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COMMUNICATION BETWEEN PARENTS OF AUTISTIC CHILDREN AND HEALTH PROFESSIONALS: CONSTRAINTS AND PROSPECTS FOR IMPROVEMENT

LA COMMUNICATION DES PARENTS D'ENFANTS AUTISTES AVEC LES PROFESSIONNELS DE SANTE : CONTRAINTES ET PERSPECTIVES D'AMELIORATION

COMUNICAÇÃO ENTRE PAIS DE CRIANÇAS AUTISTAS E PROFISSIONAIS DE SAÚDE: RESTRIÇÕES E PERSPECTIVAS DE MELHORIA

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Abstract. Autism Spectrum Disorders are a complex set of neurodevelopmental disorders, characterized by a qualitative alteration in social interaction, verbal and non-verbal communication, and restricted, stereotyped behavior. To remedy this communication deficit, a partnership between parents of autistic children and healthcare professionals is essential for the successful medical and psychological care of these children. The expertise of parents would help to improve the identification of the child's difficulties and resources by the care team, with a view to listing elements that are unrecognizable and unobservable within the care structures. To develop a bibliographical review aimed at understanding the constraints to communication between parents of children with autism and healthcare professionals, while proposing prospects for improving this partnership two databases, PubMed and Google Scholar were utilized. The inclusion criteria concerned articles in French and English published up to 2024 using the keywords "parents of autistic children", "communication", "barriers", "constraints", "health professionals", "care", "patient management". Twenty (20) articles were selected. The main constraints to communication between parents of children with autism and professionals in care facilities are related to health literacy about autism and the perception of each of the therapeutic partners in the care of children with autism. For healthcare staff, several studies report a lack of knowledge about autism, a lack of training and work overload. They also note a poor use of communication techniques, accentuated by cultural differences between parents and healthcare professionals, leading to a divergence in their perception of this disability. As for the parents, they report a high level of stress and a deterioration in their quality of life. This parental stress remains an experience influenced by parents' expectations and mistaken beliefs about the disorder. Furthermore, parents of children with autism, because of their need for social and emotional support and their difficulty in understanding information conveyed in technical language by healthcare professionals, experience a lack of trust in care providers. To improve communication between autism therapeutic partners, it is crucial to strengthen the training of healthcare professionals so that they are better equipped to interact with families, implement strategies to reduce parents' stress, and increase their level of health literacy. Communication between parents of children with autism and healthcare professionals is undeniably the cornerstone of the success of the child's therapeutic project. However, several constraints often hinder this essential communication. Strategies for improvement must be adopted in order to establish a constructive dialogue and foster an environment conducive to the development of the autistic child.

Keywords: Autism; communication; partnership; parents of autistic children; healthcare professionals

Résumé. Les Troubles du Spectre Autistique sont un ensemble de troubles neurodéveloppementaux complexes, caractérisés par une altération qualitative des interactions sociales, de la communication verbale et non verbale, et des comportements restreints et stéréotypés. Pour remédier à ce déficit communicationnel, un partenariat entre parents d'enfants autistes et professionnels de santé apparaît comme une évidence pour réussir la prise en charge médicale et psychologique de ces enfants. L'expertise des parents contribuerait à améliorer l'identification des difficultés et des ressources de l'enfant par l'équipe de soins en vue de répertorier des éléments méconnaissables et non observables au sein des structures d'accueil. Élaborer une révision bibliographique visant la compréhension des contraintes à la communication entre les parents d'enfants autistes et les professionnels de santé tout en proposant des perspectives d'amélioration de ce partenariat. Il s'agit d'une étude bibliographique effectuée dans deux bases de données PubMed et Google Scholar. Les critères d'inclusion concernent les articles en français et en anglais publiés jusqu'à 2024 en utilisant les mots clés « parents d'autistes », « communication », « barrières », "Contraintes", "Professionnels de santé", "Prise en charge", " Soins". 20 articles ont été retenus. Les principales contraintes liées à la communication entre parents d'enfants autistes et les professionnels des structures d'accueil sont liées à la littératie en santé relative à l'autisme et la perception de chacun des partenaires thérapeutiques dans la prise en charge des autistes. Pour le personnel de santé, plusieurs études rapportent un manque de connaissances sur l'autisme, un manque de formation et une surcharge de travail. Elles notent aussi une mauvaise utilisation des techniques de communication, accentuée par la différence culturelle entre les parents et les professionnels de santé, ce qui induit une divergence de leur perception sur ce handicap. Quant aux parents, ils manifestent un niveau de stress élevé et une altération de leur qualité de vie. Ce stress parental demeure un vécu influencé par les attentes des parents et leurs croyances erronées sur le trouble. De plus, les parents d'enfants autistes, en raison de leur besoin de soutien social, émotionnel et les difficultés à comprendre les informations transmises au moyen d'un langage technique par le professionnel de santé, éprouvent un manque de confiance envers les prestataires de soins. Pour améliorer la communication entre les partenaires thérapeutiques de l'autisme, il est crucial de renforcer la formation des professionnels de santé afin qu'ils soient mieux équipés pour interagir avec les familles, de mettre en place des stratégies pour réduire le stress des parents, et d'augmenter leur niveau de littératie en santé. La communication entre les parents d'enfants autistes et les professionnels de santé constitue indéniablement la pierre angulaire du succès du projet thérapeutique de l'enfant. Cependant, plusieurs contraintes entravent souvent cette communication essentielle. Des stratégies d'amélioration doivent être adoptées afin d'établir un dialogue constructif et favoriser un environnement propice au développement de l'enfant autiste.

Mots clés : Autisme ; communication ; partenariat ; parents d'autistes ; professionnels de santé.

Resumo. Os Transtornos do Espectro do Autismo (TEA) são um conjunto complexo de distúrbios do neurodesenvolvimento caracterizados por uma deficiência qualitativa na interação social, na comunicação verbal e não verbal e no comportamento restrito e estereotipado. Para remediar esse déficit de comunicação, uma parceria entre os pais de crianças autistas e os profissionais de saúde é essencial para que essas crianças sejam bem-sucedidas nos cuidados médicos e psicológicos. A experiência dos pais ajudaria a melhorar a identificação das dificuldades e dos recursos da criança pela equipe de atendimento, com o objetivo de listar elementos irreconhecíveis e não observáveis nas estruturas de atendimento. Elaborar uma revisão da literatura com o objetivo de compreender as limitações na comunicação entre os pais de crianças com autismo e os profissionais de saúde, sugerindo maneiras de melhorar essa parceria. Este foi um estudo bibliográfico realizado em dois bancos de dados, PubMed e Google Scholar. Os critérios de inclusão foram artigos em francês e inglês publicados até 2024 usando as palavras-chave "pais de crianças autistas", "comunicação", "barreiras", "restrições", "profissionais de saúde", "gerenciamento" e "cuidados". Foram selecionados 20 artigos. As principais restrições à comunicação entre os pais de crianças com autismo e os profissionais das instituições de saúde estão relacionadas à alfabetização em saúde sobre o autismo e à percepção de cada um dos parceiros terapêuticos no atendimento de crianças com autismo. Em relação à equipe de saúde, vários estudos relatam a falta de conhecimento sobre o autismo, a falta de treinamento e a sobrecarga de trabalho. Eles também observam um uso inadequado de técnicas de comunicação, acentuado pelas diferenças culturais entre os pais e os profissionais de saúde, o que leva a uma divergência na percepção dessa deficiência. Quanto aos pais, eles relatam altos níveis de estresse e uma deterioração na qualidade de vida. Esse estresse parental continua sendo uma experiência influenciada pelas expectativas dos pais e suas crenças errôneas sobre o distúrbio. Além disso, os pais de crianças autistas, devido à sua necessidade de apoio social e emocional e às dificuldades que têm para entender as informações transmitidas em linguagem técnica pelos profissionais de saúde, sentem falta de confiança nos profissionais de saúde. Para melhorar a comunicação entre os parceiros do tratamento do autismo, é fundamental aprimorar o treinamento dos profissionais de saúde para que eles estejam mais bem equipados para interagir com as famílias, implementar estratégias para reduzir o estresse dos pais e aumentar o nível de alfabetização em saúde. A comunicação entre os pais de crianças com autismo e os profissionais de saúde é inegavelmente a pedra angular do sucesso do projeto terapêutico da criança. No entanto, várias restrições frequentemente dificultam essa comunicação essencial. Estratégias de melhoria devem ser adotadas para estabelecer um diálogo construtivo e promover um ambiente favorável ao desenvolvimento da criança autista.

Palavras-chave: Autismo; comunicação; parceria; pais de crianças autistas; profissionais de saúde

1. INTRODUCTION

In the field of autism, there are major relational and communication challenges. Indeed, communicating with autistic people and their families remains a crucial component in their support and accompaniment in the care project. The information given to parents must help them better understand their children's situation, their needs and the sources of support available, so that they can make informed decisions about their health and that of their children with Autism Spectrum Disorders (ASD). Furthermore, parents of people with autism and the professionals involved report certain difficulties and especially unmet information needs, particularly during the period surrounding the announcement of the diagnosis (Brown et al.,2012; Courcy et des Rivières-Pigeon,2019; Weiss et al.,2014). Indeed, the lack of accurate, accessible, useful and easy-to-understand information is deplored by most parents of autistic children.

A number of constraints on communication between parents of children with autism and healthcare professionals are mentioned in the literature. To reflect the scope of this disorder, these obstacles will be grouped by theme and discussed in this work to address concerns about the need to develop communication tools that facilitate the transfer of information about autism between professionals in care structures and parents of autistic children.

This bibliographical review is part of our drive to improve communication and the transfer of information on current knowledge about autism. It presents the main findings we have identified from this literature regarding the production of tools to support professionals and parents in the context of autism. Several distinct factors influencing this communication will be addressed, with particular attention to autism literacy issues, parents' and professionals' perceptions of this topic; parental stress and the need for support expressed by parents of autistic children through their interaction with providers of care structures specializing in the management of this disability.

The synthesis of recommendations from the literature in this bibliography will serve as a theoretical foundation for addressing the challenges faced by parents and healthcare professionals in this care project to improve communication in this therapeutic climate.

2. INCLUSION AND EXCLUSION CRITERIA

2.1. Inclusion criteria

The search was limited to studies published between 2009 and 2024 that addressed the topic of communication by caregivers in the field of autism in children.

2.2 Exclusion criteria

This search excluded all publications dealing with communication in general. In addition, studies on other neurodevelopmental disorders in children were not considered. Review studies or clinical trials were also excluded if they did not provide data consistent with the aim of the present study.

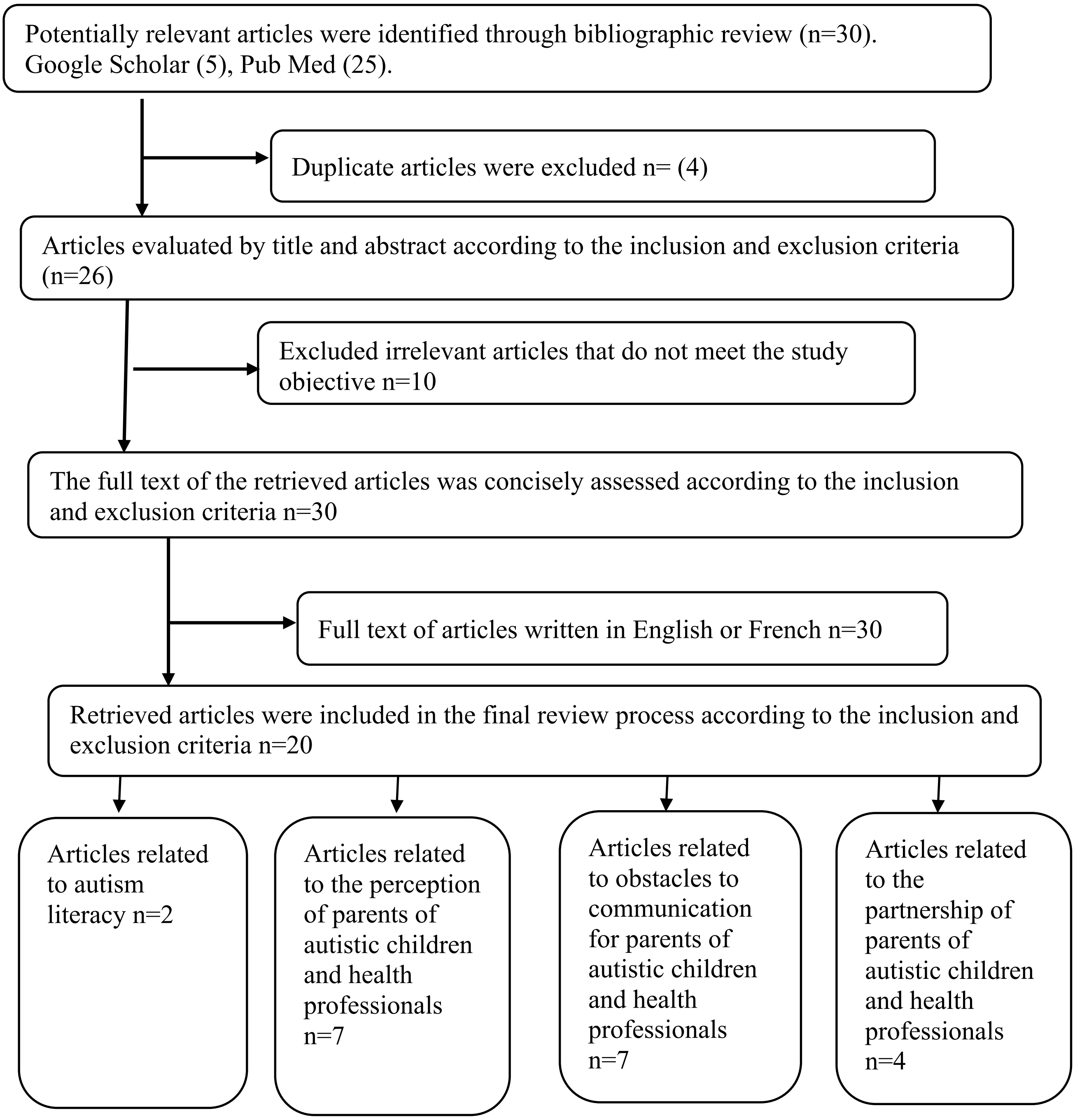

Figure 1. Methodology for processing and summarizing articles

3. RESULTS AND DISCUSSION

3.1. Literacy in the field of autism

In health, literacy refers to the knowledge, motivation and skills needed to find, understand, evaluate and use health information in order to make informed decisions regarding the use of services or support and preventive or health promotion measures, in order to maintain or improve health and quality of life. (Sørensen et Coll.,2012).

This definition is in line with the integrated and systemic approach of Sørensen and colleagues (2012), who see health literacy as the result of interactions between individuals, the healthcare system and the overall socio-political context in which these individuals consult, interpret and make choices in relation to their health. Health literacy is strongly correlated with people's health behaviours and the intensity of their use of services and care (Frisch et al.,2012). This is a very good predictor of health status, and an important factor in health care disparity (or equity) (Speros,2005). As for autism literacy, it enables parents to make more informed choices and helps them to better care for and support their autistic children so that they develop optimally. These skills also enable them to take better care of their own health. Yet research on autism literacy is almost non-existent (Godfrey Born et al.,2019; Lajonchere et al.,2016).

Literacy among parents of children with autism

Difficult access to specialized or support services, due to complex administrative procedures or waiting lists, can lead parents to misunderstand and misinterpret the information provided by healthcare professionals.

Information on autism is often presented to parents in the context of educational programs designed to enable them to continue at home the interventions initiated by rehabilitation professionals (Bearss et al.,2015a; Steiner et al.,2012). Research suggests that these interventions could be more effective if they were more focused on parents' needs, particularly their need for information and support (Smith et al.,2018; Steiner et al.,2012). This research confirms the need for more effective communication to support parents whose child has recently been diagnosed with ASD.

In this context, literacy can be understood in terms of four dimensions:

- **Access to information:** This is not enough to meet the needs of parents of children with autism in the period surrounding diagnosis. These different needs point to the need for parents to have access to various forms of informational, emotional, instrumental and recreational support.
- **Information comprehension:** Parents have risk factors associated with low literacy levels, and have expressed greater difficulty in understanding information, especially written texts.
- **Interpretation of information:** Reflects parents' sense of negative judgments about their child's behaviours, compounded by unfavourable and erroneous beliefs. This feeling is often accentuated by a sense of stigmatization that also stems from a lack of information about autism (Heidgerken et al.,2005; Jensen.,2016; Khanna et Jariwala,2012; Pescosolido,2008).
- **Use of information:** The complexity of accessing the health and social services network has been identified as a factor that can hinder informed decision-making by parents of children with autism. Complex administrative procedures and long waiting lists make access to specialized services and support difficult and can lead parents to misunderstand the information they receive. Furthermore, they may accept professionals' proposals without really understanding the implications and consequences for their support in optimizing their child's care.

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Parents need to benefit from different forms of social support, and not exclusively informational support, in order to improve their autism literacy skills. We need to rethink the design of communication around the diagnosis and its evolution in order to minimize stress for parents, and undertake targeted strategies to support parents in vulnerable situations.

Literacy among healthcare professionals

These professionals may also lack the precise information or know-how to respond to the needs and expectations of parents of autistic children. Their lack of knowledge about autism, as well as their erroneous beliefs, preconceived ideas and inadequate practices, are likely to further delay diagnosis and care. This delay is attributed to the persistence of inappropriate therapeutic approaches in the field of autism. Numerous studies have revealed wide variations between healthcare personnel in terms of their ability to identify autistic behaviours in children. (Kalra et al.,2005 ; Igwe et al.,2011 ; Bakare et al.,2009 ; Heidgerken et al ,2005).

3.2. Parental perception

Parental perception of the autistic child's development can also influence decision-making about parental involvement and commitment to their child's care and intervention (Hebert et Koulouglioti,2010a). In this respect, these parents express the need to receive a more optimistic message from healthcare professionals, particularly when they request information about their child's prognosis (Hennel et al.,2016).

Thus, it is important for them to situate their information and social support needs in a broader perspective in order to highlight the various forms of social support useful to parents of children with ASD, and in particular to those in vulnerable situations and with risk factors associated with low health literacy (Crane et al.,2018).

3.3. The perception of healthcare professionals

Among healthcare professionals, there is a frequent lack of consideration for parents of autistic children. This feeling of family isolation can be aggravated by certain attitudes or words spoken by professionals deemed inappropriate to the situation they are experiencing. At the same time, parents often criticize care institutions for the reluctance of certain professionals to make a formal diagnosis, which sometimes minimizes or even denies the existence of certain disorders, leaving parents without answers and children without appropriate support during this diagnostic wandering.

There may be differences in the perceptions of professionals and parents of children with ASD about the significance of children's behaviours, the outcome of the diagnosis, and the perceived potential impact of a diagnosis in relation to access to social support and psychological resources. However, the ability to “see” autism remains a socially situated activity, confined to the context of the professional assessment process (Pilnick et James,2013).

3.4. The partnership between parents of autistic children and the professionals involved in their care

Partnership is the most demanding type of relationship, which can be a challenge to establish. This process is based on two-way communication, includes a range of collaborative activities and involves power-sharing and recognition of each other's expertise (Cantin, 2004; Cantin,2008; Coutu&al.,2005; Epstein & al,1997; Moreau & Boudreault,2002; Prezant & Marshak,2006), with a view to achieving a common goal.

Conversely, the scientific literature shows that there are also elements that could hinder the partnership between parents and healthcare professionals. State-of-the-art data reveal a lack of staff training, awareness-raising and ongoing training specific to ASD issues (Cantin, 2005), staff turnover (Odom et al.,2011 ; Dionne & al.,2014), lack of collaboration between parents and staff in the care setting (Dionne & al.,2017) , lack of financial and material resources, lack of openness and transparency on the part of the intervention team (Dionne & al.,2014), poor consistency between interventions, as well as a low rate of participation in interventions (Paquet.,2012).

Furthermore, the implementation of reciprocal communication comes up against obstacles such as the partners' personal characteristics, lack of flexibility in the perception of each other's role and power issues (perception of inequality between partners), the partners' attitudes, unfavorable beliefs and prejudices, as well as constraints linked to the spatiotemporal environment in which this exchange takes place (Cheatham & Ostrosky, 2011 ; Elliott,2005 ; Gonzalez-Mena,2008 ; MacNaughton & Hughes,2011 ; McGrath, 2007 ; Perlman & Fletcher, 2012 ; Saint-Pierre, 2004).

Certain attitudes considered to be at the core of the caregiver-client relationship are proving difficult for healthcare professionals to adopt when communicating with clients: empathy, authenticity and congruence. Added to these attitudes are authoritarianism, judgment, investigation and interpretation. These ways of communicating are likely to generate misunderstandings and misinterpretations, and consequently constitute obstacles to the adaptation of communication in this therapeutic climate. Conversely, successful interpersonal communication in a professional healthcare relationship presupposes cooperation between interlocutors. The latter are called upon to master a repertoire of communicative behaviours, they must demonstrate the ability to adapt to different speakers and communicative contexts, and also the capacity to achieve their professional and relational goals in a way that is compatible with the goals and needs of the patient or any other interlocutor encountered in the course of their duties (Street & al., 2003).

Nevertheless, for the exchange of information to be effective, professionals in reception facilities must use certain exchange strategies, namely identifying the content to be presented, taking into account the care context, the nature of the health problem, their individual characteristics and their needs. In addition, they are asked to adapt the information to the literacy level of patients and their families, particularly with regard to the diagnosis, treatment and prognosis of the disorder (Richard et Lussier,2009).

This relationship involves anticipating the risks likely to impede interpersonal interaction between parents of autistic children and healthcare professionals, and having the ability to manage potential interpersonal conflicts and disagreements likely to arise over definitions of the problem, expected goals, choice and modalities of treatment, and the roles of each in the therapeutic process (Beaudouin,1999).

Parents are still waiting for quality information during and after the formal diagnosis. This involves making available all the knowledge they need about ASD disorders, their specific features and modes of functioning, both before and after diagnosis. The impact of this critical period calls for health professionals to initiate procedures to support carers in their journey, while promoting their child's skills above and beyond his or her difficulties, and passing on to the socio-pedagogical approaches specific to this disorder, so that they can adjust their parenting attitudes.

3.5. Satisfaction of parents of autistic children with communication with healthcare professionals

From this point of view, parents' satisfaction with the therapeutic climate is more closely linked to the attitudes of healthcare professionals and the mobilization of their relational and communicational skills. Findings from the literature on parental dissatisfaction point to a cold attitude and poor communication skills on the part of healthcare providers, inadequate information, unanswered questions from parents, messages with negative connotations and inappropriate timing for informing about the prognosis of the ASD disorder. Indeed, most parents want to know the diagnosis as early and as completely as possible, to discuss issues of concern, to express their emotions, to use a provider with an encouraging and empathetic attitude, and to feel involved in their child's care (Quine et Pahl,1987; Sloper et Turner,1993; Hasnat et Graves,2000; Cottrell et Summers,1990). In addition, the vast amount of information available to parents needs to be organized to avoid overwhelming them.

In short, to remedy this lack of family satisfaction, a full explanation of the disability, instructions on coping strategies and psychosocial resources, and the opportunity for parents to ask questions are also communication facilitators favoring the satisfaction of parents of children with ASD. In this perspective, it is important for caregivers to demonstrate feelings of empathy and maintain the necessary motivation to help families and to solicit their effective participation in terms of the time and energy to be invested (Van Haren et Fiedler, 2008).

3.6. Parental stress

Support of healthcare professionals is often compromised by the level of parental stress, which is clearly higher in these parents of autistic children than in other parents of children of the same age. This stress varies in intensity depending on its impact on family functioning, and on families' perception of the particular situation in which they find themselves (Beckman,1996; Gardou, 2002; Shank et Turnbull,1993; Tétreault et Ketcheson, 2002). Parental stress refers to “a set of processes that lead to aversive physiological and psychological reactions resulting from the parent's attempts to adapt to the demands of parenthood” (Deater,2004). The source of parental stress is inherent in the discrepancy between the parent's perception of the demands of parenthood and the resources available to accomplish it. (Deater,2004; Mikolajczak et al., 2018).

In addition to the difficulty parents have in understanding, accessing and coordinating the services received from the various institutions and professionals involved in the autism therapy project, these are all factors that contribute to parental stress. (Desmarais et al., 2018; Hodgetts et al.,2017).

3.7. The need for support among parents of autistic children

The emotional support of parents by care professionals is correlated with this need for information to be accompanied and emotionally supported throughout the care project. This need includes three dimensions of support: sharing experiences with other parents, support from family members and friends and mainly psychological support from a professional qualified in this context. These parents must get used to their child’s disability. To be effective, these forms of support must be supplemented by training for parents to develop their knowledge of autism, equip them and support them in their parental role with their child.

Some studies have already shown that parents of children with ASD frequently express needs related to their child, particularly regarding interventions (Siklos and Kerns, 2006), and needs for informational support (advice and communication strategies) to better understand their child and interact appropriately with them (Bromley et al.,2004). However, as Sénéchal and des Rivières-Pigeon point out (Sénéchal and des Rivières-Pigeon, 2009), the assessment of parents' needs should be the subject of more exhaustive studies, in order to provide them with support and adapted services.

4. CONCLUSION

Communication between parents of children with autism and healthcare professionals is undeniably the cornerstone of the success of the child's therapeutic project. Communication enables the partners to establish their roles and mandates, to choose the objectives to be worked on together with the child, and to specify how to meet the child's needs. It also enables the partners to validate their understanding, recognize their shared successes and expose their questions, misunderstandings and emotions experienced through this process of partnership and support with the child with an ASD. However, several constraints often hinder this essential communication. Strategies for improvement must be adopted in order to establish a constructive dialogue and foster an environment conducive to the autistic child's development. This review of the literature shows the importance of changing partners' perceptions and developing their autism literacy in order to communicate effectively in the specific therapeutic climate of autism.

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