Living with a congenital heart disease—Unnesessesary burden or chance for developement?

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- Medical School Graduate: University of Witten Herdecke
- Research: Montepllier/Brussels about QoL of CHD, comparing KIDSCREEN and PedsQL, linking results to exercise parameters
- Born with TGA: 3 Operations (2y: Senning, 7y: LVPA Conduit, 19y: Revision LVPA Conduit, Allograft implant.)

SOC: Important predictor of better QoL (Apers S et al. 2012 and 1013)

Moons and Norekval (2006)-factors and conditions why CHD can develop better SOC?
My aim

- To describe my **own experiences** in growing up with a heard disease and **inquire** to which extend it leads to a **personalized way of development and integrity** by being born with a **special physical and emotional constitution** and facing resistances, challenges, critical life events
Agenda

- My personal experience in living with a chronic heart condition
- Scientific view – the concept of Sense of Coherence and its components
- What can't be easily evaluated scientifically, Future research, Practical implications
The Concept of Antonovsky’s Sense of Coherence (SOC)

Concept developed to explain why some people become ill when stressed and others remain healthy

Core elements of SOC are:

- **Meaningfulness** – extend to which an individual believes that, e.g., living with an illness makes sense emotionally and leads to the motivation to cope with stimuli or stresses.

- **Manageability** - extend to which an individual learned to cope with a disease or can apply on resources to manage stressful stimuli.

- **Comprehensibility** – extend in which events in life are becoming structured, predictable, and explainable.
Discussion

What is not easy to measure or missed out? What could be touched in further studies?

**Individual accesses** to promote a good development of personality (e.g., Risk avoidance vs. Facing challenging situations)

Some aspects of my biography could have been explained in another light with other results in concepts such as hardiness, resilience or other coping strategies.

**Concept** such as **Coping and Sense of Coherence** likely to be interpreted too mechanical: Stimulus-reaction principle: Personality traits as product of certain stimuli, can miss out:

- The fact that **we are born with very individual** personal traits which influence our way in dealing with problems
- The **liberty of free choice**
Further research:

- Qualitative studies on SOC
- The role of spirituality (not just in terms of spiritual coping)
- Philosophic medical work: The impact of Illness in the context of life before birth and after death.
- Personal traits with which you are already born and ways of dealing with problems leading to personal growth
- Social relations reflected by the process of normalization (Classens et al. 2005) and in addition to a process of accepting to be different.
Practical implications:

- **Attitude** of caregivers as key element: Thinking about illness in a positive way as chance for development, without denying/ignoring true problems or anxieties. To respect the individual way dealing with an illness but uncover personal resources to be strengthen.

- **SOC** as a target for interventions in childhood to improve QOL during adulthood (Apers S et al. 2013):
  1. Educating patients and parents about disease, giving reliable information to establish selfmanagement;
  2. support individual, making living with the disease as balanced as possible and in finding solutions to faced problems
  3. individuals view lifethreatening episodes as experiences that bring about meaning to their lives. (Moons P. and Norekva°I TM, 2006).

- Specific interventions: Lifestyle interventions, talk-therapy, patient empowerment, and case management have proved to be effective strategies to enhance SOC (Forsberg KA et al. 2010, Langeland E et al. 2006, Delbar V and Benor DE 2001 in Apers S et al. 2013).

- **Ferietales**, history of Parcival for ex.(hero with personal growth)-possibility to enhance phantasies of solutions for problems.

- Apers S, Moons P, Goossens E, et al. Sense of coherence and perceived physical health explain the better quality of life in adolescents with congenital heart disease. European Journal of Cardiovascular Nursing 2013 0(0) 1–9, DOI: 10.1177/1474515113477955 cnu.sagepub.com


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