

Table 1

Main characteristics of quantitative studies

Study	Quality score (max 11)	Method	Participant characteristics	Theory	Psychosocial measures	Physiological measures	Findings
Bachanas et al (2001)	5	Cross-sectional Self-report Between groups	n= 36 CG's, 32 matched control NCG's	Transactional Model of Stress & Coping (Lazarus & Folkman, 1984)	✓		Poor CG adjustment related to more daily hassles, use of more palliative coping strategies and fewer family resources CG's who report more daily hassles report more psychological distress CG's using more palliative coping reported more psychological distress than CG's using more adaptive coping
Barbosa, Figueired, Sousa & Demain (2011)	7	Cross-sectional Self-report Between groups	n= 90 primary CG's, 90 secondary CG's Mean age 45.23 years	Transactional Model of Stress & Coping (Lazarus & Folkman, 1984)	✓		All strategies involving direct action were used and perceived as helpful by more than 50% of CG's Relying on own expertise and experience was most useful approach for both groups Planning in advance most useful and effective for secondary CG's Primary CG's used firmness, pointing out expectations, preventing problems, getting professional help and altering home environment Believing in oneself and one's ability to handle the situation were most successful emotional-cognitive strategies Increased use of problem solving coping associated with better self-rated physical health Higher use of emotional-cognitive coping and dealing with the consequences of stress were associated with poorer mental health perception Secondary CG's found distraction and avoidance strategies less effective Have a good cry useful for primary CG's and get rid of excess energy for secondary CG's
Figueiredo et al (2014)	8	Cross-sectional Self-report Between groups	n= 158 family CG's Mean age 58.39 years		✓		Effects of stressors mediated by social support, coping and appraisals High levels of avoidance coping and low levels of approach coping were related to increased depression and lower life satisfaction Greater social support and activity related to higher life satisfaction and lower depression
Haley et al (1996)	6	Cross-sectional Self-report Between groups	n= 123 white CG's, 74 black CG's Mean age 62.36/55.45 years	Stress Process Model (Haley, Levine, Brown & Bartolucci, 1987)	✓		High stress appraisals associated with higher depression Higher initial and increased use of problem focussed (PF) coping in mothers of ID predicted declining levels of burden
Kim, Greenberg, Seltzer &	7	Longitudinal Self-report Between groups	n= 246 mothers of adults with intellectual disability, 74	Stress and Coping paradigm (Pearlin et al, 1990)	✓		

Krauss (2003)			mothers of adults with mental illness Mean age 66 years				Increased emotion focussed (EF) coping in mothers of ID increased burden, decreased EF coping decreased burden High use of PF coping and low use of EF coping at wave 1 predicted declining depressive symptoms Increase of EF coping between waves 1 and 2 related to higher burden and depression and poorer relationship with the child Mothers of ID increased in PF coping over time, leading to lower subjective burden and depression and better relationships at wave 2 Being a CG significantly associated with higher levels of BP and cortisol Lower instrumental social support – higher levels of cortisol
Kim & Knight (2006)	7	Cross- sectional Self-report Between groups	n= 87 CG's, 87 matched NCG's Mean age 63 years	Sociocultural stress and coping model for caregivers (Aranda & knight 1997)	✓	✓ Blood pressure Salivary cortisol	
Mausbach, Chattillion, Roepke, Patterson & Grant (2013)	6	Cross- sectional Self-report Between groups	n= 125 CG's of spouses with Alzheimer's Disease (AD), 60 spouses not caring for AD		✓		CG had greater depressive symptoms than controls, higher NA, fear, hostility and sadness CG more likely to report less PA and joviality relative to controls Lower access to several psychological resources relative to controls CG reported greater activity restriction than NC Caregivers utilised fewer positive coping and greater negative coping strategies relative to controls Active and avoidant coping scores were similar between groups Did not differ in terms of burden or depressive symptoms Subjective reports of poor physical health higher in AA CG's
McCallum, Longmire & Knight (2007)	5	Cross- sectional Self-report Between groups	n= 35 African American (AA) CG's, 35 White American CG's Mean age 60.73/65.42 years	Sociocultural stress and coping model (Aranda & knight 1997)	✓		
Merritt & McCallum (2013)	6	Cross- sectional Self-report Between groups	n= 30 CG's, 30 NCG's Mean age 58.2/59.6		✓	✓ Salivary cortisol	Higher positive RCOPE correlated with higher cortisol slopes Increasing RCOPE scores were associated with flatter cortisol slope scores Caregiver status associated with marginally flatter but non-significant cortisol slopes than non-caregivers Higher RCOPE scores were correlated with flatter cortisol slopes for caregivers but not for non-caregivers Positive RCOPE scores were associated with flatter cortisol slope scores Higher negative RCOPE scores predicted marginally flatter negative cortisol slopes for non-caregivers but no changes for caregivers Higher combined and positive (but not negative) RCOPE scores were associated with increasingly flatter or worse cortisol slope scores for caregivers (but not controls) Caregivers who reported higher RMBPC scores, higher combined and positive (but not negative) RCOPE scores

Pakenham & Bursnall (2006)	6	Cross-sectional Self-report Between groups	n= 48 children of parents with MS, 146 children with health parent mean age 17.7 years	Transactional Model of Stress & Coping (Lazarus & Folkman, 1984)	✓		<p>were unexpectedly associated with increasingly flatter cortisol slopes</p> <p>Parental illness and greater family responsibilities related to higher distress</p> <p>Lower levels of perceived choice in caregiving and parental functional impairment associated with lower adjustment on positive outcomes</p> <p>Higher stress appraisals related to higher distress and lower life satisfaction</p> <p>Higher levels of qualitative social support related to higher positive outcomes, less distress and better health, greater number of support people was related to greater life satisfaction</p> <p>More reliance on problem solving, acceptance and seeking social support and less reliance on wishful thinking and denial = greater positive outcomes</p> <p>Greater reliance on wishful thinking and denial related to greater distress</p> <p>MS caregivers reported higher family responsibilities and somatization, lower life satisfaction and positive affect and less reliance on problem solving coping and seeking social support coping</p> <p>None of the coping strategies were related to health status</p> <p>Caregivers used 'behaviour escape' more than controls</p> <p>Caregivers showed lower levels of social support in all dimensions</p> <p>Caregivers showed higher levels of trait anxiety, depressive symptoms and both internal and external anger expression</p> <p>Caregivers showed less ability to regulate negative emotions compared to the control group</p> <p>Caregivers indicated more symptoms on all physical health subscales indicating poorer health</p> <p>Higher magnitude of cortisol response in caregivers than the controls when controlling for negative effect</p> <p>Resilience negatively correlated with somatic symptoms, anxiety, insomnia and perceived general health</p> <p>Resilience negatively correlated with Casl for the four time points and AUC</p> <p>High scores in resilience related to high levels of emotional, tangible, positive social interaction and global index of support</p> <p>When controlling for CG variables – no significant associations between resilience, somatic symptoms and severe depression – relationship between resilience and perceived general health remained significant</p> <p>Total effect of resilience on perceived general health was significant, resilience in turn predicted social support – social support predicted perceived general health</p>
Ruiz-Robledillo & Moya-Albiol (2013)	7	Cross-sectional Self-report Between groups	n= 53 parents of child with Autism Spectrum Disorder (ASD), 54 parents of health children Mean age 45.32/42.80		✓	✓ Salivary cortisol	
Ruiz-Robledillo et al (2014)	7	Cross-sectional Self-report Between groups	n= 67 parents of ASD Mean age 45.46 years		✓	✓ Salivary cortisol	

Sander, High, Hannay & Sherer (1997)	7	Cross-sectional Self-report Between groups	n= 69 CG of close head injury (acute, intermediate and long term) Mean age 39.1/45.8/45.1 years	Framework for studying family stress following TBI (Graffi & Mines)	✓	<p>Emotional/informational support had direct effect on perceived general health</p> <p>Positive social interaction showed direct effect on perceived general health</p> <p>CG's with higher resilience show better perceived health, lower morning cortisol levels and less are under the curve (AUC)</p> <p>As emotion-focused coping increased so did level of psychological distress</p> <p>Coping did not moderate relationship between burden and emotional distress</p> <p>Satisfaction with social support linked to psychological distress</p> <p>Greater use of emotion-focussed coping was related to greater emotional distress – coping style contributed to variance in BHQ scores</p> <p>Problem-focused coping not related to GHQ scores</p> <p>Coping accounted for more of the variance in BHQ scores than DRS scores</p> <p>Higher levels of subjective burden were related to greater number of symptoms on GHQ</p> <p>Amount of social support was not related to GHQ</p>
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Table 2

Main characteristics of qualitative studies

Study	Quality Score (Max 20)	Method	Participant characteristics	Theory	Findings
Azman et al (2015)	17	Semi-structured interviews Content analysis	N=15, CG's of mental ill family members, age 25-86,		Five coping strategies identified: 1. Religious coping 2. Emotional coping 3. Acceptance 4. Engage in leisure activities 5. Traditional healing
Bailey, Letiecq & Porterfield (2009)	19	Semi-structured interviews Thematic Analysis	n= 26 grand families	Double ABCX Model of Family Adjustment and Adaptation (McCubbin & Patterson, 1983)	Communicating with schools Reframing perceptions as positive
Dickson et al (2011)	16	Semi-structured interviews Interpretive Phenomenological Analysis	n= 11 spousal CG's of acquired traumatic Spinal Cord Injury		Coping with the spousal caregiver role (emotion focussed strategies): venting emotion, time out, role of support, focussing on the positive aspects of SCI Putting the pieces back together again: reducing work hours, accepting financial hardship, using paid carers, acceptance that life will never be the same, balance between adaptability and stability, positive reappraisal Need for patience Support with physical care Emotional support from family members & ministers Spirituality – strong religious convictions, church services Formal assistance – adult day care, home health services
Gerdner, Tripp-Reimer & Simpson (2007)	18	Longitudinal Semi-structured interviews Observation Ethnographic analysis	n= 15 African American CG's		
Kaplan (2010)	14	Semi-structured interviews Grounded Theory	n= 20 CG mothers		Consistent social support – friend or family member that helps with care Uncertain future affected coping and structural barriers like lack of communication
Kita & Ito (2013)	19	Semi-structured interviews Comparative Analysis/ Grounded Theory	n= 18 family CG's of frail older adults	Family Systems Theory (Bowen, 1966)	Routinisation of daily life Minimisation of competition of needs among family members Incorporate risk management strategies into daily life Integrate care methods and outside services into family culture Reconfirming the meaning and importance of the care Sharing care experiences Devising care methods to reduce time and labour
Kitter & Sharman (2015)	19	Semi-structured interviews	n= 20 CG's of traumatic brain injury	Self-determination theory	Social support was beneficial – good to talk Enriching experiences through caregiving – appreciation of life Keeping own identity Taking time out/respice

Le Dorze, Tremblay & Croteau (2009)	19	Semi-structured interviews	n= 1 adult daughter CG for aphasic father	Adaptation theory (Michallet et al 2003)	Reaction to stress was proactive: obtained information, modified communication with father and oversaw his health and treatments Used visual supports, proximity to father, communicating with others in a similar situation, self-care
McCausland & Cavanaugh (2001)	19	Semi-structured interviews Comparative method	n= 13 CG of spouses waiting for lung transplant		Social support, drawing on past experience of illnesses or deaths of parents Action: calling social support, support groups, researching online, volunteering, and therapy. Acceptance: recognition that undesirable situation could not be changed Disengagement: separation from the transplant situation – e.g. guests, working Planning: Child care, work arrangements, packing bags, telephone calls, living will. Support: emotional, esteem, information sharing, tangible support
Sun (2014)	20	Semi-structured interviews Thematic Analysis	n= 18 family CG of dementia	Stress-coping frameworks (Knight et al 2000, Lazarus and Folkman 1984)	EFC – to cope with worries, frustration and other negative feelings associated with CG. Hobbies, self-validation, informal support, counselling. PFC – compare progress with books & media Coping with physical limitations and emotional/behavioural problems of CR – physical exercise, indoor games, paid homemakers, engage in activities, lowering expectations, avoid confrontation, finding humour, technology Coping with social restrictions – find alternative entertainment than leaving house, computer games, reading Coping with financial burden – PFC seeking employment and assistance from government PFC – for family conflict Coping with pressure from social environment – withhold information Seeking an explanation, finding meaning Valuing the caregiver role, identifying benefits, recognition Coordination of care with siblings – consistent communication and effort Taking charge – initiative, decisiveness and readiness to take on the role, housing arrangements, leadership within family Spirituality – religion, social support
Thornton & Hopp (2011)	18	Semi-structured interviews Interpretive Phenomenological Analysis	n= 7 adult daughter CG's		Looking on the bright side Downward comparisons with others – considering themselves more fortunate, and coping resources as more efficient Humour when feeling helpless Acceptance- adopting innovative coping techniques Normalising problems Planning, organising and seeking information to increase sense of control Some avoidant coping behaviours
Williams, Morrison & Robinson (2014)	19	Semi-structured interviews Photo elicitation Interpretive Phenomenological Analysis	n= 13 CG's of stroke or dementia	Transactional Model of Stress & Coping (Lazarus & Folkman, 1984)	Positive marital bond was a coping strategy, affection, physical touch, feeling cared for Support from adult children
Wong et al (2015)	19	Semi-structured interviews Grounded Theory	n= 10 CG families of dementia		

Zegwaard et al (2013)	19	Semi-structured interviews Associative, inductive strategy and continuous coding	n= 19 CG who look after older adults with severe mental illness	Perceived freedom of choice – voluntary act of compassion vs unavoidable obligation, gain vs loss Togetherness, accepting inequality, autonomy Finding meaning, meaningful participation in social life Acceptance
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