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Willingness to use respite care among family caregivers in Northern Taiwan.

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AIM AND OBJECTIVES: Investigate the use of respite care among family caregivers and examine factors related to their willingness to use such care. BACKGROUND: Respite care is a pivotal service for supporting family caregivers. Although research related to respite care is not a new field in western societies, such studies have rarely been done for Asian populations. DESIGN: A cross-sectional study. METHODS: The study was conducted using a convenience sample of 100 family caregivers obtained through four home health care agencies in Northern Taiwan. Structured face-to face interviews were conducted in home settings. Caregivers were divided into a willingness group and a non-willingness group. The quantitative data were analysed using t-test, chi-square and multiple logistic regression. RESULTS: Sixty-five per cent of the caregivers interviewed did not know about respite care services. The prevalence of respite care use was 11%. Eighty-nine per cent of the caregivers had never used respite care: 60.7% of them reported that they would never use it and 39.3% of the caregivers indicated that they were willing to use respite care in the future. This study showed that willingness to use respite care was higher when the respite services matched the needs of the caregivers as well as the caregivers perceived higher caregiving burden. CONCLUSIONS: These results suggest that respite care services should be explained more explicitly to family caregivers. Also, any respite care plan must consider the family caregivers burden, both perceived and realistically. RELEVANCE TO CLINICAL PRACTICE: The willingness to use respite care is a culturally sensitive issue. Health care providers must act as advocates to improve respite care policy. They must ensure that respite care fits caregivers' needs and they must help caregivers overcome the social or cultural barriers to respite care.

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Quality of life of family caregivers of children with autism: The mother's perspective.

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The purpose of this study was to explore the relationship between the quality of life (QOL) and feeling of mothers of a child with autism. The QOL instrument was also used. A total of 104 participants completed all questionnaires, which included the Taiwan version of the WHOQOL-BREF. A final robust parsimonious structural model showed a positive correlation between the four domains of QOL. Mother's feeling was positively related to the physical and psychological domains. History of chronic disease was negatively related to mother's feeling and the physical domain. Religion was negatively correlated with the psychological and environmental domains. The study provided evidence that the WHOQOL-BREF is an adequate and appropriate instrument in the assessment of caregivers of children with autism in Taiwan. Mother's feeling, history of chronic disease and religion were related to QOL in these mothers of children with autism.

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Quality of life, health satisfaction and family impact on caregivers of children with developmental delays.

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OBJECTIVE: To study the quality of life, health satisfaction and family impact on caregivers of children with developmental delays in Taiwan. DESIGN: Cross-sectional study. SUBJECTS: The caregivers of children with diagnoses of developmental delays recruited from a teaching hospital in northern Taiwan. METHODS: The main caregivers of 48 male and 22 female children with developmental delays were recruited. WHOQOL-BREF for health-related quality of life (HRQOL), PedsQL-Health Satisfaction for health satisfaction, PedsQL-Family Impact Module and Impact on Family Scale for family impact were evaluated. The correlation of caregivers' HRQOL, health satisfaction and family impact were also studied. RESULTS: Caregivers in nuclear families had higher health satisfaction scores (78.2 for nuclear families vs. 66.9 for extended families, $P < 0.05$) when assessed by the PedQL-Health Satisfaction questionnaire. Children's age was negatively correlated with family impact, including parent (-0.272, $P = 0.023$), family (-0.262, $P = 0.029$) and total scores (-0.281, $P = 0.018$) as assessed using the PedsQL-Family Impact Module. CONCLUSION: A negative relation between impact of burden and child's age suggests that family members gradually adapt to the delayed developmental status in their children as they grow. Caregivers in nuclear families having higher health satisfaction than those in extended families may be due to Chinese cultural effects.

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Family function in cognitively normal children with epilepsy: impact on competence and problem behaviors.

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A cross-sectional cohort of 82 cognitively normal children with epilepsy attending the pediatric neurology clinic, who were aged 6-17 years and who had a similarly aged sibling without seizures or cognitive delay, were identified. The parent was asked to complete the Family Assessment Measure III (FAM-III) as well as the Child Behavior Checklist (CBCL) for both the child with epilepsy and his or her sibling. The Overall Rating Score on FAM-III did not differ significantly from the normative mean, although families scored significantly better on the Involvement subscale and significantly worse on the Role Performance subscale. Moderate correlations were found between competence and behavior problems and family function in both children with epilepsy and their siblings. In families functioning at the highest level, both cohorts did well. In those at the lowest level, approximately half of the children in either cohort had problems. For average functioning families, behavior and competence issues were more frequent in children with epilepsy than their siblings.

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How central and connected am I in my family? Family-based social capital of individuals with intellectual disability.

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Using social network methods, this article explores the ways in which individuals with intellectual disability (ID) perceive their family contexts and the social capital that they provide. Based on a subsample of 24 individuals with ID, a subsample of 24 individuals with ID and psychiatric disorders, and a control sample of 24 pre-graduate and postgraduate students matched to the clinical respondents for age and sex, we found that family networks of clinical individuals are distinct both in terms of composition and in terms of social capital made available to them by their family ties. Individuals with ID perceive themselves as less central in their own family; their family networks are perceived as less dense, less centralized, and more disconnected. Individuals with intellectual disabilities and psychiatric disorders have less family-based social capital than individuals with intellectual disabilities only. The composition of their family is also distinct as spouses or partners and children are missing. We discuss the importance of those findings for research on family relationships of individuals with ID.

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Family as a factor in cerebral palsy prevention.

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The aim of the study was to assess maternal perception of family impact on the course and outcome of rehabilitation in children with cerebral motor impairment. The study included 135 children with cerebral motor impairment. Their motor development was followed-up over a one-year period by use of structured interview with the children's mothers after 12-month rehabilitation. The course of rehabilitation was assessed by the method of locomotor system functional evaluation. The improvement achieved in motor development was significantly better in the group of children whose mothers found their relationships with extended family excellent than in those whose mothers considered it good or poor. The study showed that mothers to children with cerebral motor impairment frequently feel the lack of extended family support, being it real or perceived as such by the mothers due to their emotional sensitivity, suggesting the need of additional studies of the reasons for this. These findings indicate that greater attention should be paid by health professionals to the psychological support offered to these mothers.

Top Stroke Rehabil. 2006 Winter;13(1):14-24.

Perspectives of quality of life by people with aphasia and their family: suggestions for successful living.

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Understanding the client's perspective is essential for good practitioner care in rehabilitation after stroke, and nothing is more relevant than enquiring directly about our clients' quality of life to inform our management. Relatively little is known about how older people with aphasia consider the quality of their current lives, and this article seeks to explore this issue. Four women's accounts of their life quality are presented, as well as their husbands' or daughter's accounts of their lives. Their stories share some common elements. Who you love or share your life with; where you live; feeling independent and/or in control; and engaging in satisfying activities mattered to these women's life quality. The impact of aphasia varies across the cases, and the need to accept change for successful living is illustrated in all accounts.

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Practice standards to improve the quality of family and carer participation in adult mental health care: an overview and evaluation.

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Mental health services are required to involve family, carers, and service users in the delivery and development of mental health services but how this can be done in routine practice is challenging. One potential solution is to prescribe practice standards or clear expectation relating to family involvement. This paper describes practice standards introduced to an adult mental health service and a study that aimed to evaluate the impact of the standards on practice. Hospital and community files were audited before and after the introduction of standards for evidence of participation and surveys of carers and consumers relating to the quality of participation were undertaken. Increases in documented carer participation were found, particularly in relation to treatment or care planning. The expressed needs relating to participation varied in hospital and community settings. The majority of carers and service users were satisfied with their level of participation. The introduction of practice standards is an acceptable, inexpensive, and feasible way of improving the quality of family and carer participation, but gains may be modest.