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A comparative study of quality of life among adults with spina bifida Mary H Kalfoss*1 and Mark J Merkens²

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Background

The goal of treatment of persons with spina bifida (SB) is to add quality to their living. Few studies have examined QoL of adult persons with SB. In this study, we explored the similarities and differences in QoL of community – residing adults living in Norway and Oregon.

Method

The Norwegian sample consisted of 57 adults registered with the Norwegian Association of SB and Hydrocephalus. Adults included 38 females and 19 males, mean age 31.8 years (17 – 54 years). The Oregon sample included 34 adults attending the Child Development Rehabilitation Center, at Oregon Health Science University. Adults included 15 females and 19 males, mean age of 29.5 (17 – 49 years.) By postal survey, information was obtained assessing subjective QoL (WHOQOL – BREF, psychological distress (Hopkins Symptom Checklist), disability cognitions (Harowitz Impact of Events Scale) coping efforts (Lazarus Revised Ways of Coping Checklist), and cognitive difficulties (1- item and Broadbent Cognitive Failures Questionnaire).

Results

No significant differences were found between the samples concerning QoL, psychological distress, intrusive thoughts, coping, and cognitive problems. In the Norwegian sample, 41% suffered from depression, 19% anxiety, 38% intrusive thinking, and 43 % avoidance thinking. Further, 59% were shunted, 61% had cognitive problems affecting daily activities and 31% experienced cognitive

decline during the past six months. In the Oregon sample, 47% suffered from depression, 23.5% from anxiety, 48% intrusive thinking and 69% avoidance thinking. Further, 71% were shunted, 65% reported cognitive problems affecting everyday activities, with 33% reporting declining cognitive status. The Oregon sample used more avoidance thinking (x2 = 5.27; df = 2; p = .07). Two multiple regressions equations were explored to assess the predictive strength of generic QoL, psychological distress, disability cognitions, coping efforts, cognitive difficulties and country (independent variables) on 1- item overall QoL (dependent variable) in a pooled model. Results displayed a significant model (F 3.38; p = .004) explaining 28% of the variance in overall QoL. Generic QoL was the strongest predictor, followed by psychological distress. In investigating the same independent variables with overall health satisfaction (dependent variable), results confirmed a significant model (F 4.29, p = .001) explaining 33% of the variance in health satisfaction. Again, generic QoL was found to be the strongest predictor of health satisfaction. Country was not a significant predictor in these models.

Conclusion

Findings confirm cross- cultural similarities in subjective factors impacting QoL in community-residing adults. Work was supported by grants from the Elizabeth Foundation in Oregon and Diakonova University College in Oslo.