

# A qualitative lens on the sources of stress and coping pattern of caregivers of children with autism spectrum disorder

Somdeb Mitra<sup>1</sup>, Aditi Bhattacharya<sup>1</sup>, Debalina Mitra<sup>2</sup>, Nilanjana Sanyal<sup>1</sup>

*1 Department of Psychology, University of Calcutta, Kolkata, India*

*2 Calcutta International School, Kolkata, India*

Received on: Mar 16, 2021 Accepted on: June 28, 2021

## ABSTRACT

**Introduction:** In the Indian context, mothers of individuals having Autism Spectrum Disorder often have to face high degrees of stress due to the strenuous role of caregiving as well as the nature of disability itself. Societal factors can also contribute as stressors. Clinicians might feel at loss about how to intervene the distress of such clients as it would be mostly inappropriate to label their distress in terms of classical models of psychopathology.

**Method:** The current research aimed to rely on the participants' perceptions and hence, relied on qualitative methods. Semi-structured interviews were done with professionals as well as caregivers of ASD individuals. The interviews were audio-recorded and transcripts were analyzed using appropriate methods.

**Results:** Findings reveal that all caregivers experience significant stress, especially in the initial years. However, with time they tend to develop effective coping maneuvers. Several factors could be identified which helped as well as hindered their process of coping.

**Conclusion:** It was concluded that viewing the struggle of the caregivers from an empathetic- humanistic approach could be the most effective way to help them heal.

**Keywords:** Stress, Coping, Caregivers of Autism Spectrum Disorder

## INTRODUCTION

Autism is a developmental disability which is found in one percent of the population (APA, 2013). This indicates that more than ten million children and adults in India are likely to be affected by this condition. The prominent features of autism include persistent impairment in reciprocal social communication and interaction, restricted and repetitive behavioural pattern. These patterns are present from early childhood years and continue till adolescence and adulthood. DSM V (APA, 2013) has mentioned specifiers that indicate whether the child would require very substantial support/substantial support/support. This makes it clear that some individuals with autism spectrum disorder (ASD)

would require a great deal of support. In the Indian context, the major support has to come from the family, especially the mother, who would have to play the role of caregiver - often, till the last days of her life.

The burden of caregiving for an individual with ASD may seem unfathomable and as a response to such stress, the probability of mental health problems is greater in the caregivers (Estes et al, 2009; Khanna et al, 2011). Thus, caregivers with such high degree of distress might come to the psychologist for consultation regarding how to improve their mental health. Their distress is unlikely to be explained substantially by the usual concepts such as cognitive errors, maladaptive schemas as well as unconscious conflicts of infantile origin. Attempts to explain anguish and pain of a parent with these concepts can actually be more damaging than helpful. Hence, a modification of the stance is essential for the clinician – to listen to the “voices of the parents” who live through these experiences, face the stressors but live a productive life.

The aim of the current study was to understand the nature of lived experiences of parents with off-springs having ASD, hence a qualitative method was chosen. To be able to develop a comprehensive understanding of different possible

\*Corresponding Author Email: [ssmpsy@caluniv.ac.in](mailto:ssmpsy@caluniv.ac.in)

Cite as: Mitra, S., Bhattacharya, A., Mitra, D., Sanyal, N. (2021). A qualitative lens on the sources of stress and coping pattern of caregivers of children with autism spectrum disorder. Journal of Disability Studies. 7(1), Epub.

©IS Publications ISSN: 2454-6623 <http://pubs.iscience.in/jds>



domains of care-givers' burden, as well as get an understanding of how to make sensitive communication with the caregivers, the first step was to interview clinicians working in this field for more than a decade. As mothers are the primary caregivers, the later phases of this study was conducted on mothers of ASD individuals.

## MATERIALS AND METHODS

The study was carried out in Kolkata, and the collection of data was divided into three phases.

Phase I was interviewing professional clinicians working in this field for more than a decade. In this phase, two psychiatrists and two clinical psychologists working in Kolkata, participated. After obtaining consent for conducting and audio-recording the interview, the first author (SM) conducted a semi-structured interview with them. The interviews were aimed at understanding the possible sources of stress faced by the caregivers and methods of coping by them. After transcription, content analysis (Brod et al, 2009) was done in order to reduce the data and arrive at the different relevant domains to be covered during the interviews in the later phases. This content analysis was done independently by two psychologists – the first author and the third author (DM). The domains derived and agreed upon by both psychologists from these interviews were used to frame the semi-structured interview for the next level. The insights regarding the process of struggle faced by caregivers of ASD individuals were helpful in the data collection as well as the interpretative process used in the next levels.

In Phase II, two mothers who had off-springs with ASD as well as were working as special educators in special schools for students with ASD were interviewed by the first author (SM).

Each of them had one son in the age 9-12 years. This intermediate step not only helped in collecting final data, but also sensitised the interviewer further regarding the process in which such an interview should be conducted with mothers of ASD individuals, who are not likely to be aware of the process of psychological research.

In Phase III, five mothers having children with ASD were interviewed by the second author (AB) (she was briefed about the earlier work done as well as how the interviews needs to be conducted. She received supervision from the first author in this process). None of these parents had received any formal training for working as professionals in the field of ASD.

In each phase, informed consent was obtained from each participant and the interviews were audio-recorded (World Health Organization, n.d.). It is noteworthy here, that all the participants had one male child in the age range 6-12 years. Due to constraints of time\*, additional participants could not be interviewed. In the last two phases, data was analysed using interpretative phenomenological analysis (IPA) (Smith et al 2009). The analysis of the data was done independently by the first three authors, and the themes obtained by at least

two of them were retained for the final interpretation. The fourth author (NS), who has experience of working in the field of mental health for four decades, supervised the process, went through the themes obtained and also confirmed that her experience resonates with the findings of the current study.

At the end of the study, the conclusions drawn from the study were discussed with three caregivers of ASD individuals and they confirmed that the findings were in accordance to their lived experiences. Thus, confidence regarding the validity of the findings could be ascertained.

## RESULTS

**Phase I:** The content analysis of the data collected from the psychiatrists and the clinical psychologists gave rise to the following domains:

Possible domains of stressors were

*The diagnosis* – the word autism itself and the first understanding is a huge stressor for the parents and leads to several negative emotions.

*Symptoms ASD* – lack of communication, reciprocation as well as restricted and repetitive behavioural patterns lead to stress in many ways, including educational vocational and a wide range of other challenges.

*Biological* – individuals with ASD have high probability of having additional medical or psychiatric complications such as Bipolar affective disorder, epilepsy etc. which can add to stress of caregivers.

*Social factors* – stress from family members as well as school and society at large associated with the symptoms of the child.

*Financial factors* – the range of professional services required for ASD individuals can be varied and may lead to additional financial burden for the caregivers.

*Sexual development* – with advent of puberty comes sexual changes; a challenge which adds to the stress of parents having ASD individuals.

*Personality related vulnerabilities* – some parents tend to be more vulnerable to negative emotions which lead to a further magnified view of the problem.

Possible domains of coping were

*Resilience* – humans have capacity to be resilient to stress and it helps them cope

*Social support* – support from family as well as society at large including sensitive professionals could help to cope.

*Spirituality* – some caregivers may find strength from spiritual and religious sources of knowledge and practices.

The above mentioned domains helped the researchers to frame the semi-structured interview which was conducted in the later phases (II & III).

**Phases II and III:** As the participants recollected their experiences as caregivers, the phases II and III were merged in the process of reporting the results. The transcripts from the interviews were interpreted using IPA for each

participant. The common superordinate themes that were observed across more than one participant are mentioned below.

### **Sources of Stress**

#### **Initial stress reaction following understanding the diagnosis:**

All the participants recounted their initial stage of shock and despair following the diagnosis of Autism in their children. They mentioned their depression, despair and disbelief following the diagnosis. For example, Respondent 1 stated “After it was confirmed that my son has Autism, though I did not understand the full implication at that time, but I realized that my son will never get cured, will never respond and be able to live a normal life, I felt that the earth under my feet had slipped away... my heart sank. Upon returning home from the doctor, I was so upset, I was crying a lot.”

#### **Stress due to the non-communication of needs by the ASD individual, especially during illness**

All the respondents reported about their difficulties in understanding the problems faced by their children, especially during their episodes of physical illness. Respondent 2 reported “he cannot explain what he needs. That often becomes a problem for all of us... He was non-verbal, but would hold my hand and point at the thing he wanted. We took care of his needs, such as when he might feel hungry or go to the washroom, but problems occurred when it was not expected. When he had stomach pain, he became so restless, and we failed to understand... we even lost temper and started scolding him... later when we realized, you won’t believe how guilty I felt”. Respondent 3 also mentioned her guilt regarding her failure to understand lactose intolerance in her son which led to a lot of suffering for her and her son. Initially, giving medicines was a challenge due to the colour and smells of the medicines, which often arouse adverse reactions in ASD individuals. However, when the children understood that the medicines were helpful in bringing relief, their protests subsided.

#### **Lack of support from family members**

Respondents 1,3,5,6 and reported of their lack of support from family members. They mentioned how the family members blamed them for bearing such a child, how spouses too refused to support and gave very little quality time. Respondent 1 reported that “My father and mother in law blamed me for giving birth to such a child. They suggested that my husband should remarry... Even today, they are partial towards their other grandson (cousin of the child with ASD) and love him more.” Respondent 3 reported that “his father only gives him expensive gifts when he comes. It is detrimental. It would have been much better if he would have given some quality time...”. Respondent 4 described how the indulgence given by grandparents led to her trouble in developing discipline in her child.

### **Non-supportive and discriminant societal attitude**

Respondents 1,2,3,4,7 reported about the insensitivity and discrimination by the society at large. Respondent 3 reported that “he had difficulty adjusting to school... his peers understood that he was different and did not cooperate with him... I think parents of neuro-typically developing children should teach their children to cooperate with special children”. Respondent 4 reported “Earlier I used to be affected by the insensitive remarks by people, for example in social gatherings. I used to feel bad and cry”.

#### **Stress due to hyperactivity and odd behaviour in social situations**

Respondents 1,2,4 directly reported of feeling ashamed if their child did anything awkward in social situations. Respondent 1 reported her sense of awkwardness while travelling in the bus in the early years, as her son would be restless, might squeal and touch belongings of others. Respondent 4 reported “I used to feel ashamed of what people will think if he was restless and flapped his hands. I used to avoid social interactions due to this feeling of shame”.

#### **Stress due to lack of alternative caregiver when mother was busy**

Respondents 2, 3, 4 reported that they found it difficult to find an alternative caregiver. Respondent 3 had to quit her job in order to provide care to the child with special needs in the initial years. Respondent 4 reported how it was risky to even go out for 10 minutes to buy something from the local store, as the child might stop watching TV and may do something dangerous. Although none of the respondents stated it directly, it was evident that they faced stress because they got very little time for themselves. This was reflected in their emphasis on finding leisure time, mentioned later in attempts of coping.

#### **Financial strain**

Respondent 1,2 mentioned that caring for a child with ASD brings financial burden. However, none of the respondents emphasized much on this, probably because they belonged to middle or upper-middle socio-economic strata. Another possibility could be, acknowledging financial hurdles to a stranger, in the context of one’s child with special needs can lead to feelings of incompetence and guilt and therefore be difficult to acknowledge or discuss.

#### **False hope and non-supportive attitude by clinicians**

All the respondents experienced stress due to false hope generated by clinicians. Respondent 3 mentioned a psychologist who promised that speech would develop, which never did. This angers the respondent even after so many years. Respondent 4 reported of a paediatrician who had said that the problem would be cured with age. Respondent 7 recounted how the paediatrician rebuked her and blamed her for the lack of development in her child, which she later realised was not her fault at all, it was the course of disability itself.

### **The process of Coping**

#### **Trial and error, learning about the problem**

All the respondents had children who had received a confirmed diagnosis, at least 3 years ago. Hence, a substantial time had elapsed after they had been certain that their child had ASD. Each of the respondents reported that they resorted to trial and error methods by which they had developed substantial understanding about their children's needs. They had several hardships, but currently they do not face much stress due to lack of understanding. Respondents 1 and 2 systematically studied the problem and became experts in the field as special educators. Respondent 3 learnt actively about potential benefits of having a pet, and other issues on her own and applied them at home to successfully reduce her child's hyperactivity.

#### **Breaking complex tasks into small parts**

Respondents 1,2,4 and 6 mentioned that ASD individuals have difficulty in carrying out complex tasks. Respondent 4 mentioned, "you break the complex task into small parts and help the child master them. They would do it." Respondent 2 narrated an incident regarding her son's requirement of USG of the abdomen. She knew that her child would never cooperate in such a process where a sticky gel would be applied by an unknown individual and then a machine would be rubbed against his stomach. Hence, the mother, in consultation with her brother who was a doctor, did the following. In the first few days, mother rubbed a small steel bowl on his stomach. Then, she applied some cream and then rubbed the steel bowl for a day or two. Then, her uncle, who was little known to him, did the same process. Finally, when he was taken to the clinic and the USG was done, he showed minimal resistance.

#### **Support from family members**

Respondents 1, 2, 3, 6 mentioned about the active support they received from their family members. The husband of respondent 3 left his job and stayed back at home for quite a few months in order to support her spouse. Respondents 1 and 6 spoke of in laws and parents who provided support and encouraged them in the process. Respondent 3 mentioned "My husband always encouraged me and stood beside me. My family members made sure that I got back to my work and research."

#### **Social support outside family**

All the respondents mentioned about the importance of help received from the society beyond the immediate family. Respondent 2 mentioned that she has observed many mothers waiting to receive their child after school actively engage in discussing the problems and she mentioned that this is a good stress reliever. Respondent 6 mentioned that "staying in touch of parents of other autistic kids helps me reduce my anxiety". Respondent 4 mentioned "the situation has improved in the last 30 years, my cousin with ASD was only kept isolated as insane. Now there are seminars, awareness programs, institutions working in this field..."

### **Staying active and managing scope for leisure and enjoyment**

All the respondents mentioned the utility of staying active. Some of them (respondents 1,2) were actively working in this field, Respondents 3,4,6 were involved in other full time jobs. Respondent 5 and 7 were home-makers, who kept themselves busy in their daily schedule. All of the respondents reported the importance of having hobbies which could range from reading books, listening to music, to gardening, going out in nature, or doing some creative work. The essence was staying active would help them to distract and cope with the situation. Respondent 4 mentioned "I keep myself busy, in fact I do not give myself idle time, I do something or the other in order to keep my negative thoughts away. What would I do by thinking?" In fact, the interview of respondent 7, who was a homemaker, revealed comparatively lesser points of active coping. It was significantly briefer and the focus was more on her anxieties, stress and confusions. This indirectly indicates the possible utility of staying actively engaged outside family.

#### **Support from professionals**

Each of the respondents reported receiving a good deal of support from professionals. They got clear ideas about the diagnosis, what is to be expected from the child and how to deal with specific situations. Respondent 2 reported how special educators and psychologists in special schools helped her to comprehend and learn about what needs to be done in specific situations. Respondent 4 also reported that when she feels depressed, at times she would go to a psychotherapist and take help.

#### **Responding assertively to intolerance**

Respondent 1,2,3,4,6 reported that in the recent past they respond assertively, even slightly aggressively to the intolerant comments and actions by some members of the society. Respondent 2 mentioned "I believe that it is essential to reply back in a strong manner. I do it, and also tell other mothers that you have to be strong and give stern replies so that the other person, who does not have a basic sense of decency and dignity, would think twice before reacting similarly to another special child in the same way". Respondent 3 mentioned that she clearly refuses to go to those homes and occasions where she realizes that her child is not welcome. It is a way for her to protest and protect the dignity of the child.

#### **Grooming the self and the child**

Respondents 3,4,6 mentioned that it is essential that even after a hard and tiring day one grooms herself as well as the child. Respondent 4 said "even after a hard tiring day, you clean yourself, wear a nice cloth, tie your hair. See you would feel better when you look at the mirror. Deep within, you know you are doing a very difficult job and it is essential to take care of yourself. Similarly, for the child too, if you dress him up, comb his hair even he will feel confident".



### **Gaining acceptance over time**

Each narrative by the participants revealed their journeys starting with the significant initial stress of knowing their child's condition for the first time. However, through trial and error, support from close ones or larger society, professional help etc have helped them. All the respondents reported that currently they felt little difficulty in comprehending their child's need as well as handling them in social situations, accepting repetitive behaviours, or even tolerating or responding to negative or critical remarks by insensitive persons of the society. They had decided to not attend certain social gatherings as a mark of protest and to protect their child's dignity while being in connection with those who accepted their children with their disabilities. Respondents 1,2,3,4 reported that they realise now that even normal children have other sets of problems too. These special children are not a part of such a rat race and in a way are more beautiful than many of the so-called normal children.

### **Focusing on the present**

All the respondents reported having anxiety about the future, especially what would happen in their absence. This was one question, to which no one has any satisfactory answer. Respondents 2, 4 and 6 mentioned that they know that focusing on the future would increase their anxiety level. Respondent 4 mentioned "that is why I just focus on the present. I think of a maximum of two weeks to come. One has to accept life as it comes. No one knows what challenge is there in store for you. I have seen a lot in life".

### **Spirituality**

All the respondents accepted that spiritual orientation helped them to cope in some way. However, the manner in which it was conceptualised differed greatly across the respondents. Respondents 5,6 and 7 spoke of religious rituals and beliefs in their religion which helped them accept the suffering as inevitable as well as meaningful in some way. However, respondents 1,2 and 4 spoke of spirituality and not religiosity. They realized how this process of caregiving has made them aware of the futility of the rat race going around. Caring for their children as well as other individuals in need gave them a deeper appreciation of the true meaning of life. Respondent 3 spoke of meaningful works in the social scenario and engaging with others.

## **DISCUSSION**

Before discussing the findings, it is essential to be reflexive of the method and stance taken in the process of this research. Attempts were taken to improve the validity of the research by reading and re-reading the transcripts. More than one person independently analysed each transcript, and retained the mutually agreed upon points while staying close to the verbalised data provided by the respondents. Further validation was sought by going back to the population and checking if the findings resonated with their perceptions.

The sample size can be considered as a decent one in the field of qualitative research.

All the respondents mentioned about the stressful phases when they felt terribly depressed or had anxiety symptoms, which for some respondents (2,4) even led to panic attack like symptoms. This finding is in accordance with previous researches which indicate caregivers of ASD individuals experience much higher distress levels (Khanna et al 2011).

As revealed from the participants' narratives, one major stressor was found to be due to the symptoms of autism, especially the aspects of non-communicability of needs, hyperactivity and restricted and repetitive behavioural pattern. Mothers reported about their helplessness and incapacity to understand the child's needs especially during their illnesses – such as discomfort from fever, skin rashes or gastro-intestinal symptoms. In addition to this, the caregivers feel distressed because they realize that their children would never be able to become a part of the mainstream society and live an independent life. They would not even be able to take care of themselves and would remain vulnerable to exploitation by others when not in protection or supervision of caring others.

The above mentioned sources of stress come largely due to the nature of disability. Regarding the problem of communication, the caregivers try to come to terms with this by actively learning about the problems associated with ASD, trial and error method or seeking advice from experts or parents of other children with similar problems. Whereas, regarding the vulnerability of their offspring in their absence, no one could find a solution that would relieve their stress. The respondents tried to cope with this by saving sufficient money for the future, making the child as self-reliant as possible, and hoped for a more accepting society with institutions to take care of persons with ASD. Apart from this, they coped with this deep source of apprehension by distracting themselves and not thinking about the uncontrollable future, while focusing on how to make the present better.

However, not all the sources of stress come from the disability itself. A major part comes from the society which lacks sensitivity and perspective taking. For example, mothers feel burdened due to the need for close monitoring such individuals require, and it takes a lot of time and energy to provide such caregiving. Often this drains out a lot of energy and they feel burdened as they do not get sufficient time for themselves. Several caregivers reported that they perceive a lack of support from close family members, including their husbands. This lack of support ranged from not giving quality time, but giving materialistic gifts on one hand to being overtly critical and attacking on the other hand. Grandparents' behaviours too were reported to vary from pampering the child to neglecting the child. Thus, directly or indirectly, the close members of the family failed to provide a space to the mothers where they could feel relieved. It is noteworthy here, that such stress is common in

families with neuro-typically developing children too, but it often gets more difficult for caregivers of ASD because it is more difficult to communicate with them and change their rigid behavioural patterns.

In addition to the lack of support from the close family members, all the respondents reported being discriminated against and facing insensitive and critical comments from the society, including professionals working in the field of child-care. In the initial stage, the caregivers felt more hurt, ashamed, but with passing time they have learned to protest for the dignity of their children. They even reported that as a mark of protest to such misdemeanour, they stopped going to such places. This method of coping can be considered as a mature assertiveness.

The society which came up as a prominent stressor, came up as the biggest source of support too. Several respondents reported that their partners, parents and in-laws were supportive and helped them. They received encouragement and support which was essential for them to be able to go out and work and even have leisure time. 5 out of 7 respondents reported that they felt supported from being attached to special schools and share their experience with parents of similar children. They also reported that professionals working in the field helped them to deal with crisis situations. Respondent 4 reported that in the last 30 years, she can see a lot of progress in the management of ASD and growth of awareness in people.

The process of coping for caregivers goes way beyond dependence on extrinsic factors. In addition to learning about the problem, distracting and being assertive, the caregivers' active coping methods included – engagement in meaningful, productive work beyond caregiving responsibilities. 5 respondents were engaged in teaching or research related activities, which helped their coping. Furthermore, they engaged in creative work and also pursued hobbies, managed leisure time. Respondent 5 mentioned the importance of arranging “small house parties in low budget for like-minded mothers. Each one will bring one food item, then eat together, have a chat and enjoy their togetherness”. Spirituality, in the broader sense of the term, including empathic, pro-social attitudes and behaviour also contributed to finding a meaning.

The process of active coping, being assertive, managing leisure and deep realizations seemed to develop with time. The initial reactions were of strong negative emotions such as anger, helplessness, despair, depression and panic. However, with time, gradually the intensity of negative emotions seemed to calm down – though the vulnerability remained. This process is very much similar to Kubler-Ross's model of grief (1969). In several ways, caregiving for ASD individuals is a process that involves grieving for the loss of hope and expectations of having a healthy child. However, it is not just that, as respondents mentioned about their happiness to see small developments in their children as well as the unique bonds with their children, which they

cherish deeply. This is a prominent example of Carl Rogers (1946) belief that humans tend to grow in their own unique ways, even under stressful conditions. Thus, if one provides the caregiver with an environment where she can feel safe to experience her emotions, growth and development is an obvious outcome.

The research findings imply that therapists working in this field need to appreciate the views of Kubler-Ross (1969) as well as Rogers (1961) in order to be helpful to such caregivers. It is reasonable to expect that persons who have recently become aware of their child's diagnosis of ASD, would experience a plethora of emotions which might manifest as psychological symptoms. They might even expect or demand a quick fix to their problem. The clinician must realize that such a solution is implausible. However, the demand should not be labelled as ‘cognitive error’ (Hawton, 1989) according to the CBT model, or ‘interpreted’ as ‘impulsivity’ (Fenichel, 1945) according to psychodynamic models. It is essential to empathise that this is an expected reaction, which might trigger feelings of despair in the clinician as well. In such a condition, within the psychodynamic paradigm, Bion's (1962) supportive methods of ‘holding and containment’ can be useful. Moreover, within the CBT paradigm, at some stage, focusing on ‘activity scheduling’ and being assertive might help. The essence of treatment has to be on the belief that, with time, the individuals would deal with their grief and be able to cope. They have inner potential to reach a meaningful life. All they need is an environment where they can feel safe and unburden themselves. They are not persons with disorders, they are individuals in distress who can greatly benefit from the humanistic philosophy and person centred approach (Rogers, 1961).

Finally, qualitative research accepts the role of subjectivity of the researcher, where the researchers are motivated by a particular stance, and this subjectivity is neither possible to be eliminated, nor is it necessary (Smith et al 2009). The current researchers started this journey to hear the “voices of the caregivers”, in order to be more effective in attempts to alleviate distress of similar individuals in future. By the end of the journey, in addition to the prior agenda, we felt that the society had a lot to learn from these persons. It is our duty to let the struggles and success stories of these persons be known in the mainstream of society as well as academic psychology, which might contribute to positive growth.

## ACKNOWLEDGMENTS

The initial part, Phase 1 of the research was conducted as a minor research project under SAP DRS I, 2014-2015 by the first and fourth author. We would like to acknowledge the support and encouragement in addition to the arrangement of funds in this project by Prof. Mallika Banerjee, Retired Professor, Dept. of Psychology, University of Calcutta). The authors are also grateful to the participants who gave consent to participate in the study.

**Source of Funding:** University Grants Commission of India under Special Assistance Programme SAP-DRS Phase-I

**Conflict of interest:** None

## REFERENCES

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Washington, D.C.: Author.
- Bion, W. R. (1962a). A theory of thinking, *International Journal of Psycho-Analysis*, 43, 306- 310.
- Brod M, & Tesler LE, Christensen TL. (2009). Qualitative research and content validity: developing best practices based on science and experience. *Quality of Life Research*, 18(9), 1263-1278.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 13(4), 375-387.
- Fenichel O (1945). *The psychoanalytic theory of neurosis*. New York, Norton.
- Hawton, K., Salkovskis, P. M., Kirk, J., & Clark, D. M. (Eds.). (1989). *Oxford medical publications. Cognitive behaviour therapy for psychiatric problems: A practical guide*. Oxford University Press.
- Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of autism and developmental disorders*, 41(9), 1214-1227.
- Kübler-Ross E (1969). *On Death and Dying*. Routledge.
- Rogers, Carl. (1961). *On Becoming a Person: A Therapist's View of Psychotherapy*. London: Constable.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Los Angeles, CA: SAGE
- World Health Organization (n.d.). <https://www.who.int/groups/research-ethics-review-committee/guidelines-on-submitting-research-proposals-for-ethics-review/templates-for-informed-consent-forms>