

Anna Dąbrowska*

Sense of coherence and coping with stress in fathers of children with developmental disabilities**

The aim of the study is to analyse the sense of coherence (SOC) and strategies of coping with stress in fathers of disabled children. The research involved 128 fathers of children with Down syndrome, autism, cerebral palsy and children with normal development. Two questionnaires were used: The Sense of Coherence Questionnaire (SOC-29) measuring SOC level and Ways of Coping Questionnaire (WCQ) measuring strategies of coping with stress. The research revealed that there is a relationship between the type of child's developmental disability and SOC in fathers. The fathers with a low level of SOC more frequently used strategies of avoidance while the fathers with a high level of SOC more frequently used confrontation, positive reappraisal and playful problem solving. The results of the research indicate that looking after a disabled child may lower SOC and in turn may cause difficulties in coping with stress.

Keywords: SOC, coping with stress, fathers, developmentally disabled children

Introduction

The study investigates the relationship between sense of coherence and coping with stress in fathers of children with developmental disabilities. The concept of sense of coherence was put forward by A. Antonovsky within the framework of the salutogenic approach (1997, 2005). Crucial to this approach is the search for factors responsible for people staying healthy or becoming ill in stressful situations and whether they can hold their current position on the illness continuum. The key element of salutogenesis is the sense of coherence (SOC) defined as "(...) a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli from one's internal and external environments in the course of living are structured, predictable and explicable (comprehensibility); (2) the resources are available to one to meet the demands posed by these stimuli (manageability); (3) these demands are challenges, worthy of investment and engagement (meaningfulness)" (Antonovsky, 2005, p.34)

The concept of sense of coherence provides a good framework for dealing with the phenomenon of people experiencing extreme or chronic stress (Sęk & Pasikowski,

1998). People with a high level of sense of coherence cope better with difficulties, more frequently perceive stressors as challenges and apply cognitive-behavioural ways of coping with them. People with a low level of sense of coherence are more likely to look at difficult situations as threats and use avoidance as a way of coping with stress.

Being a parent of a child with developmental disability puts one's resources at risk (Eker & Tüzün, 2004; Ones, Yılmaz, Cetinkaya & Caglar, 2005; Pisula, 1998a, 2002). The concept of sense of coherence was rarely used in this field. Most research indicates that parents of sick or disabled children report a lower level of sense of coherence than parents of normally developing children (Margalit & Ankonina, 1991; Margalit, Raviv & Ankonina, 1992; Olsson & Hwang, 2002; Groholt, Stigum, Northagen & Köhler, 2003). It also reveals that parents with lower levels of sense of coherence use avoidance as a way of coping with stress more frequently and experience many psychological problems. Although these results help us understand the psychological situation the parents find themselves in, they fail to consider the type of child's disability, and, consequently, parents of children with different disabilities are put into the same category.

* Faculty of Psychology, Warsaw University, email: a.dabrowska@pedagogium.edu.pl

** The results presented here were analysed as part of a research project financed from research resources of Warsaw University, Faculty of Psychology: BW1616.

It is reported that parents of children with autism show an exceptionally high level of stress (Pisula, 1998b; Tarakeswar & Paragament, 2001). It is caused by the child's disabilities in cognitive, social and emotional development, difficulties in understanding and predicting his/her behaviour, problems with communication, lack of or atypical expression of emotions (Gray, 2003; Rodrigue, Morgan & Geffken, 1990). Sharpley (1997; after: Boyd, 2002) argues that lack of social as well as family's acceptance of child's "difficult" behaviour as well as a poor system of social support add to a great burden.

The two groups compared here are parents of children with autism and parents of children with Down syndrome. The situation of these two groups is different. Despite various difficulties and psychological problems, parents of children with Down syndrome find themselves in a relatively better situation than parents of children with autism and – as research data indicate - parents of children with cerebral palsy (Pisula, 1998a). Although parents of children with Down syndrome show a higher level of stress than parents of normally developing children, it is still lower comparing to the stress experienced by parents of children with developmental disabilities. Wannamaker and Glenwick (1998) reported that parents of children with cerebral palsy have a higher level of depression and helplessness, and a greater sense of parental incompetence than parents of normally developing children. Problems of this group of parents are caused in particular by the child's physical dependence and constant need of assistance throughout their lifetime. The level of difficulty that a particular situation poses may be influenced by other co-existent abnormalities (both primary and secondary). Among these co-occurring abnormalities are, for instance, intellectual disability that is found in 40% of children and also difficulties in communicating with the child (Britner, Morog, Pianta & Marvin, 2003; Mazanek, 2003).

The study sets out to analyse the sense of coherence in fathers of children with developmental disabilities. Due to the fact that most often it is the mother who looks after the child and bears more responsibilities, fathers are frequently excluded from research (Young & Roopinaire, 1994). The difficulties experienced by fathers are often ignored and their situation is viewed from the financial perspective (Hess, Teti & Hussey-Gardner, 2004; Navalkar, 2004). Despite time limitations, fathers seek information on developmental disabilities and learn about different ways of helping their child. They feel there is a clash between their professional duties and a strong need to get involved in their child's activities (Quinn, 1999; West, 1998). The younger the fathers are the stronger is their need to interact with their child and participate in his/her development. It may be related to a current transformation of the man's role in the society (Oleś & Oleś, 2001; Turbiville & Marquis, 2001). Herbert (1996; after: West 1998) states that fathers also try

to support their partners; at the same time, however, they hide their emotions and difficulties they experience in order not to worry their partners too much. On the other hand, Olechnowicz (1995) shows that fathers of children with developmental disabilities want to be perceived as strong, therefore they tend to hide their worries about psychological as well as physical well being of their child and wife.

Many studies emphasise the fact that fathers of children with developmental disabilities suffer from greater stress and depression than fathers of children normally developing (Hastings, 2003; Olsson & Hwang, 2001; Ricci & Hodapp, 2003). Veisson (2001) proved that fathers of children with developmental disabilities are more extrovert, open and responsible than fathers of normally developing children. According to Pisula (1998b), the greatest stress experienced by fathers of children with autism, Down syndrome, cerebral palsy and intellectual disabilities results from the sense of responsibility for their child and involvement in childcare. Wannamaker and Glenwick (1998) claim that a high level of stress in fathers is associated with a low level of parental satisfaction and a higher level of difficulty in their child's adaptation processes.

There is a wide variety of fathers' reactions to difficulties related to looking after a disabled child and numerous ways of coping with stress – ranging from rejection of the child and abandonment of the family to total acceptance of the child and situation (Gray, 2003; Steuden & Zdunek, 2000). Research shows that fathers often apply strategies of avoidance – they escape from the problem or get involved in other activities which keep them away from home (eg. sports, addictions or long working hours) (Olsson & Hwang, 2001; Steuden & Zdunek, 2000). According to Antonovsky (2005), people who use such strategies of coping with stress have a low level of sense of coherence. Some fathers, despite the stress, are able to deal well with difficulties by applying active strategies of coping with stress and confronting the difficult situation (Pisula, 1998a; Taanila, Syrjälä, Kokkonen & Järvelin, 2002; Young & Roopinaire, 1994). Antonovsky (1997) argues that those who choose active strategies of coping with stress have a high level of sense of coherence.

The aim of this study is to investigate the relationship between the sense of coherence and coping with stress in fathers of children with Down syndrome, autism, and cerebral palsy and fathers of normally developing children.

Formulated hypotheses:

1. There is a relationship between the sense of coherence in fathers and the type of child's developmental disability.
2. Fathers with a higher level of sense of coherence are more likely to use problem-orientated strategies of coping with stress while parents with a low level of the sense of coherence use avoidance strategies.

Method

Participants

The research involved 128 fathers:

1. 37 fathers of children with Down syndrome ($M=38,5$; $SD=8,7$); children aged between 1 and 22 ($M=9,9$; $SD=5,9$).
2. 31 fathers of children with autism ($M=40,3$; $SD=7,7$); children aged between 2 and 20 ($M=8,1$; $SD=4,7$).
3. 30 fathers of children with cerebral palsy ($M=41,9$; $SD=8,9$); children aged between 2 and 21 ($M=11,2$; $SD=6,3$).
4. 32 fathers of normally developing children ($M=38,3$; $SD=7,2$); children aged between 1 and 20 ($M=8,2$; $SD=3,8$).

The subjects examined came from Mazowieckie, Podlaskie and Lubelskie voievodships. Groups were organised according to the child's age and developmental disability.

Measures

1. *The Sense of Coherence Questionnaire (SOC-29)*

The questionnaire was drawn up by A. Antonovsky (2005) in 1983 in order to measure the level of sense of coherence. It consists of 29 questions divided into three subscales: I – Comprehensibility (11 questions); II Manageability (10 questions); III Meaningfulness (8 questions), with high scores indicating a stronger sense of coherence. It is also possible to analyse each of the subscales. The questionnaire was adapted to Polish by J. Koniarek, B. Dudek and Z. Makowska (1993). It is distinguished by its good psychometric properties – high accuracy and reliability (Pasikowski, 2000).

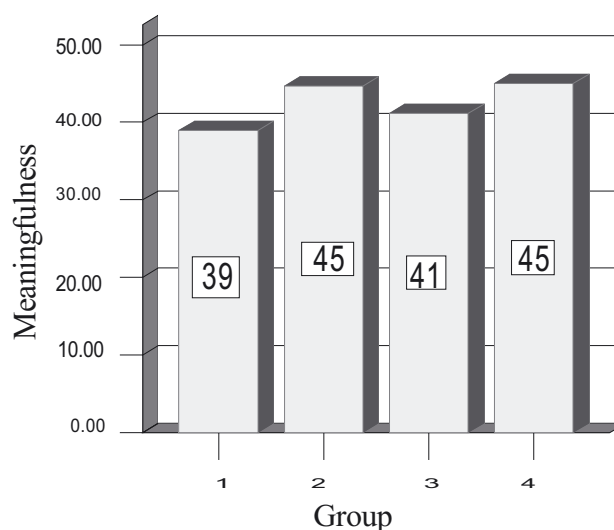
2. *Coping with Stress Questionnaire (WCQ)*

The questionnaire was designed by S. Folkman and R. Lazarus (Lazarus & Folkman, 1987). It measures the frequency of applying various strategies of coping with stress. The Polish version of the questionnaire drawn up by Pisula (1998a) was used in the research. On the basis of the factor analysis in the examination of parents of children with developmental disabilities, she came up with eight strategies, seven of which are consistent with the version developed by Folkman and Lazarus. In Pisula's analysis an extra factor was determined - resignation. The strategies thus include: (1) searching support, (2) self-blame (taking responsibility), (3) avoidance/escape, (4) distancing, (5) confrontation, (6) positive reappraisal, (7) planful problem-solving, (8) resignation.

The questionnaire consists of 66 questions.

Procedure

Fathers who agreed to participate in the research were given a set of questionnaires to fill in at home.



1. Fathers of children with Down syndrome
2. Fathers of children with autism
3. Fathers of children with cerebral palsy
4. Fathers of typically developing children

Figure 1. Meaningfulness in fathers.

Results

1. *The type of the child's developmental disability and the sense of coherence in fathers*

The results of the One-way ANOVA showed differences in relation to meaningfulness. Fathers of children with Down syndrome reported a lower level of sense of meaningfulness than fathers of normally developing children and fathers of autistic children ($F_{(3;128)}=4,723$; $p=0,004$) (Figure 1). No differences among the groups in relation to the global sense of coherence, comprehensibility and manageability were established.

2. *The type of child's developmental disability and strategies of coping with stress in fathers*

The results showed differences as far as the seeking support strategy was concerned ($F_{(3;128)}=3,501$; $p=0,018$). Fathers of children with Down syndrome applied this strategy less often than fathers of autistic children and fathers of normally developing children. Fathers of children with cerebral palsy looked for support less often than fathers of children with autism.

3. *Sense of coherence and strategies of coping with stress in fathers*

Due to the fact that differences occurred only in terms of meaningfulness, further analysis is based on the relationship of this particular variable with the strategies. The research based on quantile division revealed two groups of fathers – fathers with a high level of sense of coherence (upper

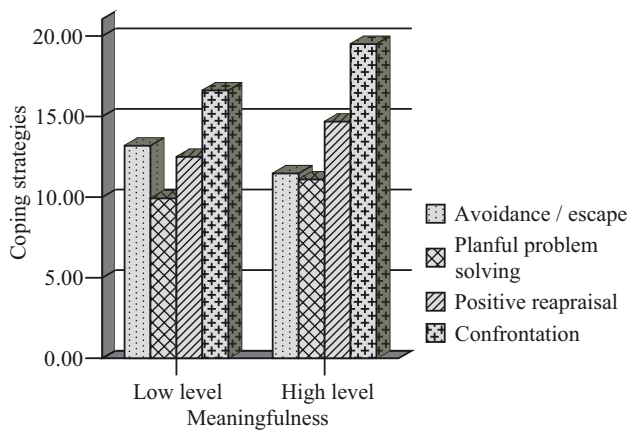


Figure 2. Level of meaningfulness and coping strategies in fathers.

quantile – 47-68) and fathers with a low level of sense of coherence (lower quantile – 19-37). The results from the t-Student Test indicated that fathers with a high sense of meaningfulness more frequently applied:

- confrontation ($t(48)=2,376$; $p=0,023$)
- positive reappraisal ($t(48)=2,385$; $p=0,002$)
- planful problem solving ($t(48)=3,104$; $p=0,002$)

Fathers with a low sense of coherence used avoidance more frequently ($t(48)=2,376$; $p=0,023$) (Figure 2).

Discussion

The aim of the research was to determine the relationship between the sense of coherence and coping with stress in fathers of children with autism, Down syndrome, cerebral palsy, and normally developing children. The results demonstrated that raising a child with a developmental disability is not associated with a lower level of global sense of coherence in those fathers when compared with fathers of normally developing children. The results are consistent with those of Groholt and others (2003), who did not establish any differences between fathers of sick and developmentally disabled children (eg. diabetes, asthma, vision and hearing disorders or ADHD) and fathers of healthy children. Similarly, Hedov and others (2002) did not find any differences regarding the level of the family sense of coherence between fathers of children with Down syndrome and fathers of normally developing children. There were also no differences in terms of global sense of coherence among fathers in the study on parents of children with intellectual disability and/or autism carried out by Olsson and Hwang (2002).

Interestingly, fathers of children with Down syndrome when compared to fathers of children with autism and normally developing children showed poorer sense of meaningfulness. The result is not surprising when one takes into consideration the difficulties and challenges that fathers of children with Down syndrome have to face. What is

surprising, however, is the fact that fathers of children with Down syndrome reported poorer sense of meaningfulness than fathers of children with autism. Authors of various publications often emphasise that a stress level in parents of children with autism is higher than that in parents of children with cerebral palsy and Down syndrome (e.g. Pisula, 1998b). On the basis of that information, one can expect fathers of children with autism to lose their resources faster and to have poorer sense of meaningfulness than fathers of children with Down syndrome.

Effective therapy that children with autism undergo may justify the results discussed above. Down syndrome is an intellectual disability and, despite parents' effort, the child does not make any progress. Moreover, with time the child's disability becomes more and more visible when compared to normally developing children (Twardowski, 1999). Parents' expectations towards their child's developmental progress are too high, not commensurate with their achievements, which causes great stress (Phua, Reid, Walstab & Reddihough, 2005). The sense of helplessness and the feeling of having little control over the child's and family's future may lead to a point where parents have little hope and are not motivated to look for more resources (Dempsey & Dunst, 2004). The children with autism, on the other hand, may improve their state if they undergo regular therapy, which is why fathers hope that their children may function relatively well in the future. This hope motivates them to put even more effort into raising their child and ensuring the best conditions for his/her development.

Antonovsky (2005) noted that long-standing stressful life conditions may influence the level of sense of coherence. He believed, however, that this influence does not have to be negative and cause a decrease in one's sense of coherence. On the contrary, he emphasised that a change in the level of sense of coherence may be positive or last only temporarily and then go back to the initial level. The data collected in the present research proved that Antonovsky's idea may be applied to fathers of children with autism who in relation to the global sense of coherence and its components did not score lower than fathers of normally developing children. Moreover, the results may find a point of reference in Quinn's thesis (1999). She observes that when parents' life situation changes (e.g. the child is diagnosed with a developmental disability) fathers already have some resources. If they use them properly, there is a chance that after some period of time they will cope even better than they did before. If they fail to do so, they risk running into adaptation difficulties. Conversely, once they have enough information and support, they are able to meet the demands and confront the situation, which enhances their parental competence.

The research demonstrated that fathers of children with autism sought support more often than fathers of children with Down syndrome. It is possible that fathers of children with autism obtain their resources from the

received support, which may result in their increased sense of meaningfulness. Fathers who rarely look for support are obviously less likely to receive it (Veisson, 2001; West, 1998). At the same time, from the very beginning fathers try to support their partners (Pisula & Dąbrowska, 2004).

A lower sense of meaningfulness poses a serious threat to the global sense of coherence. Antonovsky (1997) emphasised that meaningfulness is an emotional equivalent of the cognitive sense of comprehensibility and allows people to see the need for making an effort in order to cope with the most stressful situation. Fathers should find support groups and cognitive therapy very helpful in this situation. Lustig (2002) argues that therapy allows for reinterpretation and reappraisal of the situation. It may have a positive impact on fathers' understanding and reappraisal of the situation and the ways they confront it. In this study, it was found that fathers with a stronger sense of meaningfulness showed positive reappraisal, confrontation and planful problem solving. The lack of resources and motivation to look for them may be related to strategies of coping with stress that include avoidance and resignation, which in turn may lead to conflicts within the family and lower quality of interaction with a child (Ricci, Hoddap, 2003). The study presented here reported that fathers with a poor sense of meaningfulness more frequently used avoidance and escape as means of coping with stress.

To conclude, the collected data shall serve as a starting point for further research. The results prove that the sense of coherence and its components play an important role in coping with difficulties that arise from bringing up a child with developmental disabilities.

References

- Antonovsky, A. (1995). *Rozwikłanie tajemnicy zdrowia. Jak sobie radzić ze stresem* [Unraveling the Mystery of Health. How to cope with stress]. Warsaw: Fundation IPN.
- Antonovsky, A. (1997). Poczucie koherencji jako determinanta zdrowia [Sense of coherence as a determinant of health]. In: I. Heszen-Niejodek & H. Sęk (Eds.). *Psychologia zdrowia* [Health Psychology]. Warsaw: PWN.
- Boyd, B.A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), 208-215.
- Britner, P.A., Morog, M.C., Pianta, R.C. & Marvin, R.S. (2003). Stress and coping: A comparison of self-report measures of functioning in families of young children with cerebral palsy or no medical diagnosis. *Journal of Child and Family Studies*, 12(3), 335-48.
- Dempsey, I. & Dunst, C.J. (2004). Help giving styles and parent empowerment in families with a young child with disability. *Journal of Intellectual and Developmental Disability*, 29, 1, 40-51.
- Eker, L. & Tüzün, E.H. (2004). An evaluation of quality of life of mothers of children with cerebral palsy. *Disability and Rehabilitation*, 26 (23), 1354-1359.
- Gray, D.E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine*, 56, 631-642.
- Groholt, E.K., Stigum, H., Northagen, R. & Köhler, L. (2003). Is parental sense of coherence associated with child health? *European Journal of Public Health*, 13(3), 195-201.
- Hastings, R.P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47(4/5), 231-237.
- Hedov, G., Anneren, G. & Wikblad, K. (2002). Swedish parents of children with Down syndrome. Parental stress and the sense of coherence in relation to employment rate and time spent in child. *Scandinavian Journal of Caring Sciences*, 16, 424-430.
- Hess, C.R., Teti, D.M. & Hussey-Gardner, B. (2004). Self-efficacy and parenting of high-risk infants: The moderating role of parents knowledge of infant development. *Applied Developmental Psychology*, 25, 423-437.
- Koniarek, J., Dudek, B. & Makowska, Z. (1993). Kwestionariusz Orientacji Życiowej. Adaptacja The Sense of Coherence Questionnaire (SOC) A. Antonovsky'ego [Life Orientation Questionnaire. Adaptation of The Sense of Coherence Questionnaire]. *Przegląd Psychologiczny*, 4(36), 491-502.
- Lazarus, R.S. & Folkman, S. (1987). Transactional theory and research on emotions and coping. *European Journal of Personality*, 1, 141-169.
- Lustig, D.C. (2002). Family coping in families with a child with a disability. *Education and Training in Mental Retardation and Developmental Disabilities*, 73(1), 14-22.
- Margalit, M. & Ankonina, D.B. (1991). Positive and negative affect in parenting disabled children. *Counseling Psychology Quarterly*, 4 (4), 46-51.
- Margalit, M., Raviv, A. & Ankonina, D. (1992). Coping and coherence among parents with disabled children. *Journal of Clinical Child Psychology*, 21 (3), 202-209.
- Mazanek, E. (2003). *Mózgowe porażenie dziecięce. Problemy psychologiczno – pedagogiczne* [Cerebral Palsy. Psychological and educational problems]. Warsaw: APS.
- Navalkar, P. (2004). Fathers' perception of their role in parenting a child with cerebral palsy: Implications for counseling. *International Journal for the Advancement Counseling*, 26(4), 375-382.
- Olechnowicz, H. (1995). *Dziecko własnym terapeutą* [Child as the therapist on his/her own] Warsaw: WSiP.
- Oleś, M. & Oleś, P. (2001). Z psychologicznych aspektów ojcostwa. [From the psychological aspects of fatherhood] In: D. Kornas-Biela (Ed.). *Oblicza ojcostwa* [Faces of fatherhood] (pp.255-268). Lublin: TN KUL.
- Olsson, M.B. & Hwang, C.P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45(6), 535-543.
- Olsson, M.B. & Hwang, C.P. (2002). The sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability*, 46 (7), 548-559.
- Ones, K., Yilmaz, E., Cetinkaya, B. & Caglar, N. (2005). Assessment of the quality of life of mothers of children with cerebral palsy (primary caregivers). *Neurorehabilitation and Neural Repair*, 19 (3), 232-237.
- Pasikowski, T. (2000). *Stres i zdrowie. Podejście salutogenetyczne*. [Stress and Health. Salutogenic approach]. Poznań: Wydawnictwo Fundacji Humaniora.
- Phua, V., Reid, S.M., Walstab, J.E. & Reddihouh, D.S. (2005). Inpatients care of children with cerebral palsy as perceived by their parents. *Journal of Pediatrics and Child Health*, 41, 8, 432-440.
- Pisula, E. (1998a). *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju* [Psychological problems of parents of children with developmental disabilities]. Warsaw: Wydawnictwa Uniwersytetu Warszawskiego.
- Pisula, E. (1998b). Profile stresu u ojców dzieci z zaburzeniami rozwoju [Stress profiles in fathers of children with developmental disabilities]. *Psychologia Wychowawcza*, 5, 419-425.
- Pisula, E. (2002). Rodzice dzieci z autyzmem – przegląd najnowszych badań [Parents of children with autism: recent research findings].

- Psychiatria Polska*, 36, 95-108.
- Pisula, E. & Dąbrowska, A. (2004). Doświadczenia matek związane z otrzymaniem informacji o zespole Downa u dziecka [Mothers' experiences in being informed about Down syndrome in their children]. *Pediatria Polska*, 79(6), 460-466.
- Quinn, P. (1999). Supporting and Encouraging father involvement in families of children who have a disability. *Child and Adolescents Social Work Journal*, 16(6), 439-453.
- Ricci, L.A. & Hoddap, R.M. (2003). Fathers of children with Down syndrome versus other types of intellectual disability: perceptions, stress and involvement. *Journal of Intellectual Disability Research*, 47 (4/5), 273-284.
- Rodrigue, J.R., Morgan, S.B. & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*, 19(4), 371-379.
- Sęk, H. & Pasikowski, T. (1998). The quality of life, health and the sense of coherence in social context. *Polish Psychological Bulletin*, 29(1), 69-77.
- Steuden, S. & Zdunek, B. (2001). Psychologiczne aspekty funkcjonowania ojców dzieci z przepukliną oponowo-rdzeniową [Psychological aspects of functioning of fathers of children with meningeal-medullary rupture] . In: D. Kornas-Biela (Ed.), *Oblicza ojcostwa* [Faces of fatherhood] (pp. 407- 426). Lublin: TN KUL.
- Taanila, A., Syrjälä, L., Kokkonen, J. & Järvelin, M.R. (2002). Coping of parents with physically and/or intellectually disabled children. *Child Care, Health and Development*, 28(1), 73-86.
- Tarakeshwar, N., Pargament, K. (2001). Religious coping in families of children with autism. *Focus on Autism and Other Disabilities* 16 (4), 247-260.
- Turbiville, V.P., Marquis, J.G. (2001). Father participation in early education program. *Topics in Early Childhood Special Education*, 21(4), 223-231.
- Twardowski, A. (1999). Sytuacja rodzin dzieci niepełnosprawnych [The situation of families of disabled children]. In: I. Obuchowska (Ed.). *Dziecko niepełnosprawne w rodzinie* [The child with a disability in the family] (pp. 18-54). Warsaw: WSiP.
- Veisson, M. (2001). Parents of disabled children: Personality traits. *Social Behavior and Personality*, 29(6), 581-592.
- Wanamaker, C.E. & Glenwick, D.S. (1998). Stress, coping, and perceptions of child behaviour in parents of preschoolers with cerebral palsy. *Rehabilitation Psychology*, 43(4), 297-312.
- West, A. (1998). The piloting of a group for the fathers of children with Down syndrome. *Child: Health, Care and Development*, 24(4), 289-294.
- Young, D.M., Roopnarine, J.L. (1994). Fathers' childcare involvement with children with and without disabilities. *Topics in Early Childhood Special Education*, 14(4), 488-503.