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# Brief Report: Competence, Value and Enjoyment of Childcare Activities Undertaken by Parents of Children With Complex Needs<sup>1,2</sup>

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**Purpose:** Parents combine many roles when caring for a child with complex needs, but few studies measure parental value and enjoyment of childcare related activities. This study aimed to describe parental competence, enjoyment and value of childcare related activities, particularly healthcare related activities, when parenting a child with complex needs.

**Design and Methods:** This was a pilot cross sectional study. Ten mothers of children with complex needs rated their competence, value and enjoyment of 156 childcare related activities using the Occupational Questionnaire (Smith, Kielhofner, & Hawkins Watts, 1986).

**Results:** The mothers rated childcare related activities as important and rated themselves as competent to undertake them. Mothers disliked performing healthcare related activities, but enjoyed emotional care activities.

**Conclusion:** This study extends the current knowledge regarding the role tension described by parents of children with complex needs. The finding that parents dislike performing healthcare related activities despite self-reporting high levels of competence warrants further investigation.

**Practice Implications:** Gaining a better understanding of the role tension described by parents of children with complex needs may enable pediatric nurses to better understand the impact of home based care provision on parents and assist them to find ways to support families so this care can continue to be provided.

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PARENTS COMBINE MULTIPLE, often contradictory roles when caring for a child with complex needs (CCN) including parent, advocate, educator, case manager, nurse and physiotherapist (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Whiting, 2014). Time use research describes the amount of time spent in childcare related occupations, but there is limited information about the parents' perceptions of their engagement, meaningfulness, enjoyment and satisfac-

tion with these activities (Gevir, Goldstand, Weintraub, & Parush, 2006; Lampropoulou & Konstantareas, 1998). The Australian Time Use Survey is unusually comprehensive, but records only behavior, with no measure of how respondents feel about what they do (Craig, 2006).

The additional care requirements involved in caring for a CCN and the impact on parents is well documented (eg. Sanders, Bray, Driver, & Harris, 2013; Santer et al., 2013; Swallow, Lambert, Santacroce, & Macfadyen, 2011). Relatively few studies however have measured parental perceptions regarding childcare activities (Table 1). Enjoyment of activities has been described (Cant, 1994; Gevir et al., 2006;

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**Table 1** Examples of studies measuring meaningfulness and enjoyment of childcare activities for parents of children with complex needs.

Author/s	Sample <sup>a</sup>	Data collection tool	Variables measured	Classification of child caring	Main findings
Plant and Sanders (2007)	Mothers (n = 105) of children with developmental disability	Checklist of 22 childcare related activities	Stress associated with specific activities and Likert scale assessing stressfulness of task completion and difficulty getting activities done	1) Direct care (bathing, feeding, toileting, dressing); 2) in-home therapy; 3) attendance at appointments; 4) supervision of child; 5) play and leisure activities; 6) education and information about disability; 7) advocating for services; 8) managing child behavior	Mealtimes, cleaning up after child, settling at bedtime, supervising toileting and advocating to health professionals ranked as the five most stressful activities on a checklist of 22 different tasks. Doing therapy and giving medication ranked 7 and 13 respectively. High stress mothers found caregiving activities more difficult and associated with more difficult child behavior and lower child functioning.
Gevir et al. (2006)	Mothers of children with mental retardation MR (n = 29); motor difficulties MD (n = 30); ADHD (n = 30); typical development TD (n = 31)	Mothers Time Use Questionnaire adapted in part from Occupational Questionnaire	1) Perceived meaningfulness; 2) enjoyment derived	Activities with their children	Most meaningful occupations 'activities with child' and home maintenance, but home maintenance least enjoyable occupation. No significant difference in meaningfulness assigned to activities by different groups. Mothers of children with ADHD had significantly less enjoyment in activities with child.
Lampropoulou and Konstantareas (1998)	Mothers of deaf children (2–14 years) with no other disabilities (n = 42)	Form reporting time spent in child related activities and 'perceived affective tone'	Activities perceived as 'fun', 'neutral' or 'a chore'	1) Dressing; 2) feeding/meals; 3) bathing & toileting; 4) playing & recreation; 5) teaching/education; 6) bedtime routines	Higher stressed mothers significantly more likely to rate dressing and bathing their child and meals as a chore or neutral compared to lower stressed mothers. Mothers undertaking more dressing, bathing, feeding related activities more likely to report lack of enjoyment (neutral or a chore rating). No play/recreation activities given 'a chore' rating
Padeliadu (1998)	Mothers of children (mean age 12.6 years) with Down Syndrome DS (n = 41) & no disabilities ND (n = 41)	Form reporting time spent in child related activities and 'perceived affective tone'	Activities perceived as 'fun', 'neutral' or 'unpleasant'	1) Dressing; 2) feeding/meals; 3) bathing & toileting; 4) playing & recreation; 5) teaching/education; 6) bedtime routines	Mothers of children with DS significantly more likely to perceive time demands as 'fun' compared to comparison group ( $p < 0.001$ ). Perceiving child demands as 'unpleasant' associated with higher stress for mothers of children with DS ( $p = 0.001$ ).

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