Quality of life in alcohol related brain damaged individuals: What a good-tempered, socially integrated and highly efficient group of older adults ... or maybe not?

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Theoretical Background
Severe alcoholics typically report impaired quality of life (QoL; e.g. Peters et al., 2003), whereas self-rated QoL by alcoholics has been found to be higher than ratings provided by health care professionals (Foster et al., 2002). Findings of different research studies suggest, that alcoholics suffering from severe alcohol related brain damage (ARBD) seem unable to reliably rate their own QoL (e.g., Markowitsch et al., 1986) given dramatic deficits in cognitive and emotional functioning (e.g., Steinmetz & Federspiel, 2012).

Aims of the study
We investigate the perception of QoL and daily cognitive deficits in a group of detoxified ARBD individuals. We hypothesize that ARBD individuals systematically overrate their own QoL and underrate their cognitive deficits.

Methods
Sample
N=34 detoxified individuals (4 women) with ARBD living in a long-term care facility providing 24h care and support. Mean age = 58.1 years (SD=6.0, ranging from 48-65). Mean age at entry to the present facility was 54.2 years (SD=6.9, ranging from 41-63). The group is characterized by a history of relapse and unsuccessful psychiatric rehabilitations whereas individuals demonstrate a variety of somatic and psychiatric comorbidities that are a consequence of excessive alcohol abuse over decades.

Instruments
The same items were used for self- and expert-ratings. Expert-ratings were provided by one psychiatric nurse and one certified educator.

Quality of Life Profile for Chronically Ill Patients (PLC; Siegrist et al., 1996; Lautbach et al., 2001), with the six QoL dimensions: subjective physical and mental performance (scale 1), ability to have pleasure and relaxation (scale 2), positive mood (scale 3), negative mood (scale 4), ability to relate/contact/approach (scale 5), and sense of affiliation (scale 6). Inter-rater reliability KAlphα = .67 (95%CI, LL=.48; UL=.83).

Dysexecutive Questionnaire (DEX), a self- and expert-rating questionnaire (Wilson et al., 1996), evaluating the occurrence of behavioural, cognitive, and emotional aspects of the dysexecutive syndrome. The difference score computed by subtracting global self-rating from expert-ratings provides a measure of lack-of-insight by the patient. Inter-rater reliability KAlphα = .66 (95%CI; LL=.41; UL=.87).

QoL-Profile — self-ratings and other-ratings, norm population

Effects between both ratings range from large (|.75| for scale 4) to very large (|.70| for scale 3), with a mean Cohen’s d of |.25| (SD = .31).

Interestingly, ARBD self-ratings closely match ratings provided by a healthy norm population, with Cohen’s ds ranging from |.07| to |.25| (mean = |.18|; SD = .08). Taken together, ARBD patients seem unable to correctly perceive and interpret their QoL as demonstrated by systematically outstanding expert-ratings and in resembling ratings from a healthy norm population.

Concerning self- and expert-ratings on the three DEX sub-scores, patients are found to underrate significantly (ps < .0002) their cognitive deficits on all three scales, with a mean effect size of 2.16 (SD=.42). To investigate if a greater lack of insight on the DEX (and thus, more important cognitive deficits) is associated to higher QoL ratings by the patient, Spearman rank order correlations were computed. This hypothesis could not be confirmed as relationships were not significant and mostly negative, with a small mean effect of |.17| (SD = .15).

Discussion
The present research is, to our knowledge, the first study contrasting QoL self-ratings with expert-ratings in a sample of ARBD individuals living in a long-term care facility. Our findings demonstrate the occurrence of important discrepancies between the perceptions of the ARBD patient and ratings given by healthcare professionals. Thus, our findings suggest that ARBD patients are unable to adequately perceive their own disease and handicapped function (see also Blansjaar et al., 1992). Crucially, these misperceptions may not only disable patients from complying with a therapeutic program, but may furthermore result in the development of social conflicts and inadequate coping strategies (i.e., relapse). The origin of these misperceptions remains unclear, as the present research design disables us from inferring causal relationships between cause and effect. In this context, further research needs to demonstrate what kind of impairments (e.g., cognitive, affective) are at the origin of these misperceptions.

Literature