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Culture, Context and Existential Challenges

c. Modern Meaning-making – Adolescent Understanding of Existential Aspects in Health-related Quality of Life [HRQL]

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Aims: Present results from focus interviews concerning existential aspects related to the adaptation of the WHOQOL-SRPB(BREF) for Swedish adolescents. **Background:** Exploring existential aspects of HRQL are important when mental ill-health is increasing among adolescents in a secular context.

WHO introduced WHOQOL-SRPB in 2002 for measuring HRQL, including Spiritual, Religious and Personal beliefs [SRPB]. It is validated for Swedish adults. Now it requires adaptation for youth, even internationally. **Methods:** Pupils (age 15–19) in four groups were interviewed following WHO instructions for cognitive interviewing.

Content analysis of the transcribed interviews was conducted. Results: The pupils considered existential aspects important for HRQL. The items: Meaning, Awe, Wholeness, Peace and Hope were comprehensible for them. Faith and Personal beliefs were related to e.g. insecurity, individualism: "To believe in yourself" and traditional aspects: "I personally believe in Jesus but I do not believe in God". Spiritual Strength and Spiritual Connection did not require transcendence and could relate to various ideas e.g. nature or popular culture: "The first thing that pops up is the Lion King that talks to Simba in the clouds. It is his inner spirituality".

Conclusion: Results show the importance of adaptation of existential aspects in HRQL to the cultural (secularized) context.

Keywords: adolescents, existential, health related quality of life, WHOQOL-SRPB

d. Faith as a 'Normal Drug' in Caring Rare Disease

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In the management of both ordinary and extraordinary events, religions act as "systems of meaning" and as "systems of communication", offering cognitive, motivational, affective, as well as narrative resources, helping persons to give order to reality. Traditionally such a discursive help offered by religions, where it is viewed as "Salvation gift", is particularly significant for ill persons. Among diseases, rare ones represent a really complicated situation, being both subjective projects and personal/social identity seriously threatened.

As a consequence, persons and primary caregivers suffering with them are called to find new ways toward "normalization", in the effort to construct new certainties and meanings about the personal condition, the family situation and the parental identity.

Our study aims to investigate the role of religiosity in facing with the intense existential uncertainty offered by rare disease. Forty-four narrative interviews were conducted with parents of children suffering of rare disease and analyzed through Content and Discourse Analysis. Socio-epistemic rhetoric, metaphors, emotional markers, certainty/uncertainty markers are the interpretative lens that allowed us to understand the power of religion to offer several and specific meanings in the parental couple, fluctuating from a painful upheaval and attitudes of hope.

Keywords: disease, certainty, religiosity, system of beliefs, narrative interview, discourse analysis, normalization