

The experiences of parents with tactile defensive children

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ABSTRACT

Aim: Tactile defensiveness is a phenomenon that infringes on the daily lives of many young children and their parents. This study explored the experiences of parents of children with tactile defensiveness. As primary caregivers, parents' experiences of the condition can give valuable insight into the possible considerations regarding intervention approaches used by professionals. Relatively little research has been done on the topic.

Method: A phenomenological framework was used, gathering the data via a thematic content analysis of interviews held with seven participants concerning their experiences of the condition.

Results: It became evident that many different areas of the parents' daily living were affected. Parents reported feelings of emotional turmoil in relation to their children, including frustration, exhaustion, incompetency and not having their own needs met. They experienced that having a child with tactile defensiveness influenced the parent-child relationship. Tactile defensiveness also impacted on siblings and the relationship between the parents. However, parents also reported that they found their own unique ways of dealing with the condition which enhanced their coping abilities. The important role of psychologists and occupational therapists in providing parents with information regarding tactile defensiveness were highlighted. The findings of this study aim to guide parents and professionals alike in the process of dealing with a child diagnosed with tactile defensiveness.

Key words: Tactile defensiveness, tactile, sensory integration disorder, processing disorders

Introduction

Of the five senses, touch is the first to develop in the human body¹. Its receptors are located in the largest organ, the skin, and have a profound influence on other systems such as cognition, language, motor skills, emotions and interpersonal interaction²⁻⁵. Abnormality or irregularity of responsiveness to touch may therefore impact on the physical, cognitive, emotional and social development of the child⁵.

Ayres⁶, one of the first authors to write on the phenomenon, defines tactile defensiveness as a perceptual dysfunction, where the tactile defensive person tends to react negatively or emotionally to normal touch sensations that one usually perceives as being neutral or positive. Common symptoms include patterns of sensory avoidance, anxiety, hyper-vigilance, irritability with certain clothing textures, exaggerated personal space, withdrawal from touch and exaggerated or unusual responses⁷.

Children with tactile defensiveness experience ambivalence between a need to be touched and negative responses to touch. The fact that children with tactile defensiveness react by using withdrawal and avoidance to touch, may be perceived as rejection by the parent^{8,5}. This problem may also interfere with the normal development of meaningful peer relationships, as these children tend to avoid interactions where touch is required and this may interfere with normal play, sport and affection. Tactile defensive children commonly display aggressive behaviour, inappropriate responses and increased motor reactions and may easily offend others.⁷ Tactile defensiveness may, therefore, impact on normal emotional regulatory processes.

According to Bronfenbrenner's⁹ bio-ecological model, there is a reciprocal relationship between a child and his/her environment. This implies that the child's microsystem which includes his/her experiences of bodily sensations will have a reciprocal effect on his/her mesosystem which includes his/her parents. Tronick¹⁰ postulated that the interaction between the infant and mother is a dyadic mutually regulating process, aiming to obtain a synchronous and pleasant state for both. The behaviour of one partner can be predicted by the behaviour of the other¹⁰. Synchronous positive behavioural exchanges are therefore seen as "matches" and nonsynchronous negative behavioural exchanges as "mismatches"¹⁰. Both the parent and the child aim to repair negative affective states¹⁰. For example, when overstimulated, the infant will communicate his discomfort

by distress or anger, upon which the sensitive mother will respond by modifying her behaviour¹¹. Factors within the mother, such as stressful family lives, health problems, unresolved issues from her own childhood or unrealistic expectations of motherhood may inhibit the mother's responsiveness to her child¹².

Parents are often not aware of, or don't understand the child's tactile defensiveness, and may, therefore, not be able to respond appropriately to the child's discomfort. They may experience the child as rejecting or hostile. The discomfort, irritation, inappropriate physical and emotional responses, or behavioural problems may place severe demands on the parent-child interaction² which may lead to parental stress. Parents of children diagnosed with disorders associated with disruptive behaviour experience higher levels of stress than parents of children diagnosed with a chronic medical condition¹³. Stress can be seen as a state where the individual judges his/her response capabilities as ineffective to overcome the threat posed on him/her¹⁴ and may lead to the parent doubting his/her capabilities to overcome the challenges that he/she faces in their parenting and interaction with a child with tactile defensiveness. For this reason the parent, as well as the child react with distress, and mutually elicit inappropriate or unhealthy responses, through which parent's and child's needs may be compromised.

Currently there is no research available on parents' experiences of their tactile defensive children, the role tactile defensiveness may play in the parents' interaction with their child or how parents cope with children with tactile defensiveness. Therefore, the aim of this study was to explore these aspects.

Method

Sampling method

A qualitative design was used in this study. Due to the nature of the specific variable (tactile defensiveness), participants were purposively selected. Occupational therapists in Potchefstroom and Newcastle (South Africa) were contacted to introduce the aims of the research to them. They were requested to discuss possible participation in the research with parents who had children with tactile defensiveness who might be interested in participating. The contact information of the parents who were interested in participating was supplied to the researcher. These parents were then contacted and the necessary arrangements made. Seven parental couples of



children diagnosed with tactile defensiveness, with ages ranging from 5-10 years (7 male and 3 female), were willing to participate. Of the 7 invited couples, only 1 couple dyad responded and in the remaining 6 instances only the mothers participated. Geographical distribution consisted of 5 participants living in the North-West province, and 2 participants living in Northern KwaZulu Natal.

The researchers were psychologists from the North-West University, Potchefstroom Campus. They received assistance from occupational therapists who used the Touch Inventory for Preschoolers as well as parent interviews and observation to identify children who demonstrated the characteristics of tactile defensiveness¹⁵.

Data collection and analysis

For this particular study a phenomenological approach was used as it is an exploratory method that allows the researcher to engage with participants who have experienced the phenomenon in question i.e. tactile defensiveness. Semi-structured interviews¹⁶ were conducted by the first author to gather qualitative data via the use of a situation in which the respondent is allowed the time and space to talk about their opinions on a focused subject. In this case the focus was on the parents' experiences of their tactile defensive children. Interviews were started with a general research question: "Tell me about your experiences as a parent of a child diagnosed with tactile defensiveness." Further questioning and probing was aimed at expanding responses to the general question.

All of the interviews were conducted by the first author at the participants' homes; a familiar environment in which they could freely share their experiences. Interviews were recorded on digital audiotape and transcribed verbatim afterwards. The transcribed data was then examined for the presence of themes that arose within the text by means of a thematic content analysis¹⁷. Themes extracted from the gathered data were identified and then integrated into meaningful descriptions of the essence of the phenomenon¹⁸. After the themes had been extracted, operational definitions were assigned to each and they were categorised according to primary and secondary themes. The majority of the interviewees were Afrikaans speaking and the interviews were translated into English. All findings were peer debriefed by means of repetition of the thematic content analysis by a second researcher¹⁹.

Ethical Considerations

All participants voluntarily participated in the study and gave informed consent for interviews to take place and data to be used in the study. The aims of the research as well as the participants' possible roles and contributions were discussed. Participants remain anonymous and as far as possible any information that may reveal their identities has been withheld or changed. All parents were aware that their child was diagnosed with tactile defensiveness (as identified by the occupational therapist) and all were in the process of treatment. No risk was involved in the questions answered by participants and therefore no harm was done. The study was approved by the Ethics Committee of the North-West University, Potchefstroom, South Africa.

Findings

The results were categorised in four main themes, namely: the parents' experiences of having children with tactile defensive syndrome and the accompanying emotional turmoil; the perceived effect tactile defensiveness has on the parent-child relationship; the effect on the family; and coping with tactile defensiveness. Each of the main themes is made up of a number of sub-themes.

Theme 1: Parents' emotional experiences of a child with tactile defensiveness

Parents reported feelings of high emotional turmoil in relation to their children with tactile defensiveness. They felt incompetent to handle the problems arising from having a child with tactile defensiveness, and that their own physical needs were not met. A lot of these emotions were caused and accompanied by feelings of ignorance and 'not understanding'.

Exhaustion: According to the parents who participated in the study there is a significant amount of physical and emotional strain that exacerbates the parenting experience. Due to this strain they felt a sense of energy depletion or exhaustion. There were a number of reasons why parents experienced this, ranging from children's irregular sleeping patterns "...so you get very little sleep and it is exhausting" (Parent #7) to the emotional demands they claim from parents: "...with him I was spiritually and physically exhausted..." (Parent #3).

Parents reported that their tactile defensive children were easily awoken and restless during sleep because they are irritated by bed sheets, and this leads to sleeping problems: "I was awake with him up to 18 times per night" (Parent #1). Parents shared that the experience of having children with sleeping problems invariably also had an effect on their own sleeping patterns, and consequent feelings of exhaustion.

Frustration, guilt and negativity: Parents reported that negative feelings such as resentment and disappointment were evoked within them as a result of the difficulties tactile defensiveness posed. They also testified that they felt guilty about the negative feelings toward their child, as well as the fact that they were not able to manage the condition perfectly. Feelings such as "frustration and guilt" (Parent #1), "feel bad" (Parents #4 & 5) emerged due to inability to understand and manage their child. Parent #3 reported: "I get mixed feelings, sometimes I really love my child, but there are days that I wished he wasn't there". The parents in this study experienced that the tactile defensive child demands so much special attention that they do not have sufficient time to actualise their own potential, and this even impacts on their careers. "If my child didn't have this problem, I would have been more career orientated" (Parent #1). These negative feelings experienced by the parents of children with tactile defensiveness were often accompanied by feelings of guilt.

Incompetency: It appears that parents doubted their ability to deal with the situation or to successfully administer the treatment. As Parent #3 said, "You feel incompetent; you wonder what you are doing wrong". Parents play a substantial role in the treatment process, such as in the application of the Sensory Summation Technique by Wilbarger and Wilbarger²⁰, which gives the parents specific guidelines to which they have to adhere. Many of them stated that they were unsure whether they were doing it correctly and effectively, and this uncertainty increased their anxiety. Some parents felt overwhelmed by the special needs of their children and were uncertain about their own competency to satisfy these needs. "It sometimes feels as if I am sitting with my hands in my hair" (Parent #6).

Parents' need for physical touch is not met: In the process of building an attachment relationship with the child, parents feel the need to touch, hug and kiss the child, but characteristic symptoms in tactile defensiveness include withdrawal from touch and avoidance of interaction. In this study parental needs were not met. Parent #3 said, "When I was pregnant with my first son, I dreamt of how we would play together, but when he was born he didn't even want me to hold him. He doesn't like it when you kiss him, you mustn't touch him, and you cannot even give him a hug". This often led to feelings of disappointment and loss: "It's hard when your child doesn't want you to hold him. It still is. You know when he comes and hugs me or sits on my lap; it's like manna from heaven. It's not something he often wants" (Parent #7). Parents perceived the child's withdrawal as rejection and subsequent emotional distress can occur "...it hurts me, because I like physical touch" (Parent #4).

A lack of information and knowledge about the condition: Most parents had never heard of the condition and reported not knowing that "such a thing existed" (Parent #4) (meaning "tactile defensiveness") until their child was diagnosed. It was an unfamiliar term with unpredictable consequences for them, and no way to conceptualise or make sense of it, and "ignorance made it very difficult" (Parent #2). The general experience was that even years after their child was diagnosed there is still a lack of information on the subject and parents find it difficult to explain to others exactly what is wrong with their child. What was astounding for them was the



fact that many professionals who had dealt with their children had no knowledge about the syndrome. Parent #1 commented: "Teachers are very ignorant about the whole thing and our children suffer".

Theme 2: Influence on parent-child interaction

It was reported by the parents that having a child with tactile defensiveness has an influence on the parent-child relationship. These children are handled differently, and parents acknowledged that they tend to overprotect these children and that parental-child conflict was experienced.

Change in the physical handling of the child: Due to the child's resistance to touch, the parents' physical handling of the child was compensating in nature. Parent #3 explained, "As a baby he never liked being held. I always had to hold him so that he is away from my body". Parents avoid gentle touch and they minimise it in order to keep the child comfortable, often using more pressure: "When I touch him gently he would say: "harder, harder, don't rub my back so softly" (Parent #4).

Parents' tendency to overprotect the child: The parents reported that they are often overprotecting their child and that they buffer the child against his/her environment. Nearly all participants stated that they felt a need to protect their children when they came into contact with others, to such an extent that they "keep him away from other people" (Parent #3) or avoid potential unfamiliar environments such as "dinner parties" (Parent #1). This over-protection is often inappropriate. "With him I react completely way-out because I want to protect him..." (Parent #4). In an attempt to regulate the child's behaviour, as Parent #6 explained, "you become overprotective and a control freak and it's difficult not to do all the child's external processing for her".

Increased conflict between parent and child: According to the parents in this study, there was an escalation in the frequency and intensity of conflict due to pent-up frustration and friction that occurs in the parent-child relationship. Parents describe the conflict as "clash" (Parent #2), leading to "fights, fights, fights!" (Parent #6). They experienced distress because of the emotional demands that the child placed upon them, as well as the effort of coping with the struggles that tactile defensiveness poses. Parents could often not understand why the children seem to be disobedient or "why these children do things differently" (Parent #2). All the parents reported that the conflicts were often the result of frustrations. The parents admitted that due to frustration they also often reacted in a hostile or negative manner, becoming "irritated and angry" (Parent #6). The parents' reactions were also often intense, as Parent #1 described: "...there are days of frustration that you as the mother want to throw a tantrum" while Parent #4 indicated: "You know, he drives me insane and I want to...sometimes I want to kill him".

Theme 3: The influence of tactile defensiveness on relationships in the family

Parents reported that having a child with tactile defensiveness also impacted on the siblings and sometimes caused marital problems.

Conflict between siblings: It appears as if younger siblings especially do not understand the condition and they become envious of the attention that the tactile defensive child gets and this escalates conflict between them, "...it definitely caused conflict between the children..." (Parent #3). Parent #5 explained: "...he hates kisses and it's a problem...my little girl loves kissing and hugging; she is very affectionate so she gets very hurt. So she will then fight with him". Some parents also reported that "...one child will feel that I am defending the other one" (Parent #3). Jealousy because of all the attention the tactile defensive child receives – also from professional people- emerged: "The other 2 children become envious, because X has a special aunt (psychologist) that she visits from time to time who gives her attention and they don't" (Parent #6).

Conflict in the parents' relationship: Managing the condition places high demands on the parents' frustration tolerance "...you become short tempered" (Parent #1), making them more vulnerable to distress; and predisposing them to conflict. Parent #3 explained: "...it definitely created conflict between my husband and me. Many times you are angry and stressed and then you fight and you

make comments about each other that are not true and you say and do things that hurt". Parents agreed that a lot of the conflict was related to sleep deprivation and becoming exhausted. Differences in the handling of the child also caused conflict in parents' relationship: "...my husband will get angry with me because I allow it and he doesn't" (this refers to situations when the child walks naked in the house because his clothes irritate him) (Parent #5).

Theme 4: Coping with tactile defensive children

Parents reported that having knowledge, as well as having certain personality traits helped them to cope with the situation. Sharing of the responsibility alleviated the stress they experienced. They also emphasised the role of the multi-disciplinary team in the treatment of the child.

Information clarifies the context of the child's behaviour: It was reported that once knowledge on the syndrome was gained, parents were able to interpret the child's behaviour within the context of the disorder. This insight helped to lessen the anxiety experienced and to help the parents understand the reasons why the child acts in a certain manner, like Parent #2 stated "...if you have the information it makes things easier, because now you know why they do certain things". Parent #3 indicated that reading about tactile defensiveness "helped". Knowledge facilitated the parents "to understand every little emotion that the child experiences" (Parent #6) and to realise that the child's emotion wasn't necessary angled at him/her. This parent said that reading and gaining knowledge was important as: "I realised that the child wasn't challenging me, it was all about the situation. To make that split is important, because then you understand that she isn't angry with you but with the world". The role of knowledge and the empowering effect it has was explained by Parent #2 who said: "...the occupational therapist gave me reading material and there was also a place in Johannesburg with a website and once I started reading it was easier to understand the child's symptoms". Parent #6, (who is an occupational therapist) agreed that knowledge helps parents to cope by saying "...if it wasn't for the fact that I am an occupational therapist myself and interested in this line of work, it would have been worse for me".

Character strengths within the parent. This specific sub-theme consists of character strengths that made it easier for parents to cope with the problem. Firstly, acceptance played an important role in dealing with the challenges as Parent #1 indicated: "I have accepted that my children need certain things from me and that is why I have put certain mechanisms in place..." It was found that when parents accept the condition as something chronic, but realise they can manage the situation, they were able to start adjusting and "...then you can relax about the small things" (Parent #2). Parent #5 explained: "I look at other people in town whose children have life threatening illnesses and then I think, whatever I have to go through with my boy is alright, I can deal with it".

Secondly, parents' assertive personalities made it easier to cope with the staring and judgmental eyes of the community. Specifically two parents stated that people would see that their child misbehaved, but they wouldn't dare interfere or point fingers because of the fact that the mother's assertiveness blocked it: "I think that teachers at the pre-school were cautious of me, because I am a 'and what is your problem'-type mother" (Parent #2) and "Anybody who knows me will tell you that I don't take any nonsense" (Parent #7).

Lastly hopefulness and experiencing that "...things are improving" (Parent #1) and realising that "...everybody has got problems..." (Parent #5) played a substantial role in the coping abilities of parents. Hope also emerged in statements such as "If my children can grow up happy and well, let this be my biggest burden" (Parent #5) and "...the way you love your child, is all that matters" (Parent #5). It is noteworthy that parents' character strengths played a substantial role in their coping with the syndrome. They used these strengths that were already available to them to overcome many of the challenges they faced. Parent #2 stated that "becoming older" also made her realise that "I am not perfect", and that it helped her in dealing with her child's tactile defensiveness and the conflict it causes between them.



Sharing of caretaking responsibilities brings relief: Some of the participants stated that there have been times that other people helped with the caretaking responsibilities. People such as nannies, family members and others gave parents the opportunity to do things that are usually not possible due to the required attention the child demands. According to participants, emotional and physical relief was experienced by having the opportunity to leave the child with somebody else at times. Parent #5 indicated: *"My husband and I recently went to a concert and we left him at my mom and it was really such a relief to know that I don't have to worry about him"*. Likewise Parent #7 said: *"...we sometimes leave her with our domestic worker and she is wonderful"*. To be able to leave the child with somebody else *"took away a lot of my tension and gave me time to breathe"* (Parent #1). The use of nannies, family members and other people was therefore essential for the group of participating parents.

The role of professional intervention in the management of tactile defensiveness: Parents perceive the multidisciplinary team as an important part in the treatment and management of the condition. In particular, all the parents in this study made use of occupational therapy and found it beneficial in that *"...occupational therapy helped to normalise and stabilise it..."* (Parent #6). All the parents stated that occupational therapy made a significant improvement in the child's aversion to touch. The supportive role of the occupational therapist was also explained by Parent #7 who said: *"I don't know what would have become of my child if there was no occupational therapist. It has a huge influence"*. Furthermore, the majority of parents agreed that psychologists played an important role as psychotherapy *"...helped her to effectively release her conflict"* (Parent #6). Even dieticians play an important role *"...to help me to keep his diet balanced"* (Parent #1). The role of a multi-disciplinary approach was also emphasised: *"the occupational therapist and the psychologist worked together during the time that my child was diagnosed and it was great! Every person is a specialist on their terrain and it was excellent for feedback"* (Parent #1). Making use of the multidisciplinary team gave some parents a sense of relief, possibly because their anxiety was lessened by the fact that somebody with more knowledge was helping them take care of the problem: *"It takes away a lot of the pressure"* (Parent #1).

Discussion

In this study, having a child with tactile defensiveness was described as a distressing, difficult and challenging experience. Lopez-Wagner et al,²¹ mention that sleeping problems in children invariably leads to loss of sleep for the parents as well, which may result in negative emotional reactions. Similarly parents with asthmatic children who have sleeping difficulties complained of fatigue²². Parents reported that negative feelings such as resentment and disappointment were evoked within them as a result of the difficulties tactile defensiveness posed. They also testified that they felt guilty about their negative feelings toward their child, as well as the fact that they were not able to manage the condition perfectly. Guilt is commonly experienced in parents of children with other problems such as asthma²². Children with tactile defensiveness may display behavioural problems similar to that of children diagnosed with attention deficit hyperactivity disorder (ADHD)^{23,24}. Parents of children diagnosed with disorders associated with disruptive behaviour such as ADHD, experience higher total stress than parents of children diagnosed with a chronic medical condition¹³. Fewer prospects for personal growth for parents of disabled children have been reported in the literature²⁵. This is congruent with what some of the parents in this study stated: the experience was that the tactile defensive child demands so much special attention that the parent does not have sufficient time to actualise their full potential.

Children's reactions to tactile defensiveness lead to negative responses from their parents. There is a bidirectional parent-child influence when negative emotions are evoked²⁶. This implies that when a child reacts with negative emotions, the parent is more likely to react with negative emotions as well, and vice versa. This two-way system has the potential to exacerbate the situation as there is also a relationship between the limbic system and sensory

modulation in a sense that anxiety can amplify tactile defensiveness²⁰. It can thus be concluded that there is a three-way interplay between the level of tactile defensiveness, parent's negative emotions and the child's negative emotions. This situation, therefore, creates a downward spiral as the system feeds itself with negative loops.

This may lead to interpersonal problems between the parent and the child. As physical touch plays an important role in the attachment relationship between parent and child, the whole bonding experience may suffer, especially if a parent is not aware of the underlying syndrome. Parents may perceive the child's withdrawal as rejection and subsequent emotional distress can occur. An unsatisfied parental need for touch may lead to resentment and negative feelings projected onto the child, leading to worsening of the situation. Due to the child's resistance to touch, the parent's physical handling of the child is accordingly compensating in nature. Parents avoid gentle touch and they minimise it in order to keep the child comfortable. Even light touch applied to the child's skin, can cause an aversive reaction from the child²⁷. The negative reactions to physical contact as reported by the parents in this study are characteristic of tactile defensiveness.

Wilbarger and Wilbarger²⁰ report that tactile defensive children often develop behaviour mechanisms where they would organise their environment and restrict the family's activities to protect themselves from tactile stimulation. The phenomenon was coined by these authors as "parents held hostage," as they play into this system that the child created. Parents will take on the role of protectors, trying to buffer the child against his/her environment. This was confirmed by this study and nearly all participants stated that they felt a need to protect their children when they came into contact with others or unfamiliar environments. The implications of overprotectiveness of the child include low self-esteem and poor socialisation.

The results of this study also indicated that tactile defensiveness may impact on sibling relationships. It appears that younger siblings especially do not understand the condition, and they become envious of the attention that the tactile defensive child gets, and this escalates conflict between them. Some parents also reported that they defend the tactile defensive child against his/her siblings, possibly in an attempt to protect the child. Tactile defensive children may appear unpredictable and irritable to those who do not understand them². This may lead to an increase in conflict between siblings. The child's negative reactions to touch can be perceived as hostility by a sibling or peer, leading to rejection.

The parents in this study reported that once knowledge of the syndrome was gained, they were able to interpret the child's behaviour within the context of the disorder. This insight helped to lessen the anxiety experienced and to help the parents understand the reasons why the child acted in a certain manner. Providing clear and useful information to parents of children diagnosed with any condition is seen as one of the most helpful actions that can be taken by any professional. Parents of children with asthma, ADHD, cerebral palsy, Down Syndrome, psychiatric disorders and neurological disorders all state that their levels of anxiety were higher before gaining sufficient information on their children's conditions^{22,28}. Also, parents placed a high premium on professionals who can provide them with practical and accurate suggestions^{22,28} for handling their child. This is an important consideration for any professional working with the parents. It is evident that parents need information as soon as the child is diagnosed, because it can help them to manage the syndrome more effectively by providing them with knowledge of what they can expect and what to be prepared for.

Providing information to parents plays a crucial role in the professional's treatment plan. However, it often happens that the information given is focused on the child and his/her needs and the child's broader environment is neglected. Preparing parents beforehand on the possible consequences of tactile defensiveness for their own relationships is as important as the information regarding the child. They need to know that the stressors will challenge their psychological resources making them vulnerable to conflict in their marriage. Unfortunately, the theories of what sensory defensiveness is and why it occurs, are still in the process of development, imply-

ing that even the experts are not in agreement as to the aetiology and dynamics of the condition. This uncertainty elevates anxiety, because parents have difficulty constructing a model to understand the condition and to determine the effect it will have on their lives¹.

All the parents stated that occupational therapy made a significant improvement in the child's aversion to touch. Even though occupational therapy does not eliminate the symptoms altogether, it improved the child's behaviour which made it easier for parents to handle them. Making use of the multidisciplinary team gives parents a sense of relief, possibly because their anxiety is lessened by the fact that somebody with more knowledge is helping them take care of the problem. Even though the occupational therapist plays the primary role in the intervention, help from other disciplines assists in the management of secondary symptoms. Psychological intervention should focus on the secondary symptoms of the disorder such as the negative impact on the child's self-concept and ventilation of frustration and emotional lability⁵. Dieticians can help parents to find a balanced diet that includes food that the child is willing to eat²⁹.

This study emphasised the reciprocal relationship between a child and his/her environment and how the child's microsystem (including bodily sensations) can have a reciprocal effect on his/her mesosystem (including parents and siblings). In the process of understanding parents' experiences and the meaning that they attach to it, insight was gained that may have an influence on therapeutic intervention, psycho-education and parental guidance in the management of the condition. The importance of paying attention and giving consideration to the parents' voice is highlighted by the enormous role that they play in the management of the condition. Intervention is a two-way system that flows between the professional and the family. The implication is that professionals play an important role in psycho-educating the parents on what the syndrome entails, as well as to prepare them for the possible consequences thereof. Therapeutic interventions – not only occupational therapy – but also psychotherapy have proved to be valuable. The role of a multi-professional team is also once again proved as being of paramount importance.

Limitations of this study

This study explored the experiences of seven parents of children with tactile defensiveness from a relatively homogeneous demographic background and it is not representative of all people in similar situations. All participants were from middle to high socio-economic standings and had the necessary resources to deal with the challenges that they faced. Many parents in South Africa do not even have the resources to satisfy basic needs, let alone being able to afford treatment. All but one of the participants was female and, therefore, conclusions are more relevant to mothers of tactile defensive children and not necessarily applicable to fathers.

Conclusion

On the whole the research has found that although there are many stressors experienced by parents of tactile defensive children, including interpersonal problems in the family, exhaustion, lack of information, feelings of incompetence and other negative feelings, it appears that they were able to cope. Having hope that things will improve, or that they will in the end be able to manage, played an important role in coping. Once parents were able to integrate the child's condition as being part of their lives, they were able to "get on with it." By using these different coping strategies they were able to deal with the situation through experiential learning and in the process provided professionals with knowledge that can be shared with others in similar situations.

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