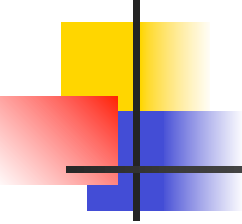


Living with a congenital heart disease- Unnesseary burden or chance for developement?

Raphael Dorka

- Medical School Graduate:University of Witten Herdecke
- Research: Montepplier/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.)

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- Adolescents with CHD-stronger SOC (Nio K. 2010, Neuer B et al. 2011, Apers S et al. 2012 and 1013)
 - 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 developement** 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** – extent to which an individual believes that f. ex. living with an illness **makes sense emotionally** and **leads** to the **motivation to cope** with stimuli or stresses
- **Manageability** - extent to which an individual **learned to cope** with a disease or **can apply on resources** to manage stressful stimuli
- **Comprehensibility** – extent in which events in life are becoming **structured, predicable 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** (f. ex. 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**



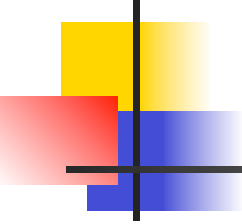
Further research:

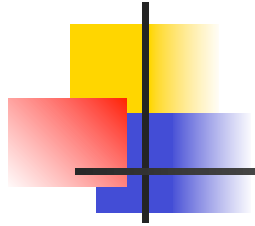
- **Qualitative studies on SOC**
- The **role of spirituality** (not just in terms of spiritual coping)
- Philosophic medical work: The impact of **Illness** in the **context of life before birth and after death.**
- **Personal** traits with which you are **already born** and ways of dealing with problems 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^ol 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.(heroe with personal growth)-possibility to enhance phantasies of solutions for problems

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