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AN EXPLORATION OF CARER BURDEN AND POSITIVE GAIN IN DEMENTIA: THE ROLE OF EXECUTIVE FUNCTIONING DEFICITS, MANAGEMENT STRATEGIES AND EXPERIENTIAL AVOIDANCE

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PLAN



- Background and aims of study
- Methodology and measures
- Findings
- Implications for potential use of ACT with caregivers
- Outcomes – what we measure and how we do this



BACKGROUND



- What do dementia caregivers struggle with most?
- Systematic review – focussing on behaviour changes and ‘carer burden’
 - Proposed mechanisms included:
 - Carer attributions
 - Time spent in caring role/ relationship
- Issues with concept of burden
- Very few studies into mechanisms in this process



THE STUDY (AIMS)



- The study aimed to explore:
 - The relationship between types of executive function deficits (EF) and dimensions of carer burden and positive gain (PAC)
 - The role of dementia management strategies and experiential avoidance as potential mechanisms
 - The impact of age, gender and type of relationship



THE STUDY (METHODOLOGY)



- 110 dementia caregivers from all over Scotland (SDCRN & NHS)
- Measures:
 - DEX – executive function (5 subscales)
 - ZBI – burden (impact on caregiver life; guilt; frustration/embarassment)
 - PAC – positive aspects of caregiving
 - DMSS – dementia management strategies scale
 - EACQ – experiential avoidance in caregiving scale
- Data analysed with correlations and multiple regression



FINDINGS

(EF DEFICITS AND BURDEN)



- EF deficits most significant predictor of overall burden, BUT:
- Different types of EF deficit predictive of different dimensions of burden:
 - Inhibition ($b=0.37$ [0.05,0.67], $p = .03$) - impact on caregiver life
 - Negative affect ($b=0.37$ [0.05,0.64], $p = .03$) – guilt
 - Executive memory ($b=0.22$ [0.01,0.40], $p = .06$) - frustration/embarrassment
- EF deficits were not predictive of lower levels of PAC



FINDINGS (MANAGEMENT STRATEGIES)



- Carers who used more negative strategies were more likely to experience higher levels of burden, esp. impact on caregiver life ($b=0.43$ [0.13,0.67] $p=.01$) and guilt ($b=0.18$ [0.07,0.31] $p=.01$)
- Carers who used more positive strategies were more likely to experience higher levels of PAC ($b=0.30$ [0.06,0.50] $p=.01$)
- These effects were independent of level of behaviour experienced
- Potential to intervene by changing responses of carers without changing behaviour itself



FINDINGS (TYPE OF RELATIONSHIP)



- Adult children were more likely to experience guilt than spouses ($b=-2.48$ [-4.95, -0.18], $p = .02$)
- Spousal caregivers more likely to experience both frustration/embarrassment ($b=3.82$ [1.52, 6.20], $p = .002$) AND positive aspects of caregiving ($b=7.93$ [0.54, 17.30], $p = .04$)
- So, looks like it is possible to experience high levels of negative thoughts/emotions, while ALSO experiencing personal benefits from the caregiving experience...



FINDINGS (EXPERIENTIAL AVOIDANCE)



- Carers who used active avoidant behavioural strategies (e.g. distraction, avoiding asking for support) were more likely to feel guilt ($b=0.20$ [0.02, 0.37], $p = .04$)
- Cognitive subscales of EACQ were problematic
- Issues with measuring EA in this population and in general



OUTCOMES A DIFFERENT PERSPECTIVE?



- Numerous studies exist measuring 'carer burden', but how meaningful is this if no focus on separate aspects and how realistic that any intervention can reduce this?
- Are PAC related to valued living?
- Are positive aspects such as PAC, QOL, valued living, relationship quality more amenable to change?



WHAT NEXT?



- Could we focus on changing caregivers' responses to their situation rather than aspects of the situation itself?
- Would an increased understanding of the function of behaviour enable caregivers to take a more compassionate stance/increase positive responses?
- Would an ACT based approach help caregivers to handle their negative internal experiences without getting caught up in these, and reconnect with their values?



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