

What about the siblings? Self-regulation, agency, and quality of life in siblings of children with Celiac Disease

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Introduction

Over the past 25 years, there has been an increasing prevalence of celiac disease [1]. This is a chronic, multiple-organ, autoimmune disease in genetically predisposed individuals, precipitated by the ingestion of gluten. There is no cure for celiac disease; only strict adherence to a gluten-free diet can prevent both short and long-term consequences [2]. However, associated food-related restrictions, and its implications, can have a serious impact on the individual's dietary consumption, social interactions, family's dynamics, and economic costs [3]. Confronted with this life-long situation and close monitoring requirement, impact of the celiac disease is not circumscribed to the individual with the diagnosis, but also to caregivers and extended family [4,5]. Little attention has been given to the impact of celiac disease on siblings, who share common genetic and the same within-family environment [5,6]. Particularly in case of children, during key developmental periods of childhood, detrimental consequences can be more serious on emotional and behavioral issues [4,6].

Method

The main goal of this project is to evaluate the role of self-regulation and agency processes in the quality of life and school achievement of siblings of children with celiac disease. Thus, a book chapter, a systematic review, and two empirical studies (qualitative and quantitative) will be performed.

Analysis and results

Results from the chapter and systematic review show that how life-style restrictions affect quality-of-life and emotion regulation of siblings vary across individuals depending on how effectively they use self-regulation strategies. Self-regulation comprises processes that allow individuals to control personal, behavioral, and environmental influences that affect human actions [7]. Research shows that individuals can be taught how to self-regulate their behavior and improve their confidence in successfully self-managing their behaviors to achieve a desired outcome [8]. Children who self-regulate their behavior have low likelihood of displaying externalizing and internalizing problems; tend to be high achievers academically and reach higher education qualification later in life; and tend to have a low likelihood of long-term unemployment in adulthood [9]. Recent studies suggest a better compliance to a gluten-free diet when self-regulation strategies are combined with agency, i.e., the ability to influence one's functioning and the course of events by one's actions [10,11].

Conclusion

Next steps of this project involve the development of a qualitative study with semi-structured interviews to the sibling, parents, and the child with celiac disease, aged 12-19 years, to explore the functioning, structure, and autonomy in Portuguese families that live with celiac disease, as well as the relationships between siblings and parents and their use of self-regulation strategies. Additionally, a quantitative study will be conducted online to assess the relationships between variables that mediate quality-of-life, emotional self-regulation, and school achievement, with the possibility of extending this study to other countries. Results will provide in-depth knowledge that will contribute to the development of effective guidance for families and health professionals. This project also aims to raise awareness to this topic, reinforcing the key role of psychology advocacy in improving the disease management and relationships of all involved.

Acknowledgements

This PhD Project is supported by a PhD studentship (2020.07940.BD) of the Portuguese Foundation for Science and Technology (FCT; Fundação para a Ciência e a Tecnologia, I.P.), funded with allocations from the State Budget of the Ministry for Science, Technology and Higher Education and with allocations from the European Social Fund, to be made available under PORTUGAL2020, namely through the North Regional Operational Program (NORTE 2020).

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