	Break into groups and implement their cases with committed action plans for the group and each participant People describe experiences
	Processes awareness	Assessing preferences and avoided stimuli using a structured questionnaire (SSPAQ) Feedback on the individual scoring
	Committed action	Individual paper activity, describing a committed action plan, with details on problem-solving (for aversive stimuli) and enrichment (for appetitive stimuli)
	Closing	People have an opportunity to share their reactions to the workshop
	Mindfulness	Homework

care staff. The training is working on different tasks: 1) to promote a willingness to experience the full range of emotional responses (including aversive ones); 2) to corroborate the use of flexibility when judging "personal progress", driven by the level of alignment to one's values; 3) to reduce the control of thoughts through mindfulness practices [20]. The authors of PACT recently reported results when using mindfulness-based practices with family carers of adults with learning disabilities and challenging behavior [44]: data show that mindfulness/ACT can change long-standing response behaviors, build personal resilience, and improve mental health.

The authors (within Fondazione Sospiro Onlus, Cremona, Italy) tried to explore these contributions and introduced and adapted these approaches since 2006 in their facilities, developing a protocol for a training workshop dedicated to all staff members, as part of its multi-component organizational reform package [45]. The constant collection of data related to organizational processes, clinical treatments, and staff stress/wellbeing [23] confirmed the importance to address individual factors and to promote psychological flexibility, in combination with planning, support, and intervention at the organizational level. Consequently, the training protocol has been shaped during time (based on outcomes and feedback), and now it's planned 2-4 times every year to members of all residential facilities for adults with NDD and challenging behaviors. The training's aim is to improve the quality of life of those supporting people with NDD. The training workshops are split into four meetings (four hours each; once a month), for groups of 15-20 professionals (with different role and experience). Schedule, components, and descriptions are listed in *Table 1* below, as an example (consistent with the literature, [46]) to be considered and adapted for every type of service.

The training is focused on psychological processes, and uses metaphors, video examples, individual/pair/group exercises (experiential, paper and verbal), to work on the following objectives: a) to increase awareness of staff on how they are using inflexible responses; b) to clarify personal and shared values; c) to plan and make commitments (dedicate time to activities meaningful for them); d) to increase opportunities to access available reinforcements, increasing the chance to live positive (and less painful) experiences (at work and in their daily lives); e) to increase global awareness of their life and to get the best they can from it.

The effectiveness of ACT for work organizations in terms of reducing stress, raising psychological wellbeing, and increasing workers' willingness to use innovative practices is confirmed [46]: organizations should take into consideration how to implement specific support plans aligned to these processes.

CONCLUSIONS

The quality of life of clients and staff members should be a main concern for organizations and professionals involved in the planning and evaluations of services offered to people with neurodevelopmental disorders (NDD).

Despite the paucity of empirical and theoretical research on stress and burnout among professionals working with people with NDD, the interest is growing. We have now a better understanding of the variety of factors impacting stress and increasing the risk of burnout and its negative consequences (including malpractice and abuse).

Behavioral sciences and applied behavior analysis offer procedures and protocols based on evidence, to implement effective preventive actions, addressing both the organizational and the individual factors. Research should definitely grow and improve, but service providers can have access to this body of science and start to have a higher impact of contexts and people's wellbeing.

Authors' contributions

The first Author reviewed literature and wrote the paper; the remaining Authors collaborated with the revision of the paper.

Compliance with ethical standards

The Authors, in accordance with the policy of their institutional review board, obtained the approval of the research by the Internal Scientific Committee.

Conflict of interest statement

The Authors declare that they have no conflict of interest.

Informed consent

Informed consent has been obtained by the Authors, for the patients involved in the study, and no reported data can be referred to individual identity.

Submitted on invitation.
Accepted on 19 March 2020.

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