Protective and risk factors of health in caregivers of people with autism spectrum disorders

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Abstract
Introduction
Caring for people with autism spectrum disorders has been related to several consequences for caregiver’s health. Informal caregiving is recognised to lead to chronic stress, in which there is often alteration of physiological systems, in particular, the endocrine, immune and autonomic nervous systems. However, several variables have been shown to modulate these effects and can therefore be considered protective or risk factors for caregivers’ health. Risk factors have been investigated in multiple studies, but there has been less research on protective factors of health. The main aim of the present critical review is to analyse and integrate research about health disruption in caregivers of people with autism spectrum disorders, considering protective and risk factors that have been found to be health modulators.

Conclusion
Caregivers of people with autism spectrum disorders have poorer health outcomes than the general population. Higher levels of resilience, emotional intelligence, and social and institutional support have been shown to be protective factors, while maladaptive coping, more severe autistic symptoms and behavioural problems of the care recipient and emotional contagion of caregivers have been found to be risk factors for health disruption in this population. Although various interventions have considered some of these variables, there is no integrative model for interventions in this population, including both protective and risk factors. To fill this gap, we suggest an integrative model based on the available evidence. This model could guide clinicians when implementing preventive and treatment intervention programmes for reducing health complaints in caregivers of people with autism spectrum disorders.

Introduction
Autism spectrum disorders (ASDs) are characterised by difficulties in communication, social interaction problems, repetitive patterns of behaviour and restricted interests. Due to the chronic nature of ASDs, caring for offspring with this diagnosis entails being under high levels of stress for a long time. In turn, this could produce alterations in the body’s homeostasis, considering that caregivers have cope with numerous challenges every day associated with their caregiving role. In particular, these daily challenges could suppose a threat for allostatics, a set of processes that allow the body to maintain homeostasis under changing environmental demands. Consequences of this chronic stress exposure have been demonstrated when physiological systems involved in these processes and self-reported health have been evaluated in previous research.

The main aim of the present review is to characterise the impact of caregiving on caregivers’ health by reviewing the principal studies conducted in this population in which biological and self-reported markers of health have been analysed. Furthermore, it also seeks to identify the protective and risk factors that have been shown to modulate the association between caring for an offspring diagnosed with an ASD and health outcomes. Finally, an integrative model will be proposed including the variables that have been found to have a protective effect or to enhance health disruption in caregivers.

Discussion
The authors have referenced some of their own studies in this review. These referenced studies have been conducted in accordance with the Declaration of Helsinki (1964) and the protocols of these studies have been approved by the relevant ethics committees related to the institution in which they were performed. All human subjects, in these referenced studies, gave informed consent to participate in these studies.

Endocrine and immunological alterations
Although few studies have analysed immune and endocrine system markers of health in caregivers of people with ASDs, recent research has revealed serious impairment of both systems in this population. As previously described, caring entails high levels of stress. This fact has been related to altered endocrine function through the disruption of the hypothalamic-pituitary-adrenal axis (HPA), cortisol awakening response (CAR) being one of the most studied markers of HPA functioning. CAR is characterised by increased levels of cortisol from awakening to approximately 30 min later, it is been suggested that an increase in cortisol level of 2.5 nmol/L is a normal...
rise. This response could be altered in individuals undergoing chronic stress, and its alteration has been found to have health-related effects. Although one study did not find differences in CAR between caregivers and non-caregivers, a recent study showed higher CAR in the former, attributing this to an effect of the anticipation of care demands. Following the anticipation hypothesis, secretion of morning cortisol is known to depend on the anticipation of the upcoming demands perceived by individuals. According to this explanation, caregivers could perceive greater demands on them than non-caregivers, and this fact could explain their higher cortisol levels.

Furthermore, when the functioning of the HPA axis has been analysed through cortisol responses to laboratory stress, caregivers of adolescents and adults with ASDs showed a blunted cortisol response compared with caregivers of children with ASDs. These results support the idea of an altered endocrine system in caregivers of people with ASDs, this being more pronounced in caregivers with older offspring.

An alteration in the HPA axis entails negative consequences for health, one of the proposed mechanisms being the disruption of related immune functioning. A recent study has shown that caregivers of people with ASDs presented lower levels of immunoglobulin A (an antibody involved in immune processes), than non-caregivers, in response to laboratory stress. Furthermore, higher levels of C reactive protein, a proinflammatory biomarker, have been observed in caregivers compared with non-caregivers. Other markers of immune status, such as the antibody response to vaccination, have also been found to be altered in caregivers of people with ASDs.

**Autonomic alterations**

Autonomic nervous system (ANS) is another system that is closely related to the stress response and health, electrodermal activity (EDA) being one indicator of its functioning. In response to laboratory stress, caregivers of people with ASDs exhibited lower EDA compared with non-caregivers and, in addition, the associations between EDA and somatic symptoms were different in caregivers and non-caregivers. While a higher EDA was related to poorer health in caregivers, the opposite association was found in non-caregivers. A chronically stressful situation such as caring for offspring with ASDs could modulate the relationship between emotional responses and health. In the context of caregiving as a source of chronic stress, this predisposition could be detrimental to the health of caregivers. Nevertheless, the aforementioned hyperreactivity could have protective effects in caregivers. Having lower responsivity than the general population could entail developing a capacity for controlling emotional responses, which would, in turn, help maintain homeostasis. Our group have previously suggested that such a capacity could be an adaptive process to reduce disruption, including health complaints, caused by high levels of chronic activation. That is, a constant state of alert in individuals under chronic stress could have negative consequences for health.

On the other hand, caregivers showed higher mean systolic blood pressure than non-caregivers. This fact could be related to the risk of cardiovascular disease being higher in caregivers than non-caregivers and confirms the altered functioning of the ANS in this population.

**Self-reported health**

The majority of studies analysing health status in caregivers of people with ASDs have considered self-perception of health (rather than biological indicators). With this approach, significant differences have been observed in perceived health between caregivers and non-caregivers. Caregivers of people with ASDs have a poorer perceived general health and quality of life, as well as a higher number of somatic symptoms than non-caregivers. Furthermore, caregivers presented higher rates of depression and anxiety symptoms and of social dysfunction. While it has been demonstrated that caregivers of people with ASDs suffer from poorer health outcomes, studies have also identified several psychosocial and psychological trait variables of caregivers and characteristics of care recipient that could dampen or enhance the association between caring and health disruption. Results of studies investigating these protective and risk factors of health affection in caregivers will be considered in the following section.

**Risk and protective factors of health**

Although increasingly researchers are considering protective factors for health in caregivers of people with ASDs, the majority of classical studies have been focused on risk factors.

**Autistic symptomatology and behavioural problems**

The most studied risk factors have been those related to autistic symptomatology and functionality of the offspring. The severity of autistic symptomatology has been associated with a greater impairment of health. However, behavioural problems prevail over autistic symptoms in studies in which the two variables have been compared. This pattern is attributable to the functionality and the severity of the ASDs studied. Hence, in high-functioning autism behavioural problems of the offspring are likely to prevail over autistic symptoms; however, this might not be the case in classical autism.

**Coping**

Although several studies have reported that problem-oriented coping...
could be beneficial for caregivers’ health compared with emotional and escape coping, a recent study has indicated that cognitive escape coping could also protect health in caregivers. It seems that the effects of coping on health status depend on other variables, such as the perceived control in the face of challenges associated with the caregiving role. Specifically, caregivers with high-perceived control of the care situation could benefit from active coping strategies. However, caregivers with low-perceived control could benefit from other types of coping strategies focused on escaping from the source of the stress, in this case, the care recipient. Indeed, several studies have concluded that respite interventions, involving removing the caregiver from the stressor, are the best approach for improving health in caregivers. In this regard, institutional support for caregivers offering (among other services) respite care for the care recipient could have enormous benefits in this population, as will be explained below.

Regarding protective factors, recent studies have evaluated the effects of social support, institutional support and various other trait variables of caregivers, such as resilience and emotional intelligence (EI).

Institutional support
Access to institutional support (specifically, multidisciplinary support organised by a patients association, including self-help, training, leisure activities and psychological therapy) has been found to have beneficial effects on the health status of caregivers of people with ASDs. In a recent study, self-reported health and CAR were compared in institutionalised caregivers, non-institutionalised caregivers and non-caregivers. Non-institutionalised caregivers reported more gastrointestinal symptoms and a buffered CAR response than those in the other two groups. Further, although in supported caregivers, the area under the curve of the cortisol response was higher than in the other two groups, cortisol levels were similar to those obtained in non-caregivers. These findings reinforce the importance of institutional support through multi-component interventions for improving the health of family caregivers. In the light of the results, it could be hypothesised that institutional support reduces stress perception and care demands, this being reflected in the reduced somatic symptoms and CAR alterations in supported caregivers compared with those who did not receive this type of support.

Social support
Several studies have reported lower perceived social support in caregivers than general population, probably due to the social isolation characteristic of the care context. Specifically, caregivers reported less structural and perceived social support than non-caregivers. On the other hand, this factor has a protective effect for health complaints in this population. Higher levels of social support have been associated with an adaptive CAR, lower systolic blood pressure and better health outcomes. Furthermore, social support mediates the association between resilience and perceived general health in this population. Higher resilience was related to high-social support, probably because resilience enables individuals to look for social support in an effective manner. However, at the same time, the availability of social support could be higher in resilient caregivers, since they may maintain better social networks and thereby receive greater social support, protecting their health status.

Empathy
As explained, there is a strong association between the severity of autistic symptoms of the care recipient and health outcomes in caregivers. Our recent research has shown that this association is mediated by the empathic traits of caregivers. Empathy can be divided into cognitive (the intellectual ability to identify the feelings and thoughts of others) and emotional (the sharing of the emotional experience of another person) empathy and only the components of emotional empathy seem to mediate this association. In the case of anxiety, personal distress was the only significant mediator, whereas for depression, both emotional empathy components (empathic concern and personal distress) were significant mediators. It could be supposed that higher emotional empathy enhances emotional contagion in caregivers and, therefore, promotes psychological disruption.

Resilience
Caring for offspring with ASDs has shown to be a promoter of resilience in the caregivers. However, few studies have analysed the association between resilience and health outcomes in this population. Our recent study has shown that resilient coping is a protective factor for health complaints. Specifically, higher scores in resilience were associated with less anxiety, insomnia, and depression as well as fewer somatic symptoms. Moreover, caregivers with high resilience had lower morning cortisol levels than those with low resilience. These results could indicate that low resilience in caregivers compromises their ability to bounce back from the stress derived from caring. Indeed, it has been postulated that highly resilient individuals have an ability to keep the HPA axis in an optimal range of functioning – with an effective adaptation of this axis to the stressful situation.

Emotional intelligence
EI has shown a protective effect for health disruption in several populations. In our recent study different associations have been found

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between each component of EI and health outcomes. Although, the factor clarity was related to lower rates of somatic symptoms and better perceived general health, attention was associated with a larger number of symptoms and poorer perceived general health. Furthermore, caregivers with low attention to feelings and high clarity and repair abilities had lower morning cortisol levels. Following the insensitivity hypothesis, caregivers may be aware of the negative emotions in life, but some individuals have an ability to repress thoughts about these feelings or avoid this type of emotions. This explanation is similar to that proposed in our previous study in which we found that escape-style coping could have a protective effect for health disruption in ASD caregivers. This fact takes on special relevance in the care context, in particular, given the high levels of negative emotions promoted by caring for people with ASDs.

Conclusion
Marked health disturbances in caregivers of people with ASDs have been described along studies. This effect has been replicated after employing biological markers of health, which are more objective and reliable indicators than subjective and self-reported measures. However, the association seems not to be direct, as several variables modulate the negative consequences on health. Specifically, characteristics of the offspring, fundamentally variables reflecting the severity of their autistic symptoms and behavioural problems, seem to be among the most important risk factors for health complaints in caregivers. Other variables related to caregivers themselves, such as coping and emotional contagion, have also a significant weight in modulating health consequences in caregivers. Results are mixed regarding coping, whereas emotional contagion seems to be detrimental for psychological functioning, being associated with high rates of anxiety and depression. Less attention has been paid to positive variables and their ability to protect caregivers’ health. So far, resilience, EI, institutional and social support have been found to have this effect. On the basis of this analysis, we propose a theoretical model integrating the analysed risk and protective factors of health in caregivers of people with ASD (Figure 1).

Future studies are necessary in order to analyse the application of this model in prevention and intervention programmes aiming to reduce health disruption in caregivers of people with ASD. Establishing and validating effective interventions, based on the variables analysed, would produce an important advance in the prevention and treatment of health problems in caregivers of people with ASDs. Furthermore, such models allow protocols to be developed to help professionals assess the risk of caregivers’ health being affected by their caregiving role. That is, clinicians would be able to classify caregivers based on their risk of specific health disturbances, creating profiles and justifying the implementation of psychological interventions for certain groups of caregivers. Preventing health disturbances would be likely to reduce the costs associated with caregiving, taking into account the high rates of medical visits, medication consumption and overall use of healthcare resources by caregivers.

Abbreviations list
ANS, autonomic nervous system; ASD, autism spectrum disorder; CAR, cortisol awakening response; EDA, electrodermal activity; EI, emotional intelligence; HPA, hypothalamic-pituitary-adrenal.

References


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