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Formal supports improve QOL for parents of children with disabilities: Systematic review; and, Mothers caring for a child with a disability require dynamic, tailored support services to return to paid work

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Sylvana Pasini

A report submitted in Partial Fulfilment of the Requirements for the Award of

Bachelor of Science Occupational Therapy (Honours)

Faculty of Computing, Health and Science,

Edith Cowan University.

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Formal Supports Improve QOL for Parents of Children with Disabilities: Systematic Review

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Summary Statistics (Journal of Family Studies Restrictions)

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Formal Supports Improve QOL for Parents of Children with Disabilities: Systematic Review

Abstract

Purpose: Parents caring for a child with a disability (PCCD) may experience adverse effects on quality of life (QOL) due to role demands, hence it is important to evaluate available support services. This paper aims to systematically review current research examining the impact of formally provided, parent-focused emotional or informational interventions on QOL for parents caring for a child with a disability or chronic condition. Procedures: Electronic searches of five databases (2001 – 2011) were conducted and reviewed against the study eligibility criteria. All levels of evidence were included, and studies were evaluated against standard quality assessment criteria by two reviewers. Principle Conclusions: A range of adequate quality studies were identified (qualitative and quantitative), and evidence suggests positive results for the utilisation of parent-focused interventions at improving parental QOL. Given the methodological limitations and small number of eligible studies included in the review, generalisability to the wider community is restricted.

Keywords: Parent, carer, informational, emotional, support, impact

Author: Sylvana Pasini

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Submitted: October 2011

Abbreviations

PCCD: Parents caring for a child with a disability

QOL: Quality of life

Formal Supports Improve QOL for Parents of Children with Disabilities: Systematic Review

Introduction

The Australian Bureau of Statistics (ABS, 2009) reported that there were approximately 2.6 million carers in Australia in 2009, 29% of those were primary carers. Primary carers provide the most informal care to an individual who has one or more disabilities or is older than sixty years, and is likely to be ongoing for six months or more (ABS, 2009). According to the ABS (2009), primary carers usually care for a relative, and 23% provide care to a child. This equates to approximately 173,420 parents providing primary care for a child with a disability in Australia. The number of Australians providing informal care to a family member is expected to grow at 2% per annum, in line with the population growth (Access Economics, 2010). Factors which may impact the number of parents caring for a child with a disability (PCCD) in Australia are de-institutionalisation (House of Representatives, 2009), an increased number of people with a disability or profound restriction requiring care in the community, a preference to supply informal care to meet emotional and family obligations (AIHW, 2004a), and advances in medical interventions leading to longer lives for children living with medical conditions and disabilities (McCabe & Shaw, 2010). Therefore, it can be expected that the need for parents to assume the primary caring role for their child with a disability will continue to rise.

This review is important because PCCD have been identified as experiencing high levels of stress, caregiver burden, financial strain, have low wellbeing, and often suffer from their own physical and mental health decline (Brehaut et al., 2004; Cummins et al., 2007; Davis et al., 2010). As a result of compounding issues and lack of support in their role, these parents' quality of life (QOL) is often impacted (Davis et al., 2010; Resch et al., 2010). The World Health Organisation (1997) defines QOL as an individual's subjective view of their life, encompassing the cultural, environmental and social context of which they live. As QOL is influenced by these previously mentioned contexts, it can be inferred that the QOL of PCCD can be affected by the amount and type of carer supports they receive.

There are several supports available for carers to assist them in their caring role, and can be identified as either informal or formal (Tsai & Wang, 2009). Informal support has been identified as support received from family members or close friends (ABS, 2005), where formal support is provided by an organisation or agency (Tsai & Wang, 2009). The types of supports available for carers can be grouped into three broad areas: informational, emotional, and practical assistance (Redmond & Richardson, 2003; Tsai & Wang, 2009).

Informational support assists the caregiver in their caring role, by providing knowledge, education or advice in regards to the caregiver's situation (Tsai & Wang, 2009). Informal informational support can be provided in the means of advice from friends and family (Shin & McDonaugh, 2008), and formal information provision can be delivered via telephone, face-to-face, through the internet (Leonard et al., 2004), or via educational carer workshops. A recent systematic review identified that informational assistance was found to be an ineffective intervention for carers delivered on its own (Eagar, Owen, Williams, Westera, & Marosszeky, 2007). However, the majority of literature identified in the aforementioned review reported on caregivers of people with dementia (Eagar et al., 2007).

Emotional assistance can aid in assisting the caregiver emotionally and psychologically, by alleviating psychological and emotional stress (Shin & McDonaugh, 2008). It can be formally provided in the structure of support groups and counselling, and informally provided by friends and family by somebody who will listen and provide encouragement to the caregiver (Tsai & Wang, 2009). Hastings and Beck (2008) reviewed stress interventions for parents, which focused on group based cognitive behavioural techniques (CBT). Conclusions indicated that group based CBT interventions benefited parents in reducing stress, particularly in mothers, and indicated that there was some value to parent led support networks (Hastings & Beck, 2008).

Practical support can be in the form of respite, in-home assistance and funding (Tsai & Wang, 2009). Respite is a service provided to the care recipient, which allows the carer to have some free time to engage in other activities besides the caring role (Strunk, 2010). A vast majority of informal Australian caregivers identified respite as one of the most important formal supports (Cummins et al., 2007), with evidence to support that respite improves the parent-child relationship and reduces parental stress (Strunk, 2010). In-home assistance is a service provided either by professionals or family members, where the care-recipient is assisted with tailored services in their own home (Forde, Lane, McCloskey, McManus, & Tierney, 2004). These services can be in the form of equipment provision, leisure activities and assistance with activities of daily living for the care recipient (Forde et al., 2004). Much like respite, these services also provide the caregiver with time to engage in other tasks, which has the potential to reduce parental stress (Forde et al., 2004). In addition to these practical supports, financial assistance can be provided by the government, to help carers with the potentially increased costs of providing care for an individual with a disability, however most payments are means tested, so not all carers are eligible (ABS, 2005; Redmond & Richardson, 2003).

Interventions addressed in this review will cover any formal emotional or informational support, defined as a service provided through or organised by an organisation, which aims to improve the QOL of PCCD. The intervention must be targeted at the parent and include QOL outcome measures. All levels of studies will be included in the review. Past research has indicated coping resources, such as self esteem and social support, aid individuals in minimising stressful events (Taylor & Stanton, 2007). Thus, it can be anticipated that the findings of this review will indicate that parent focused interventions will positively impact on the different QOL outcomes for parents.

Methods

This review followed the techniques and principles of systematic reviews, with the process guided by the PRISMA statement (Liberati et al., 2009). A review protocol was developed in order to guide the reviewer's process. Electronic searches of five databases were carried out in order to locate relevant studies for inclusion in this review. Cumulative Index of Nursing and Allied Health Literature (CINAHL, 1978-2011), MEDLINE (1978-2011), PsychInfo (1973-2011), Family Abstracts (1985-2011) and Web of Science (1990-2011) were selected for use. Each database was searched from 2001 to 16 June 2011, in order to locate the most recent studies over the preceding ten year period. The main search terms were caregiver, support, program, service, intervention, quality of life, wellbeing, burden, stress, child and disability. With assistance of a librarian these terms were exploded, truncated and refined in order to tailor the search (Appendix A). The searches were not limited by study type, however studies were restricted to only include those which had been published in an English language peer reviewed journal.

A *priori* criteria was determined and applied to abstracts. Studies were included in the review if they described: 1) a formal emotional or informational carer support service targeted at parents caring for a child with a disability or chronic condition, and 2) had a QOL outcome measure for parents. There were no limitations on frequency and length of the intervention. Outcomes of interest included wellbeing, occupational engagement, depression, stress, strain, burden, anxiety, frustration, self-efficacy and health. Parents were to be adults, 18 years and over. Studies including both or one parent were included, however given that most primary carers of a child with a disability are mothers (AIHW, 2004b), the majority of participants were female. Studies were excluded if they only measured the impact of informal supports, if the care was provided to the child under a contract for services (i.e., paid care), if the intervention was focused on the child receiving the care, if the outcome of interest was solely service satisfaction, or if the intervention was exclusively practical support (such as respite). A systematic review was recently conducted on respite for families caring for a child with a disability (Strunk, 2010), hence it has been recently addressed.

Assessment of Methodological Quality

Independent assessment of the study quality was performed by two reviewers. The quality was assessed using the quantitative and qualitative forms developed by Kmet and colleagues (2004). The forms include a series of questions (qualitative checklist contains 10 questions and quantitative form has 14 questions) and a scoring system to review study quality. Guidelines and instructions for each type of form were utilised to assist the reviewers in determining the quality of the studies. The reviewers used the forms to determine a score, and rated the studies quality as strong (more than 80%), good (score 70-80%), adequate (50-70%), or limited (less than 50%). Due to the limited number of suitable articles available, studies were not excluded from the review based on quality. Discussion between reviewers was the means used to resolve any disagreement.

Data Extraction

Using the guidelines stated in section seven of the Cochrane Handbook for Systematic Reviews of Interventions (2005), two independent reviewers extracted data from the studies. The data extracted included the study objective, QOL domains, participants, participant selection, participant characteristics, intervention, study design, outcome measure, outcome and quality. Following data extraction, levels of evidence were determined via guidelines (Melnyk & Fineout-Overholt, 2005), and discussion between reviewers was the means used to resolve any disagreement.

Data Synthesis and Analysis

Given the limited number of protocols described, range of interventions and varied study designs, a meta-analysis was not possible. Hence in order to summarise findings, a narrative synthesis was undertaken. See Table 1 for a summary of qualitative studies and Table 2 for quantitative studies (Appendix B). If sufficient data was reported, effect size was calculated using G-Power version 3.1.3 software (Faul, Erdfelder, Lang, & Buchner, 2007).

Results

Electronic searches of databases located 1504 potential articles from Web of Science, 74 from Medline, 220 from CINAHL, 285 from PsychInfo and 21 from Family Abstracts. The total number of articles located across all searched databases, with duplicates removed, was 2041. Titles and abstracts were reviewed using the inclusion criteria, with 35 articles accepted for the preliminary search. Full text was obtained for each of these articles, and they were further screened against inclusion criteria for eligibility. Through full text review of the 35 articles remaining, 11 did not specify a specific intervention, nine did not have a QOL outcome, and five had child focussed interventions. This resulted in the acceptance of ten articles for the review (Appendix C).

All of the included articles described parent focused interventions that impacted on QOL outcomes. Three studies were RCTs (Bilgin & Gozum, 2009; Roberts, Mazzucchelli, Studman, & Sanders, 2006; Tonge et al., 2006), 4 studies used quasi-experimental, pre-test post-test design (Hudson, Cameron, & Matthews, 2008; Hudson et al., 2003; Keen, Couzens, Muspratt, & Rodger, 2010; Todd et al., 2010), and one study reported using pre and post test design, however only qualitative findings were reported (McGuire, Crowe, Law, & VanLeit, 2004). One study utilised an action research design (Mackey & Goddard, 2006), and one was a quasi-experimental case study (Palit & Chatterjee, 2006).

Quality Assessment of Studies

The quality of the articles included for review ranged from adequate to very strong (Appendix B). Shortcomings included small sample sizes, lack of blinding, limited accounting of confounding variables, high dropout rates for measuring follow up data, and limited reporting of effect size. Given the nature of the participants' caring responsibilities included in the review, it was evident that attrition contributed to the shortcomings. This can be common in research involving human subjects (Ahern, 2005). The majority of the assessment tools of interest had good psychometric qualities. However, one study utilised a questionnaire with fourteen questions, which had only been evaluated by three experts in the field on face validity (Palit & Chatterjee, 2006). Limited options for answers were available for participants to select, hence results have been interpreted with caution.

Interventions

There were a variety of parent focused interventions evaluated in the selected studies. Authors described seven interventions which can be categorised as informational supports. One study had an interactive education program, combined with educational booklets, in order to reduce burnout (Bilgin & Gozum, 2009), and another with an additional counselling component (Tonge et al., 2006). Two studies reported on the same protocol, the "Signposts for Building Better Behaviour" program, which utilised eight advice booklets for parents to assist with developing their own action plan for managing their child's behaviours, and managing their own stress (Hudson et al., 2008; Hudson et al., 2003). Keen and colleagues (2010) described an intervention based on decreasing parenting stress and increasing parent competence. This intervention was delivered through workshops and home-visits, in comparison to a video based delivery of the strategies learnt in the workshops. Another study utilised the 'Stepping Stones Triple P' (SSTP) program, which included clinic visits, home visits, workbooks and a video, aimed at managing child behaviour, and an extra module on partner support and coping skills (Roberts et al., 2006). The final education based study utilised group based parent training sessions, based on the principles of social learning theory to effect change (Todd et al., 2010).

Three studies described emotional support programs for parents. One was a psychosocial occupational therapy intervention, "Project Bien Estar", which was aimed at promoting health and wellness, delivered individually and in group settings (McGuire et al., 2004). Palit and Chatterjee (2006) described a parent-to-parent counselling program monitored by psychologists. The other study utilised a health mentoring approach facilitated by nursing students and academics, to improve the health and wellness of parents caring for a child with disability (Mackey & Goddard, 2006).

Outcomes of Interest

The outcomes of interest were related to three broad areas of QOL and included wellbeing, mental health and burnout. While these studies considered other outcomes not relating to QOL, only the variables of interest have been reported on.

Wellbeing

Wellbeing was the outcome of interest in two studies, one used a mixed methods design (McGuire et al., 2004). The other study was qualitative, using participant self report and discussion to report on wellbeing. This study also reported on health outcomes (Mackey & Goddard, 2006). Following intervention, mothers and their families reported that health mentoring was found to be a valuable strategy for promoting their own health, and enhanced levels of wellness and coping. By participating in group and individual sessions of a psychosocial occupational therapy intervention, “Project Bien Estar”, mothers stated that it was a positive addition to their lives and their sense of wellbeing was improved (McGuire et al., 2004). Statistically significant changes were not able to be reported given the studies’ designs.

The Parenting Sense of Competence Scale (PSOC) (Johnston & Mash, 1989) was utilised in three education based studies, to measure parental satisfaction and perceived efficacy of their role as a parent (Hudson et al., 2008; Hudson et al., 2003; Keen et al., 2010). Hudson and colleagues (2008) reported positive PSOC outcomes for their group, individual and telephone delivered interventions for both mothers and fathers, with large effect sizes reported on the self efficacy subscale for mothers in the individually and telephone delivered interventions (d = 0.91, d = 0.97 respectively). This is consistent with the earlier findings of Hudson and colleagues (2003), reporting overall moderate effect sizes for mothers on the PSOC efficacy subscale for group, telephone and self-directed intervention, with results maintained at follow up. Differences were found between the professionally supported and self-directed intervention by Keen and colleagues (2010), with parents in the professionally supported group showing an improvement in self efficacy post-intervention, however the intervention was most effective for parents demonstrating lower self efficacy scores at pre-intervention.

Mental health

Two studies reporting on the educational intervention, ‘Signposts Program’, used the Depression Anxiety and Stress Scale (DASS) (Lovibond & Lovibond, 1995) to measure parental mental health (Hudson et al., 2008; Hudson et al., 2003), however Hudson and colleagues (2003) only utilised the stress subscale. Small effect sizes were found for mothers on all DASS subscales post intervention ($d = 0.27, 0.19, 0.35$), and on the stress subscale for fathers ($d = 0.20$) (Hudson et al., 2008). Hudson and colleagues (2003) reported a reduction in stress which was maintained at 4-6 months follow up, however no difference was found among experimental groups. The DASS stress subscale was used by Roberts and colleagues (2006) to measure the effect of the SSTP on parental stress. Significant effects were not indicated, however almost one third of mothers in the intervention group reported stress reductions post-intervention. One study used the Parenting Stress Index (PSI) (Abidin, 1995) to measure child and parent related stress, with the professionally supported intervention resulting in reduced levels of child-related stress post-test (Keen et al., 2010). The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used in one study, with findings of significant post intervention improvements (Todd et al., 2010). Large effect sizes were reported for post intervention reductions in anxiety ($p < .0005$, $d = 0.88$) and depression ($p < .0005$, $d = 0.84$) (Todd et al., 2010). Palit and Chatterjee (2006) used a researcher developed questionnaire to measure the impact of a parent-to-parent counselling program, with 71.5% of participants reporting a reduction in anxiety, and 72.5% a reduction in parental frustration. The General Health Questionnaire (GHQ-28) (Goldberg & Williams, 1988) and Parental Stress Thermometer was used in one education based program with two intervention groups and a control (Tonge et al., 2006). Findings demonstrated an overall GHQ-28 improvement in mental health for both treatments at follow up ($F = 2, 97$, $p = 0.007$). Longer term alleviation of stress symptoms were found for participants in the behaviour management intervention as opposed to the counselling based intervention, and a greater improvement post-test for those with higher pre-test stress scores (Tonge et al., 2006).

Burnout

Burnout was the outcome of interest in one educational program (Bilgin & Gozum, 2009), which utilised the Maslach Burnout Inventory (MBI) as an outcome measure (Maslach & Jackson, 1981). Post intervention findings indicated statistically significant differences between the intervention and control groups in the emotional burnout subscale ($p = 0.046$, $d = 0.36$). Following completion of the education programme intervention, the mean score of mothers in the intervention group significantly decreased from pre-test with lower scores indicating less emotional burnout. Effect size was calculated as medium ($d = 0.58$, $p < 0.05$).

Discussion

This systematic review found adequate qualitative and quantitative evidence to support the use of formal, parent-focused, informational and emotional interventions for PCCD to positively impact a variety of outcomes associated with parents' QOL. Some studies reported significant results between intervention and control groups, and most reported improvements, even if they were not statistically significant. None reported adverse effects or deteriorations. Effect sizes from these studies ranged from very small to large. However, the results need to be interpreted with caution due to the methodological quality and limitations of the studies, small number of included studies, and recruitment of participants.

Studies for this review were located electronically from five databases, and were limited to peer-reviewed and published studies over the preceding ten years. Grey literature was not included, which may have yielded some quality research in this area.

The education based RCT aimed at reducing maternal burnout by Bilgin and colleagues (2009) had strong methodological quality, and medium effect sizes were reported for the intervention group. However all mothers were recruited from Eastern Turkey, therefore generalisation to the wider population may be limited. Most studies recruited the parents / participants based on their child's diagnosis and characteristics, hence effects for parent outcomes were varied. Some results indicated that the interventions were most effective at reducing parent's symptoms when the parents were experiencing higher levels of distress pre-test, than those within the normative range (Roberts et al., 2006; Tonge et al., 2006). Therefore it can be said that if further research was undertaken in these areas, they could recruit parents based on their characteristics at pre-test, in order to provide a clearer picture of outcomes for this group. Roberts and colleagues (2006) reported that approximately one third of participants engaged in extra modules of coping skills or a partner support program which included marital communication and parenting teamwork, or mood management and coping skills, however this was not reported on as the numbers were too small (n = 8). Results may have been influenced differently if the sample was larger and this module was assessed. However results were not statistically significant, although positive.

Palit and colleagues (2006) reported positive outcomes on anxiety and frustration reduction through a parent-to-parent counselling program. However the psychometric properties of the outcome measure and reporting of results could be questioned, as the degree of symptom reduction was not explicitly identified, introducing the possibility of bias. The other two support programs were qualitative in nature, with positive findings for participant wellbeing in the short term, however the long term benefits of these support programs were not assessed (Mackey & Goddard, 2006; McGuire et al., 2004).

Despite the limitations, there were three RCTs of good to strong quality included in the review, two of which reported significant outcomes for educational interventions impacting on mental health and burnout (Bilgin & Gozum, 2009; Tonge et al., 2006). Educational interventions with professional support seemed to benefit parents more than information provision on its own (Keen et al., 2010). This is supported by past findings which found that information provision alone is not an effective intervention (Eagar et al., 2007). It can be inferred that these informational / educational, and emotional support interventions have a positive impact on a variety of QOL outcomes for PCCD. Given that these parents can experience both positive and negative impacts on their QOL in caring for a child with a disability (Davis et al., 2010), it is essential that professionals are able to deliver effective programs in order to educate and provide support to parents as a preventative measure or in times of need. If parents have improved QOL, mental health and wellbeing, it is also possible that the benefits will be transferred to that of their children (Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007).

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Appendix A

Search Strategy

Search Strategy: CINAHL, Medline, Family Abstracts, Psychinfo

Limiters: Date: 2001-2011, peer reviewed, abstracts searched.

1. care*
2. caring
3. 1 or 2
4. support*
5. service*
6. program*
7. intervention*
8. 3 or 4 or 5 or 6
9. "quality of life"
10. wellbeing
11. well-being
12. QOL
13. depress*
14. stress
15. burden
16. health
17. psych*
18. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14
19. child*
20. disab*
21. 19 or 20
22. 3 and 8 and 18

Appendix B

Table 1

Description of Included Qualitative & Mixed Methods Studies

First author, year of publication, country	Design and sample	QOL outcome & Intervention	Main QOL findings	Methodological Quality	Limitations
Mackey **2006** **Australia**	Participatory action research (Level 6) Purposive sampling. Families of child/children with a disability (n = 5), final-year Bachelor of Nursing students (n = 10), nurse academics (n = 2)	Health and wellness A health-mentoring project to support mothers and families of children with disabilities aimed at educating families to engage in health promotion practices	Health mentoring was found to be a useful strategy for promoting the health of mothers and their families Families reported enhanced levels of wellness and coping	Kmet score: Adequate (70%)	Small sample of families, recruited from one location, limits transference of findings to other settings Long term benefits of intervention not assessed, unknown
McGuire **2004** **US**	Mixed methods, randomised allocation pre test - post test (Level 6) Mothers who had at least one preschool or school-aged child (ages 3-14 yrs) with significant functional disabilities (N = 23)	Wellbeing A psychosocial occupational therapy intervention "Project Bien Estar". Six weekly group sessions and an individual session at the beginning and end of the group intervention. Designed to increase satisfaction, time use, and occupational performance for mothers of children with a disability Questionnaire completed post intervention for 'things learnt and changes made'	The Person-Environment-Occupation (PEO) model was used to frame the discussions in the intervention Some mentioned that the intervention was a positive addition to their lives. They learnt the importance of taking care for themselves, and balancing their lifestyle to improve wellbeing Some mothers changed their child's school environment to be more supportive of their child. In these instances, the mother's well-being was linked to their child's wellbeing	Kmet score: Adequate (50%)	Did not report on quantitative results or any information on the control group, hence results interpreted with caution. Only group discussion findings reported.

Table 2

Description of Included Quantitative Studies

First author, year of publication, country	**Design and sample**	**QOL outcome & Intervention**	**QOL outcome measures**	**QOL outcomes**	**Methodological Quality**	**Limitations**
Bilgin **2009** **Turkey**	RCT (Level 2) Mothers of children with an intellectual disability (N = 90)	Burnout **Intervention** (n = 45) One hour interactive education programme and educational booklet on children with ID, organisations/resources and coping with stress **Control** (n = 45) No intervention, on a waitlist	**Maslach Burnout Inventory** 2 subscales (emotional burnout and personal success) Subscale of interest for review = emotional burnout	Mean of intervention group on emotional burnout subscale pre-test to post-test 22.24 ± 6.59 to 17.97 ± 7.96 (p <0.05) Calculated effect size = 0.58 (medium) Means between groups, post-test results, statistically significant (p = 0.046): Calculated effect size = 0.36 (small)	Kmet score: Strong (93%) Random allocation. Allocation concealed from recruiting independent researcher, and second author, was blinded to group assignment	First author was not blinded to group allocation Generalisability to the wider population is limited as all mothers were recruited from Eastern Turkey
Keen **2010** **Australia**	Pre-test post-test (quasi-experimental, comparative study) (Level 4) Families with A child aged between 2-4 yrs with a clinical diagnosis of ASD, based on the diagnostic criteria specified in the DSM-IV received within 6 months prior to participation in the study (N = 39)	Stress **Intervention A:** Professionally supported (2 day workshop and 10 home visits). Families (n = 17) Mothers (*n* = 17) / Fathers (n = 16) **Intervention B:** Self-directed (video based on strategies learnt in workshop, and activity sheets). Families (n = 22) Mothers (*n* = 22) / Fathers (n = 21)	**Parenting Stress Index (PSI) (child and parent related stress subscales)** & **PSOC (parental satisfaction and efficacy subscales)** Pre, post and at 3 months follow up. _**Child measures were also utilised but not relevant to this review**_	The professionally supported intervention resulted in reduced child-related parenting stress and increased parenting self-efficacy relative to the self-directed intervention Provision of information via self-directed video alone did not impact on parenting stress levels, or perceptions of parenting competence On average, PSI ratings for child-related stress were 7.8 points lower for parents in intervention A than B	Kmet score: Strong (91%)	Lack of full randomisation Small group sizes No control

Tonge **2006** **Australia**	RCT (Level 2) Parents (principal caregivers) of preschool children aged 2 ½ -5yrs, with recently diagnosed, strict DSM-IV diagnosis, autism Parents recruited on their child's diagnosis.	Mental health **Intervention** (n = 35) PEBM, 20 week, manual-based parent education and behaviour management intervention-including stress management **Intervention** (n = 33) PEC, 20 week, manual-based parent education and counselling intervention **Control group** (n = 35) No intervention	**General Health Questionnaire (GHQ-28).** Four subscales: somatic symptoms, social dysfunction, anxiety & insomnia, and severe depression. Used pre and post intervention and at 6 month follow-up. **Parental Stress Thermometer**. Visual analogue scale measuring general stress, level 0-4 (0=none, 4=very very much)	Both treatments resulted in significant and progressive improvement in GHQ total at follow-up (F = 2, 97, p = .007) and mental health significantly improved over time in the 54% of principal caregivers who had the highest levels of mental health problems **Stress Thermometer** PEBM significantly benefited over no treatment, when pre-test stress scores were above 96th percentile. PEBM alleviated stress symptoms better then PEC in the longer term	Kmet score: Strong (86%)	Parents were recruited on child's diagnosis
Hudson **2008** **Australia** **Wide scale evaluation of Hudson (2003)**	Pre-test post-test (pre experimental) (Level 4) Parents and carers of children with an intellectual disability (N=2119) Mothers (n=1,551) Fathers (n=396) Others (n=172)	Depression, anxiety and stress **Intervention** (6 sessions over approx 12 weeks – delivered as part of a normal service delivery system). The 'Signposts for Building Better Behaviour' program (8 information booklets, a video and workbook – covering broad areas of managing child's behaviour, dealing with stress, family as a team). The program was delivered	**The Depression Anxiety and Stress Scale (DASS).** **&** **Parent Sense of Competence Scale (PSOC)** **(Satisfaction and efficacy subscales)** (Pre-test post-test and at 3 month follow up). ***Many other outcome measures were used but were not of relevance to this review. Some parenting scales, other*	Outcome by participant type, effect size ***Mothers*** **DASS**(n = 689) Depression: 0.27 (small) Anxiety: 0.19 (small) Stress: 0.35 (small) **PSOC** (n = 688) Efficacy: 0.54 (medium) Satisfaction: 0.49 (small) ***Fathers*** **DASS**(n = 159) Depression & anxiety: non-significant (ns). Stress: 0.20 (small)	Kmet score: Strong (82%)	No control group High overall dropout rate (21%) Completed post-test measures (n = 889). Completed follow up measures (n = 277). Only mothers' data was reported for results on different modes of delivery due to the small sample sizes of fathers and others

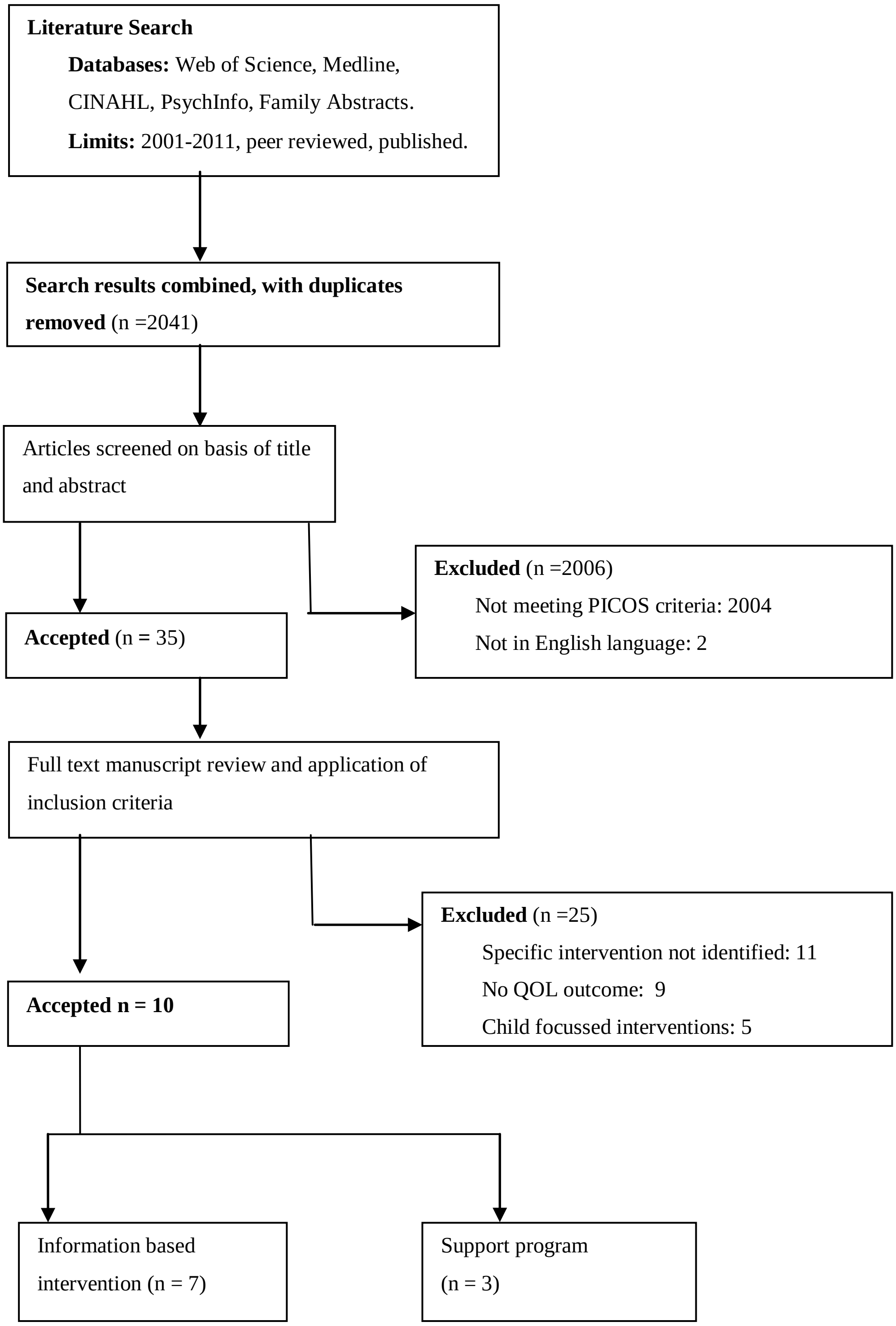
		via several modes (numbers of participants completing both pre and post test): **1) Group** (n =741) **2) Individual** (n = 109) **3) Telephone** (n = 36) **4) Self-directed** (n = 3)	*child scales***	**PSOC** Efficacy: 0.49 (small) Satisfaction: 0.37 (small) ***Others*** **DASS** (n = 48) **& PSOC** (n = 46/45)**:** ns		
Roberts **2006** **Australia**	RCT (Level 2) Families of children registered with DSC, aged 2-7yrs, with developmental disabilities (n = 47)	Stress **Intervention** (n = 24) The SSTP. An individually delivered 10-session parenting program, including clinic visits and home visits, workbook and video – aimed at managing child behaviour, and an extra module on partner support and coping skills. **Control** (n = 20) Waitlist control, usual early intervention services.	**DASS (stress subscale)** Pre, post and 6 month follow up	No significant effects were found for mothers or fathers with normative levels of stress at pre-test. No deterioration was shown at follow-up, however there was no significant maintenance However 28.6% of mothers in the intervention reported reliable stress reductions at post intervention. Stress results limited due to non-significant effects	Kmet score: Good (75%)	Extra module on partner support and coping skills (n = 8), was not assessed due to the small sample size.
Todd **2010** **UK**	Pre-test post-test. (Pre experimental) (Level 4) Parents /carers of children aged 4-11yrs, requiring significant educational support (N=22)	Depression and anxiety Group based parent training intervention incorporating modelling, home practice, problem-solving and extensive role play in order to support parents learning	**Hospital Anxiety and Depression Scale (HADS).** 14-item questionnaire assessing the presence and severity of anxiety and depression	HADS Scores Anxiety N = 22 Pre = 11.4 (SD = 4.69) Post = 7.9 (SD = 3.31) Significance <.0005 Effect size 0.88 Depression N = 22 Pre = 8.8 (SD = 4.09)	Kmet score: Good (73%) Good psychometric properties of HADS, however author noted other measures could be used to validate the	Conclusion limited as no control group, therefore may be confounding variables affecting outcome Dropout rate 12% (n=3), but 2 did so due to bereavement, and one with

	Male (n = 3) Female (n = 19)	Broad themes addressed: Understanding child’s behaviour, managing parental stress, facilitating communication		Post = 5.7 (SD = 3.41) Significance <.0005 Effect size 0.84	interventions effectiveness on the parents (eg.PSI, QOL)	no contact
Hudson **2003** **Australia** **Initial evaluation of the Signposts Program**	Pre-test post-test (pre experimental) (Level 3) Mothers of children with an intellectual disability aged between 4-19yrs (N = 115)	Depression, anxiety and stress **Intervention** ‘Signposts for Building Better Behaviour’ program (8 information booklets, a video and workbook – covering broad areas of managing child’s behaviour, dealing with stress, family as a team). Delivered via several modes: **1) Group** (n = 46) **2) Telephone** (n = 13) **3) Self-directed** (n = 29) **Control** Waitlist (n = 27)	**DASS (only stress subscale used)** & **PSOC (only efficacy subscale used)** Pre-test, post-test and 4-6 months post intervention for follow up ***Many other outcome measures were used but were not of relevance to this review. Some parenting scales, other child scales***	Difference in means, pre-test post-test. Group (n = 26), Telephone (n = 5), Self-directed (n = 8), Control (n = 26) **DASS** (Stress): Group: pre 11.5, post 10.5 Telephone: pre 10, post 9.2 Self-directed: pre 11.4, post 7.8 Control: pre 13.3, post 15.1 **PSOC** (Efficacy): Group: pre 26.2, post 28.6 Telephone: pre 26, post 29 Self-directed: pre 24.1, post 24.3 Control: pre 24.7, post 24.2	Kmet score: Adequate (68%)	Lack of full randomisation High dropout rates. Only 57% of participants completed post-test measures Changes maintained at follow up, however only (n = 13) group, (n = 5) telephone, and (n = 7) self directed completed follow up measures No difference among experimental groups

Palit **2006** **India**	One shot case study (pre-experimental) (Level 4) Bengali parents of children with CP and multiple disabilities (n = 50).	Anxiety, frustration The 'Parent-to-Parent Counselling Program'. Based on psychological counselling and group psycho-therapeutic techniques. Supervised by a psychologist or rehabilitation psychologist	**A 14 item evaluation questionnaire** was developed to measure the impact of the program. Likert scale, 4 option answers. **One question relating to anxiety. One related to frustration and helplessness**	71.5% of the parents admitted the program reduced their level of anxiety 72.5% admitted parental frustration had reduced	Kmet score: Adequate (57%)	Only face validity of the questionnaire was validated, by three experts in the field Limited responses in questionnaire. Did not report on level of frustration or anxiety change (1-4 on likert scale) chosen by participants, therefore results interpreted with caution

Appendix C

Flowchart



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Text: Should usually be divided into sections with headings (eg Introduction, Methods, Results, Discussion, and Conclusions).

References: Should be pertinent to the text and not a complete review of the literature unless such be the purpose of the article. Note especially the proper style (APA) for references, both in text and reference lists. Footnotes may appear as endnotes, at the Editors' discretion.

Tables, figures and appendixes: Should be supplied at the end of the main text, with their desired locations cross-referenced within the text. Tables and figures should be numbered consecutively in separate sequences and each given a brief title. Vertical rules should not be used. Each table should be cited in the text in consecutive order. Tables should be used only when necessary to clarify important points but not duplicate information in the text.

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Mothers Caring for a Child with a Disability Require Dynamic, Tailored Support Services to Return to Paid Work

Sylvana Pasini

Summary Statistics (Gender, Work & Organization Restrictions)
Word length for the manuscript: 7334 (approximately 7000)
Word length of the abstract: 146 (max 150)

Mothers Caring for a Child with a Disability Require Dynamic, Tailored Support Services to Return to Paid Work

Abstract

In comparison to mothers from the general population, mothers caring for a child with a disability (MCCD) are faced with a long term caring role which must be balanced with other life roles. The overall aim of this research was to explore the perceived support needs of MCCD to successfully return to paid employment. A mixed methods approach was utilised, consisting of questionnaires and a semi structured interview. This study reports on the reasons for returning to work (RTW), the different barriers experienced in RTW, and the specific needs required to overcome these barriers. Finances, alternative care for children, skills and confidence, employment issues, perceived lack of services, and complex prioritisation of needs were the main themes explored. It was found that MCCD require individually tailored and dynamic supports to enable a return to work. Implications for future research and the occupational therapy profession are discussed.

Keywords: primary carer, work experience, job canvassing, formal support, informal support.

Abbreviations

MCCD: Mothers caring for a child with a disability

RTW: Return-to-work

Mothers Caring for a Child with a Disability Require Dynamic, Tailored Support Services to Return to Paid Work

Introduction

MCCD can be faced with various obstacles, and often care for their child is a prolonged or lifelong role (Murray, 2006). Although there has been a considerable amount of research undertaken to explore the issues facing MCCD in maintaining employment (Parish, 2006, George et al., 2008), there is a paucity of research exploring the specific needs of unemployed mothers wanting to return to the workforce. No literature was found that identified and prioritised these mothers' return-to-work needs. Hence there is a need to conduct research in order to explore what these mothers believe would assist in facilitating a return to paid employment.

The Australian Bureau of Statistics (ABS, 2009b) reported that there were approximately 2.6 million carers in Australia in 2009, 29% of those were primary carers. Primary carers provide the most informal, unpaid care to an individual in the areas of self-care, mobility or communication, for a duration of at least six months (ABS, 2009b). Primary carers usually care for a relative, and in 2009 23% provided care to their child (ABS, 2009b). In Australia, mothers were the primary carers in 92% of parent primary carers of children with a disability aged zero to 14 years (ABS, 2008). Carers play a valuable role in Australia's health care system through the provision of approximately 1.32 billion hours of care per year, which if replaced with formal care would cost 40.9 billion dollars per annum (Access Economics, 2010). This cost would be further compounded if the value of potential workforce participation from the carers is considered (Access Economics, 2010). Factors which may impact the number of parents caring for a child with a disability in Australia are de-institutionalisation (House of Representatives, 2009), an increased number of individuals with a disability or profound restriction requiring care in the community, and a preference to supply informal care to meet emotional and family obligations (AIHW, 2004). Therefore, it can be expected that the need for mothers to assume the primary caring role for their child with a disability will continue to rise.

It has been shown that caring for a child with a disability can have both positive and negative impacts on the quality of life (QOL) of parents (Davis et al., 2010). One aspect which can be impacted by caring for a child with a disability can be the engagement in and occupational performance of paid employment (Parish, 2006, George et al., 2008). Paid employment can offer many benefits to carers such as financial security, social interaction (Becker, 2000, ABS, 2009), structure and meaning to daily routine, sense of identity and respite from carer duties (Stiell et al., 2006). Carers have indicated that maintaining their worker role can balance out their caring role and positively impact wellbeing (Matire et al., 1997). Carers who are in paid employment also have the opportunity to maintain their social networks, therefore may be less vulnerable to social isolation (Becker, 2000). Parents caring for a child with a disability indicated that work enabled them to retain their adult identity by socialising with other adults (Stiell et al., 2006). Therefore, even though there are difficulties in combining work and care, the positive impacts of paid employment appear beneficial to MCCD with the right supports in place.

The Model of Human Occupation (MOHO) (Kielhofner, 2008), was chosen to frame the research to provide a uniquely occupational therapy perspective. MOHO is an occupationally focused and client centred model that assists in prioritising client’s needs, and has associated resources aimed at individuals’ role as a worker (Kielhofner, 2008, Velozo et al., 1998). MOHO focuses on an individual’s occupational participation and performance, and the interaction between their; 1) motivation (volitional sub-system), 2) routines (habituation sub-system), and 3) abilities (performance capacity sub-system). These interactions are embedded in, influenced by, and given meaning to, by their environment (Kielhofner, 2008).

The overall aim of the research was to explore the supports MCCD needed to successfully return to paid employment. Specifically, this was addressed through the following objectives:

1. Describe the characteristics of MCCD who want to return to paid employment.
2. Explore the reasons MCCD want to return to paid employment.
3. Describe the barriers to returning to paid employment, as perceived by MCCD.
4. Discover the supports currently being utilised by MCCD to facilitate returning to paid employment.
5. Identify the unmet needs of MCCD wanting to return to paid employment, in relation to personal actions, informal supports and formal service provision.
6. Prioritise the most important supports perceived by MCCD to assist in returning to paid work.

Given the complex caring situation of MCCD combined with other life roles, it was anticipated that the proposed research would find that individual return-to-work services would not be as effective as a combination of services tailored to each individual carer that addressed all aspects and barriers in the their lives.

Methods

Research Design

A mixed methods design from a post-positivist approach was used, allowing an integration of methods which addressed limitations of each approach, and allowed the researcher to prioritise participants’ identified needs (Creswell, 2007, Depoy and Gitlin, 2005),. There was a paucity of literature identified on the prioritised unmet needs for MCCD to return to work, with the majority of information limited to government reports and grey literature. Therefore, the qualitative interviews allowed the researcher to develop an in-depth understanding of the return-to-work issues faced by the target population (Depoy and Gitlin, 2005). The quantitative data, in the form of demographic questions and standardised measures, allowed the researcher to describe the socio-demographic and QOL characteristics of the participants, and position the sample in relation to the normative population.

Paradigm and Assumptions

The PRECEDE-PROCEED model was used to guide the methodology. It is a model which describes a nine phase process to diagnose health needs, implement interventions and evaluate outcomes (Green and Kreuter, 1999). The research utilised the first phase of the model, the social assessment, which aimed to identify individuals' perception of their own needs and quality of life (Green and Kreuter, 1999, US Department of Health and Human Services, 2005).

Sample

Participants were recruited through the online databases of Kalparrin and Carers WA, two Western Australian organisations that aim to assist carers in their caring role (Kalparrin, 2011, Carers WA, 2011). Participants were recruited by convenience sampling, and met the following inclusion criteria to enable homogeneity:

- The participants were mothers and primary carers of at least one child with a disability (child's age could range from newborn to adult, and child could have any type of disability),
- Aged 18 – 64 years,
- Residing with their child,

- Not engaged in any form of paid employment, however had worked in paid employment in the past,
- Were seeking paid employment or wanting to re-engage in paid employment within the next six months, and
- Lived in metropolitan Perth, Western Australia.
- Individuals were excluded if they were non-English speaking or had inadequate language skills to complete the questionnaire, participate in the interview or give consent.

Ethics and Consent

This study followed the guidelines of the National Statement on Ethical Conduct in Human Research (2007). The research protocol was approved by Edith Cowan University Human Research Ethics Committee, Kalparrin and Carers WA board. Participants were provided with written information regarding the study requirements, and were given the opportunity to contact the researcher to clarify any questions prior to consenting to participate. Informed written consent was obtained from all participants prior to commencing data collection. Confidentiality was maintained throughout the study, with all identifying data removed during transcription. Data was stored in a locked cabinet or on the researcher's computer, password protected. Data will be stored at Edith Cowan University in line with the University's data storage guidelines. All names in this report are pseudonyms.

Data Collection

Quantitative Data

Participants completed a written questionnaire prior to the interview (Appendix A). This enabled them to complete it at a convenient time, and to gain a greater understanding of what the study involved prior to consenting to the interview. The questionnaire covered demographic data and three objective measures of quality of life (QOL). These measures were chosen as they allowed a comparison to recent (Cummins et al., 2007, Cummins et al., 2010, Joyce and Daly, 2010, Marks et al., 2001, Health Survey Unit Epidemiology Branch, 2010) and current research studies (Evans, 2008). The specific questions and measures are described below:

Demographic: The demographic questionnaire was based on ‘The Wellbeing of Australians – Carer Health and Wellbeing’ study by Cummins and colleagues (2007). This allowed comparison with the wider Australian female caring population.

Physical and Mental Health: The SF-12 Health Survey Version 2 (SF-12v2) (Ware et al., 2002) is a 12 question self report measure, which captures perceived physical and mental health of individuals, and holds good psychometric properties. The physical health component score (PCS) and mental health component score (MCS) were used in this study. This measure was chosen, as it allowed comparison to the mean physical and mental component scores for women from ‘Health and Wellbeing Survey of Western Australia’ (Joyce and Daly, 2010, Health Survey Unit Epidemiology Branch, 2010).

Wellbeing: The Personal Wellbeing Index (PWI) (International Wellbeing Group, 2006) measures subjective wellbeing, over seven quality of life domains. It is intended for use on adults aged eighteen and over, and can be answered verbally or written. Recent normative data is available from large population surveys of carers and the general population within Australia (Cummins et al., 2007, Cummins et al., 2010). The PWI possesses good psychometric properties (International Wellbeing Group, 2006).

Role Balance: The Role Balance Scale (RBS) (Marks and MacDermid, 1996, Marks et al., 2001) is an eight item, five point likert scale, which was used to measure the different aspects of role balance (enjoyment, attention, importance, satisfaction and effort). The RBS was utilised as it does not take a dichotomous view of work and life. It was the most appropriate measure as the target sample for the study do not work. Marks and colleagues (2001) study of working mothers was utilised as a comparative data set for the current study, as their sample had more similarities with the present studies participants. Alpha coefficient was 0.64 for wives.

Qualitative Data

Semi structured interviews were conducted with each participant in a location of their choice, and were approximately one and a half hours in duration. Interview questions (Appendix B) were developed in consultation with partner organisations, and through reviewing the literature and resources related to the Model of Human Occupation (Kielhofner, 2008, Velozo et al., 1998). Questions were developed to include empowering phrasing, such as used in motivational interviewing techniques (Ivey et al., 2010). During the final phase of the interview, participants were asked to prioritise their required RTW supports, which allowed the researcher to gain a greater understanding of the complexity and importance of their needs (Cline, 2008). This was performed by writing identified needs on individual post-it notes, and allowing the participant to arrange or group them in hierarchical order as desired. Interviews were voice recorded with the permission of the participant, and transcribed as soon as possible to ensure data accuracy (Depoy and Gitlin, 2005). Hand written field notes accompanied the recordings to capture visual cues and researcher reflections (Depoy and Gitlin, 2005).

Data Analysis

Quantitative Data

The PWI was scored as per the instruction manual (International Wellbeing Group, 2006), the SF-12v2 was scored using the scoring software supplied (QualityMetric, 2004-2010), and the RBS was scored following instructions in two journal articles (Marks et al., 2001, Marks and MacDermid, 1996).

Data was entered into PASW Statistics 18, version 18.0 (SPSS Inc, 2009) for comparison with normative data. Scores were then double checked for accuracy by the researcher. Visual inspection of histograms and the Shapiro-Wilks Test were utilised to test for normality. This revealed that none of the variables were normally distributed, therefore non-parametric statistical tests were undertaken to analyse data. Medians and ranges were used to describe the data and the One way Wilcoxon Signed Rank Test was used to compare the sample median to normative means (Experiment Resources.com, 2011).

Qualitative Data

Transcripts were coded and analysed using NVivo software version 9.1 (QSR International Pty Ltd, 2011). Framework analysis was selected to guide this process as it allowed the researcher to code data into pre-determined themes identified from the literature and consultation with partner organisations, along with allowing new themes to be created as they emerged (Richie and Spencer, 1994). Framework analysis is divided into five stages which cover familiarisation, identifying a thematic framework, indexing, charting, and mapping / interpretation (Lacey and Luff, 2001).

Maintaining Rigour

In order to ensure the overall rigour of qualitative research, trustworthiness was addressed. Trustworthiness comprises of the following four elements; credibility, dependability, transferability and confirmability (Lincoln and Guba, 1985). It was addressed by sending a summary of preliminary research findings to all participants and the two partner organisations to provide feedback and clarification if desired, maintaining an audit trail, reflective journal, and checking data with an experienced supervisor (Depoy and Gitlin, 2005).

Results

Participant Characteristics

Five mothers participated in the study, with a median age of 43.5 years (range 38 – 49yrs). Four mothers had one child with a diagnosed disability, and one mother had twins, both of which had a disability. All mothers had more than one child living in the family home, ranging from two to four children. Three mothers were married, one lived with her partner, and one was separated. One mother had a partner in a fly-in fly-out job, and two had partners that often worked away. Most of the mothers received very little or no informal support from friends or family.

The mothers lived in various metropolitan Perth suburbs and had total household incomes ranging from $15000 to $150000 dollars. All mothers received a government payment or allowance to assist in their caring role. Three received the Carers Allowance, two of which also received the Family Tax Benefit. Two received the Carer Payment, two had a Health Care Card, and one also received a Parenting Allowance (Appendix C).

Three women had not worked since commencing a carer role for their child with a disability, and two had worked intermittently in part-time paid jobs. Mothers' previous job titles, as defined by DEEWR (2001) included human resources manager, hotel service manager, teacher, secretary and pharmacy sales assistant. These mothers had been caring for their children for a median of 6.5 yrs, and had been unemployed for a median of 5.5yrs (range 3 - 11.5yrs). Their children with the disability were aged between five and seventeen. Their children's primary disabilities were either autism or Down syndrome, and some children also had other health conditions and co-morbidities.

Table one represents the descriptive statistics of the QOL questionnaires, as calculated using the one way Wilcoxon Signed Rank Test (Appendix D). It demonstrates that the mothers' physical health, as scored by the SF-12v2, was not significantly different from the normative WA female population aged 16 yrs and over, but their median mental health score was significantly lower (40.55, $p= 0.043$) (Health Survey Unit Epidemiology Branch, 2010). Their well-being was not significantly different from Australian female carers, however when compared with an Australian female general population, the difference could be described as approaching a trend towards significance (47, $p= 0.138$). Their perceived role balance was also not that different from working mothers, but could be described as a trend toward significance, as the p value sat between 0.05 and 0.1.

Qualitative Findings

There were six main themes that emerged from the study (Appendix E). One theme related to motivators to return to work. Four themes were related to barriers, and related needs, for returning to work. These were alternative care for children, skills and confidence, labour market, and perceived lack of support. The final theme was difficulty with prioritisation of needs.

Motivators to Return to Work

Mothers identified multiple reasons for wanting to return to work, however the main findings were: financial, social interaction, achievement, and respite.

Financial

Three mothers identified financial reasons as a priority to return to work, to manage the high costs of living and their children's health care needs. As Peta voiced:

> *I guess predominantly its financial reasons. 1)We had planned for me to continue working after Paul was born, 2) We thought we were only having one child, and 3) We didn't realise we were going to have a special needs child which is really putting a strain on the finances... The mortgage isn't sustainable.*

Along with high costs, mother's identified a desire for financial independence in meeting their or their child's needs. This was articulated by Melissa:

> *Just to know that there is something that I can fall back on if something doesn't work out. Because before, I always had my own money, and then you become reliant on someone, and you lose a bit of your dignity that way.*

Social

Social interaction and confidence building were seen as largely influencing reasons to RTW for the majority of mothers. Angela, who cared for her twins with autism, expressed the need to re-integrate into the workforce as a '*mental necessity',* and voiced the following:

> *I'm very isolated, I don't know anybody who's not a carer or a therapist...if I'm not putting myself out there to do things like this, I actually don't leave the house. There can be days where I go without eating or getting changed out of my pyjamas.*

This feeling resonated through the other interviews, with adult interaction also mentioned as a benefit to returning to work.

Achievement

The majority of mothers noted that gaining a sense of self-worth and achievement was a reason to return to work. A want of '*independent recognition*' and '*accomplishment*' emerged through the interviews. As Melissa said, *'You have that sense of self worth, knowing that you've achieved something'.*

All of the participants voiced that they thoroughly enjoyed being a mother, and were passionate about their children's needs. However, they could also see the benefit of getting recognition from a source other than immediate family. This was illustrated by Norine:

> *But to have that independent recognition, because your kids tell you that they love you, and it's nice. And your husband says you're doing a good job. But you hardly ever get it from an independent source.*

Respite

Respite wasn't a primary driving force to return to work for any of the mothers, but was still addressed as an influencing factor. One mother strongly disagreed that mothers would go to work to get respite from their children, and there was no question that these mothers loved their children. However, when questioned, most of the other mothers saw work as an outlet for them to do something different, other than house work and parenting duties, and as Norine said:

> *I guess to occupy me with something that's not just the day to day, because the day to day can be a bit dull. And I can understand why women go to work, and get cleaners in, because it's so boring just doing washing and dishes and cleaning cat hair and all of that... I didn't go to university to do this.*

Melissa added that she felt as though she needed some time out from home based duties to enable her to do something for herself, *'Because it's just full on at home... I'd just like to do something different'.*

Norine explained that she wouldn't see work as an outlet to get away, but she felt as though there was something missing in her life: '*I know there are a lot of women that go to work to escape, but I don't want to escape, but I do want something'.*

However, the same mother later added that if she didn't have something to do for herself, that respite may become the main aim to return to work, and said: *'It's not my main aim, it may end up being like that, but it's not my motivation'.*

Alternative Care for Children

Barriers:

Mothers spoke of the difficulties encountered when attempting to find alternative care for their children. This seemed to be most problematic in school holidays, before and after school, when attempting to return to work, and when wanting to integrate their children in mainstream childcare facilities. As their children had health care needs, and aides at school, it was difficult to find a carer for those specific times before and after school and during school holidays, that was educated enough on their children's' needs and could integrate with their routines.

Claire, who cared for her 17 year old son with high functioning autism, spoke of the frustration with barriers encountered when trying to find care to enable her to return to work:

> *...and you call these places and that's where the barriers go up. And they say "no we don't do it if you're returning to work, we only do it for respite".*

The mothers expressed challenges in attempting to integrate their children in mainstream childcare facilities. Peta, who had no family assistance in her caring role, explained that she was hesitant when considering after school care for her 6 ½ year old son with high functioning autism, '*because he's high functioning, and he's an intelligent little boy, his* *behaviour is often misjudged as bad behaviour'.* She was concerned this often led to her parenting skills being questioned.

Expressed Needs:

These mothers identified that for child-care services to meet their needs, they would need to be available at times of need, reliable, have disability educated staff, and be consistent.

The mothers identified that childcare would be most beneficial if it was available at times of crisis. As Peta stated, '*That's just what's scary about returning to work because, what if something comes up? What do I do?'*

The reliable nature of the service would limit stress and frustration with current caring supports, as Claire spoke of her own issues employing a student through a university:

> *And I put a thing [advert] up here for a uni student, but they have the same problems that my son has. Their timetables change each semester, and over December / January they like to do proper jobs or go to the beach with their friends. So it's not very reliable for me. You need someone reliable like a grandma or something.*

Peta expressed her need for an agency that could provide disability educated carers to enable her to undertake vocational training and employment:

> *For me to return-to-work, I might need to have a facility where I could take the children and say "hey I know that you guys can take my children and know about my children and can take care of them", and I can do what I need to do.*

Consistent child care workers and environments would enable the children to have a set routine and established rapport, as indicated by Peta: *'Same person, same place....where the people are trained and they know the best thing, they have the right stuff set up'.*

Skills and Confidence

Barriers:

Lapsed job-specific and job-seeking skills, limited time and money available to learn new skills or update skills, and low confidence were identified barriers to RTW.

As most of the participants had been out of paid work since the birth of their child with a disability, they recognised that their previous vocational and job-seeking skills had potentially lapsed. Two mothers had been engaged in intermittent part-time paid employment since commencing the carer role for their child, so had maintained a degree of job-specific skills, but still noted they could always do with assistance to update skills on the latest technology and resume development. Peta said:

> *I think the skills are a barrier to return, and I think as well when you're out of work for any period of time, things change, especially these days, technology just moves along so quickly.*

Another barrier identified by the mothers was being able to find the time and money to enable them to do courses to update their skills. Peta stated:

> *Being able to find the time to do the study that I would need to do to return. So that could be a factor. Another factor could be financial...well I assume if you do any course they cost money, but the private course is $1500. So it's a case of where do we put the money? Here or there? And when I think of $1500, I think "wow that's like 10 visits of floor time [therapy] for my son", so that's the hard thing for me to weigh up, it's the money.*

Lack of confidence and mental readiness was also mentioned by the majority of mothers as a barrier. Being out of work for a long time had impacted some mothers' confidence in their own abilities, and caused doubt if they were capable of actually returning to work. Melissa voiced the following about how she was feeling about her own abilities and confidence: '*Being a carer for so long, you feel like 'gosh I'm so stupid' and you don't feel capable of doing anything else but this'.* Angela added that she feared she may not be able to interact with customers in the workplace, and felt as though she had lost the ability to make informal conversation.

Expressed Needs:

Assistance to develop job seeking skills, obtain work experience, and engage in counselling and peer support were expressed needs, and were seen as highly important by the majority of the mothers.

Most mothers expressed that they possessed a degree of skills associated with job preparation such as resume development and interview skills, however could see the benefits of being up to date with employers' requirements. Norine voiced her concern with potentially lapsed job seeking skills, and the benefits of being provided with some guidance and reassurance to build her confidence again:

> *I feel like I may be so out of touch that what I think I can do...it seems to me that what I was able to do worked before, but because it's been so long I don't know what's changed. So just to make sure that I'm up to date with the latest.*

Work experience was seen as an avenue to improve confidence and demonstrate skills, without the pressure of payment. Melissa said that she *'would actually value it a great deal, because someone is taking the time to teach me in a practical environment, it's a fantastic thing'.* Angela added:

> *I think to do volunteer work, where you're appreciated, would get your own confidence back up. To go: 'you know what, I'm good at this now, and I should get paid for it'. And the pressure would be off to get the pay check at the end of the week, knowing that you've done a good job.*

Most of the mothers could see the benefits of peer support and counselling, to have a sense of cohesion with others in a similar situation to them. This was explained by Melissa:

> *...because you know what you are blabbering on about is not silly or isolated or just your own thing. Because if there are four in a group, you hear that they are thinking the same thing that I have. We have something in common.*

Developing mental readiness and confidence was identified by nearly all of the mothers as something they could benefit from, as explained by Peta:

> *I guess it's getting my head in the right place, and making sure you're ready. The changes that have actually taken place in workplaces over the time you've been out of the workplace... you need to be ready for change.*

Mothers noted that they would need to update or learn new skills, at a time suitable for their needs and at an affordable price. As Claire noted:

> *I probably have to do some TAFE short courses. I mean, although I know how to do things like Excel, Outlook and Publisher, I don't have any formal certificates....I'd have to arrange a weekend that my husband was around or other son was here. I couldn't leave him, as the course would be nine to five, so I'd need someone around.*

Labour Market

Barriers:

The majority of mothers spoke of their concerns with finding an employer or workplace that could be flexible and supportive enough for their needs. Most mothers were looking for part-time work within school hours, to enable them to retain their parenting role and be somewhat available for their child. Mothers also expressed they may need to take leave at short notice to meet their child's disability related needs. Hence, their needs were quite specific and required some level of understanding from employers and colleagues.

Employers' lack of understanding and empathy towards the caring role was seen as a barrier to work. Claire, who was seeking part-time work within the retail sector, relayed a conversation that occurred during a recent job interview:

> *I said I'll be honest with you, it hasn't affected my working hours to date, but my child has mild autism. Instead of messing around my team members on days that I will need off, I'd*

> *rather just commit and be here every day for my 3 days a week. She just shut the book and that was it. "Oh well I'm looking for someone reliable, thanks for your time". She didn't even check my references.*

Expressed Needs:

Job canvassing, work experience to up-skill and with the potential of a job offer, and traits of the ideal employer / employment setting were discussed as needs. Mothers expressed the potential benefits of job canvassing by somebody who had empathy towards carers and understood their situation. Norine explained:

> *That would be part of selling yourself. Like, someone else is already saying, "I've got this person here". Even the fact that someone's saying, "I think you could suit this job", you know, advocating on your behalf. I mean, how much confidence would that give you? They think you can do it, they're telling the company that they think you can do it, so that's half the battle won.*

Work experience was again seen as beneficial, but within this theme it would allow a potential job to be "tested". Peta explained:

> *It gives you a bit more of an idea... You may have remembered all the great things about your job, you may have forgotten about the rotten things... Sometimes our perception of what a job entails may be really wrong.*

Claire also noted the potential benefits of work experience to employers in overcoming their initial objections to employing a woman who had a child with a disability:

> *I think it would be good for the employer too...because then the employers would find out that there are some good workers out there... they just need to be given a go.*

Participants felt that work experience may facilitate a job offer, pending completion of specified training courses. Angela explained the benefits of potential secured employment following work experience, to reduce disruption to her family:

> *So I would need at least some sort of reassurance or guarantee that – 'yes, you can come and work for us if you do this course'. Then I don't mind putting my life in turmoil – or going through that hard process of getting those qualifications to go back to work.*

Mothers spoke about the characteristics and traits of the ideal employer and employment, identifying a need for empathy toward their situation, flexibility with start / finish times and the potential to allow them to leave work at short notice if required. Angela provided an example of her need for flexibility, with:

> *If someone offered me a job tomorrow and understood my situation I'd love to start straight away. My biggest hurdle is that my son has a low immune system and is always sick. So even though he's at school four days a week, he could be home two or three days at a time, for weeks on end. And I'd need someone who understood that.*

Angela further added that it was not only beneficial for the employer to have a level of understanding, but also for work colleagues to have some education on the complexity of carers' situation. This seemed as though it would minimise the pressure of explaining to colleagues why you may be 'quiet' or 'tired' every shift, and foster a sense of support within the workplace:

> *But I think it's also good for people to be aware that... it's obviously very draining at home. So to have that understanding within the workplace. Not for them to have to cover for the person, or for them to pull their weight extra for the person, but just to have that understanding.*

Perceived Lack of Support

Barriers:

Mothers identified a perceived lack of informal and formal support, their perceived negative views of employment agencies, and frustration with existing services to address their caring needs as barriers to RTW.

The majority of mothers explained that they had not utilised any supports to assist them in their return to work, however many had negative perceptions of formal employment support services. However Melissa, a mother who cared for her daughter with Down syndrome, attempted to utilise the services of an employment agency with no success. Melissa voiced her frustration when enquiring about employment services:

> *I've gone to an employment agency... so they look at (my) records and they see I have a child with a disability, so I'm not required to look for a job. Therefore I'm not entitled to the intensive employment service that they can provide, like getting my resume done, or marching me to an employer or things like that.*

Three mothers identified that they were aware of services, such as employment agencies, that could assist with a RTW. However they perceived these services were not designed with an understanding of carers' needs, as Angela voiced:

> *I know there are places. You might say to someone "we need a place that can look for jobs for people", and they will go "oh well, that's what all of these agencies do". But you become a number with those agencies, and again they don't really understand the specifics of looking after someone with a disability.*

Mothers also spoke of the difficulties in trying to access services, funding and information that could assist in their caring role, and potentially their RTW. Melissa explained:

> *So when you look to access supports, you seem to be clawing constantly, and getting nowhere. It adds to your stress and frustration, and you end up hating something and say "I really don't need this. I don't need to deal with something that's meant to help, but adds to the headache".*

Melissa then added that navigating the system was difficult, and described it as *'You feel like a puppet. Somebody pulls the strings and they are in control of our lives'.*

Expressed Needs:

Mothers identified the need for a service that was specifically designed for MCCD, including flexible funding and information provision to address RTW barriers. Angela voiced that staff members assisting mothers with their RTW needs would need to have an understanding about caring for a child with a disability, and show empathy towards their situation: '*I think the person doing the job canvassing needs to understand...and be empathetic enough to that when they ring up an employer to actually sound genuine'.*

Claire explained that her son was able to utilise EDGE employment services which assisted with finding suitable employment for his needs. She voiced that felt as though something designed like that for MCCD would be highly beneficial, and added '*they do a SWET program (School, Work Experience, Traineeships), and you could do something like that for parents. There could be an agency set up, exactly along those lines'.*

Funding was needed to enable the mothers to use it for their needs, whether it's for child care or their own training. Melissa spoke of the idea of truly flexible funding, "*When they are granting funding, to get them to be flexible enough to allow us to achieve our objectives."*

Participants also spoke of the desire for equity in information provision, to break down the barriers and reduce frustration. Melissa explained that she only learnt about different carer entitlements after speaking with other carers, and Peta described the complexity in understanding her entitlements: *'What I can and can't have, what I have access to, what I don't have access - it's very difficult to know these things'.*

Difficulty Prioritising Needs

Mothers were able to identify the services and supports they would need to return to work. The participants agreed on five main support needs: (1) before / after school care for their children, (2) confidence building, (3) skill acquisition, (4) job canvassing and (5) work experience. However, when the participants were asked to prioritise their supports, there was a lot of discussion and disagreement about the hierarchy and grouping of support needs. Therefore, my expectation of identifying ordered and prioritised supports was not met. However the following was found:

a) Services cannot be offered in isolation, and

b) The supports were not identified in a simple, sequential order.

This supports the need for individualised and case managed services to address these mothers' return to work barriers, if a durable employment outcome is to be achieved.

Discussion

MOHO (Kielhofner, 2008) has been a useful framework for examining the support needs of MCCD (Appendix F). The findings of this research have shown that women are motivated to RTW due to the intrinsic features of employment (volitional sub-system), and that they have support needs relating to all three sub-systems and the environment.

In relation to the volitional sub-system, mothers were motivated to RTW for intrinsic benefits related to feeling important and competent, and the enjoyment of doing something different. However to achieve this, one of the main areas of support they required was building their confidence and mental readiness. The participants had significantly lower mental health than the normative population, which is supported by international literature (Brehaut et al., 2004, Murphy et al., 2006). The women also had a complex set of values and priorities in relation to their unmet support needs for entering employment. Therefore, these mothers may benefit from assistance with improving their confidence, mental readiness and goal clarification.

The habituation sub-system was relevant to mothers' routines, which seemed to be based around their child's routines. Hence, there is a need for the mother to find an employer who is flexible enough to accommodate these routines. This is congruent with research identifying mothers' occupational goals, outlining the need to interweave their vocational role with the family's routines (Donovan et al., 2005). Therefore, assistance to systematically explore all possible vocational options may assist mothers in identifying occupations and employers suited to their needs.

The performance capacity sub-system was negatively impacted by the mothers' absence from paid work, as it was challenging to keep their job specific skills recent. This lead to lowered confidence, and impacted negotiation and communication skills. Stiell and colleagues (2006) identified similar findings through their research, with carers of children with a disability, and the impacts caring had on professional development. A service which addresses both individual and common skill deficits may be beneficial.

The environment was one aspect where many barriers and unmet needs were identified. Mothers required greater support formally and informally. However, as the majority of mothers lacked informal support, they would require their needs to be met in a formal capacity. Past research also identified a lack of informal support as one of the external barriers to return to work for MCCD (Stiell et al., 2006). Childcare requirements had to be met in an appropriate manner, to provide time for these mothers to engage in training, job seeking and work. There was a want for understanding colleagues and supportive employers to enable mothers' vocational choices and to balance that role with being a mother, which have also previously been identified in past research (Arksey, 2002, Burgess et al., 2007). Government based agencies were needed to provide flexible funding and fully informed employment agencies promoting inclusion. Past research by Yeandle and colleagues (2007) indicated that carers perceived the main barrier to RTW was that services were not able to meet their needs. The environment was perceived as one of the major barriers to returning to work, hence there is a greater need for education in a wider context.

Clinical Implications

This study highlighted the complex nature of being a mother and primary carer for a child with a disability. Combining this role with the possibility of a worker role can often be an overwhelming and sometimes daunting challenge for these mothers. The motivators and barriers to return to work, as identified by the participants in my study, were similar to past research exploring working parent carers' needs and issues (Stiell, Shipton, & Yeandle, 2006).

Occupational therapists, along with other allied health professions, have a long history of providing workplace rehabilitation services, where they have traditionally helped people with disabilities to return to work (Ross, 2006). Occupational therapists would be a suitable profession to provide these services, as they view an individual in a holistic manner, considering motivation, routines, abilities and occupational settings (Kielhofner, 2008). The findings from this research study conclude that there may be the potential for MCCD wanting to return to paid work to benefit from a service modelled on the Australian Workplace Rehabilitation Service Delivery Continuum (HWCA, 2008). This could include a series of individual and group sessions concurrently, to help these mothers address their needs in returning to work (Appendix G). Past research supports that individual and group sessions facilitated by professionals, for parents of a child with a disability, are more effective than information provision on its own (Keen et al., 2010, Eagar et al., 2007), and professionally facilitated parent-to-parent counselling reduces frustration and anxiety (Palit and Chatterjee, 2006).

Research Implications

The introduction of the above services could occur in the context of further research, where the other eight phases of the PRECEDE-PROCEED model are explored to plan, implement and evaluate the intervention (Green and Kreuter, 1999). In order to evaluate the program, the highest level of evidence to determine the effectiveness of the intervention would be provided through a randomised controlled trial (Melnyk and Fineout-Overholt, 2005).

Limitations

The limitations of this study included recruiting participants solely from metropolitan Perth, Western Australia; hence views of those living outside of this area were not included. Participants were only recruited through two Western Australian organisations; therefore those not affiliated with these organisations were unable to participate. The timeframe of the research was relatively short, therefore only allowing one interview to be undertaken with each participant. Depoy and Gitlin (2005) state that five to ten participants would suffice for a qualitative study sample size for interviews, in order to gain a representation of the phenomenon under study, however the sample size was still relatively small. Unforseen events caused high dropout rates, however given the nature of conducting research with humans, this was to be somewhat expected. Therefore saturation may not have been achieved and generalisability to the wider population is limited and should be interpreted with caution. To address this, future research should be undertaken employing a larger sample size, including employed mothers, so they can discuss how they overcame their issues in obtaining paid work.

Summary

Past research has identified that mothers who are primary carers of their child with a disability, face complex and multiple issues in their caring role that require support (Stiell et al., 2006, Yeandle et al., 2007). This study has added to the body of literature, finding that these mothers require individually tailored formal supports to enable them to reach their vocational goals. By providing a case managed services based on the Australian Workplace Rehabilitation Service Delivery Continuum, occupational therapists could facilitate a sense of empowerment for these mothers to achieve their goals, and open up opportunities they may not have been able to achieve without significant difficulty on their own.

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Appendix A

Demographic questionnaire

1. Age (years & months) ____________________________________
2. Postcode & suburb____
3. Are you Aboriginal or Torres Strait Islander? (please tick)
    - ☐ No
    - ☐ Yes, Aboriginal
    - ☐ Yes, Torres Strait Islander
4. Who do you live with? (tick more than one if necessary)
    - ☐ Your partner
    - ☐ One or more children
    - ☐ One or more adults who are neither your partner nor your parents
    - ☐ One or both of your parents
5. What is your marital status at the present time? (please tick)
    - ☐ Never married
    - ☐ Separated but not divorced
    - ☐ Divorced
    - ☐ De facto or living together
    - ☐ Married
    - ☐ Widowed
6. Your income (please indicate your households total income before tax)
    - ☐ Less than $15,000
    - ☐ $15,000 - $30,000
    - ☐ $31,000 - $60,000
    - ☐ $61,000 - $90,000
    - ☐ $91,000 - $120,000
    - ☐ $121,000 - $150,000
    - ☐ $150,000+
7. Do you receive a Centrelink payment or benefit? Y / N (tick more than one if necessary)
    - ☐ Carer Allowance (child under 16)
    - ☐ Carer Payment (child under 16)
    - ☐ Carer Allowance (person 16 and over)
    - ☐ Carer Payment (person 16 and over)
    - ☐ Carer Supplement
    - ☐ Family Tax benefit
    - ☐ Health care card
    - ☐ Other ____
8. How long have you been providing care for your child? (please tick)
    - ☐ Less than 6 months
    - ☐ 6 months - 2 years
    - ☐ 3 - 9 years
    - ☐ 10 - 19 years
    - ☐ 20 years or more

SF-12v2 Health Survey

(Cannot print the SF-12v2 due to copyright, but it will be utilised. Refer to the following website for an example of the questions http://www.sf-36.org/demos/SF-12v2.html)

Personal Wellbeing Index

* The following questions ask how satisfied you feel, on a scale from zero to 10. **Zero** means you feel completely dissatisfied. **10** means you feel completely satisfied. And the **middle of the scale is 5**, which means you feel neutral, neither satisfied nor dissatisfied.

Thinking about your own life and personal circumstances, how satisfied are you with**:**

	Completely Dissatisfied					Neutral			Completely Satisfied		
Your life as a whole?	0	1	2	3	4	5	6	7	8	9	10
Your standard of living?	0	1	2	3	4	5	6	7	8	9	10
Your health?	0	1	2	3	4	5	6	7	8	9	10
What you are achieving in life?	0	1	2	3	4	5	6	7	8	9	10
Your personal relationships?	0	1	2	3	4	5	6	7	8	9	10
How safe you feel?	0	1	2	3	4	5	6	7	8	9	10
Feeling part of your community?	0	1	2	3	4	5	6	7	8	9	10
Your future security?	0	1	2	3	4	5	6	7	8	9	10
Your spirituality or religion?	0	1	2	3	4	5	6	7	8	9	10

Role Balance Scale

*Thinking about your own life and circumstances, to what extent do you agree with these statements**:**

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Nowadays, I seem to enjoy every part of my life equally well.	1	2	3	4	5
I am pretty good at keeping the different parts of my life in balance; I generally don't let things "slide".	1	2	3	4	5
Some things I do seem very important, but other things I do are a waste of my time.	1	2	3	4	5
Everything I do feels special to me; nothing stands out as more important or more valuable than anything else.	1	2	3	4	5
There are parts of my life that I don't care much about, and there are other parts that I care deeply about.	1	2	3	4	5
Work time, classes and study time, partner time, friend time, family time, leisure time – I find satisfaction in everything I do.	1	2	3	4	5
I try to put a lot of myself into everything I do.	1	2	3	4	5
There are some things I like to do so much that I often neglect other things I also care about.	1	2	3	4	5

Appendix B

Interview guide

1. First of all, could you please tell me about your household composition, or who lives in your home?
2. Does your get any assistance or support from your family to help with your caring role? Do you get any formal assistance?
3. Tell me about what is involved in your caring role for your child?
    - What is the age of your child/children?
    - What is your child's primary diagnosis?
    - Does your child have any other conditions or care needs?
4. Tell me about your work life prior to becoming a carer for your child?
    - What type of paid work did you do? (job title / industry)
    - What types of hours and days did you work?
    - How important was your job to you?
    - What aspects of your job did you enjoy?
    - What aspects of your job did you feel most proud of that you did well?
    - What was the reason for leaving your last job?
    - When did you leave your last job?
5. Can you tell me about some of the reasons you are interested in returning to paid work?
6. When are you hoping to return to work?
7. What type of paid work are you interested in?
8. What is your motivation for choosing to seek that particular type of paid work?
9. What actions have you taken so far in regards to looking for paid work?
10. What support or assistance have you had to look for paid work so far? (formal / informal)
    - If identified - how did you find out about and access formal services?
11. Have you encountered any difficulties in accessing formal services? If yes, please provide details.
12. What are some of the barriers that you feel may impact on your return to paid work?
    - Personal
    - External / System / Environments
13. What do you think you will have to do or change to enable you to return to work?

14. Thinking as creatively as possible, what types of services do you think would be helpful to support you to find and maintain suitable paid work? Why?

15. In what way could you see the following services would be helpful in assisting you in a successful return to paid work?

- Services that assist with:
    - Determining a realistic goal for returning to work (realistic, based on transferable skills / interests, requirement for work hours and labour market requirements etc)
    - Borrowing clothes for interviews, such as a "clothes library"
    - Developing job seeking skills (resume, application letters, selection criteria, interviews)
    - Confidence building
    - Developing physical and mental readiness
    - Developing skills in negotiating flexible working arrangements
    - Work experience programs or on the job training to develop skills in the workforce
    - Job canvassing (contacting potential employers to try and find a match between carers' and employers' needs)
    - Learning skills to assist with effective time management and juggling multiple roles
    - Emotional support and peer support

16. What do you think would be the most important service(s) or support(s), or combination of services/supports that would help you return to paid work?
(Use identified services on stick-it notes to assist participant to prioritise)

17. Is there anything else you would like to share as part of the interview?

Appendix C

Government Benefits Definitions

Carer Payment:

An income support payment for people who, because of the demands of their caring role, are unable to support themselves through substantial workforce. Income and assets tested.

- **Basic Rates (per fortnight)**
- Single - $689
- Member of a Couple - $519.40

Carer Allowance:

A supplementary payment to people who provide daily care and attention at home for an adult or child with a physical, intellectual or psychiatric disability, or someone who is frail and aged. It may be paid in addition to other payments. Not income or assets tested

- **Basic Rates (per fortnight)**
- $110
- $1000 Child Disability Assistance payment to be paid annually to a person receiving Carer Allowance on 1 July for each child being cared for under 16 years of age.

Family Tax Benefit (FTB):

Payments to help families with the costs of raising children. Consists of FTB part A & FTB part B.

- *Family Tax Benefit Part A* helps you with the cost of raising children.
- *Family Tax Benefit Part B* is an extra payment for single parents and families with one main income to help with the costs of raising children. Part B is limited to families where the primary earner has an adjusted taxable income of $150,000 or less per financial year.

Health Care Card (HCC):

A card issued to certain Centrelink customers, that entitles the card holder to a limited range of health, household, educational, recreational and transport concessions.

Parenting Payment:

A payment that provides financial assistance for people who are principal carers of a child / children. It can only be paid to one person who cares for a child.

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Appendix D

Table of Results: QOL Questionnaires

Table 1: Participant Characteristics Comparison Using One way Wilcoxon Signed Rank Test

Participants (n=5)	SF-12 v2 PCS	SF-12 v2 MCS	PWI total	RBS
Range	21 - 62.33	27.6 - 45.38	26 - 80	2.25 - 3.5
Median	45.99	40.55	47	2.5
Normative means	51.91	50.53	57.82[a] 75.2[b]	3.47
Comparison to normative means	*p*= 0.5	*p*= 0.043*	*p*= *0.50*[a] *p*= 0.138[b]	*p*= 0.078

Alpha level set at 0.05

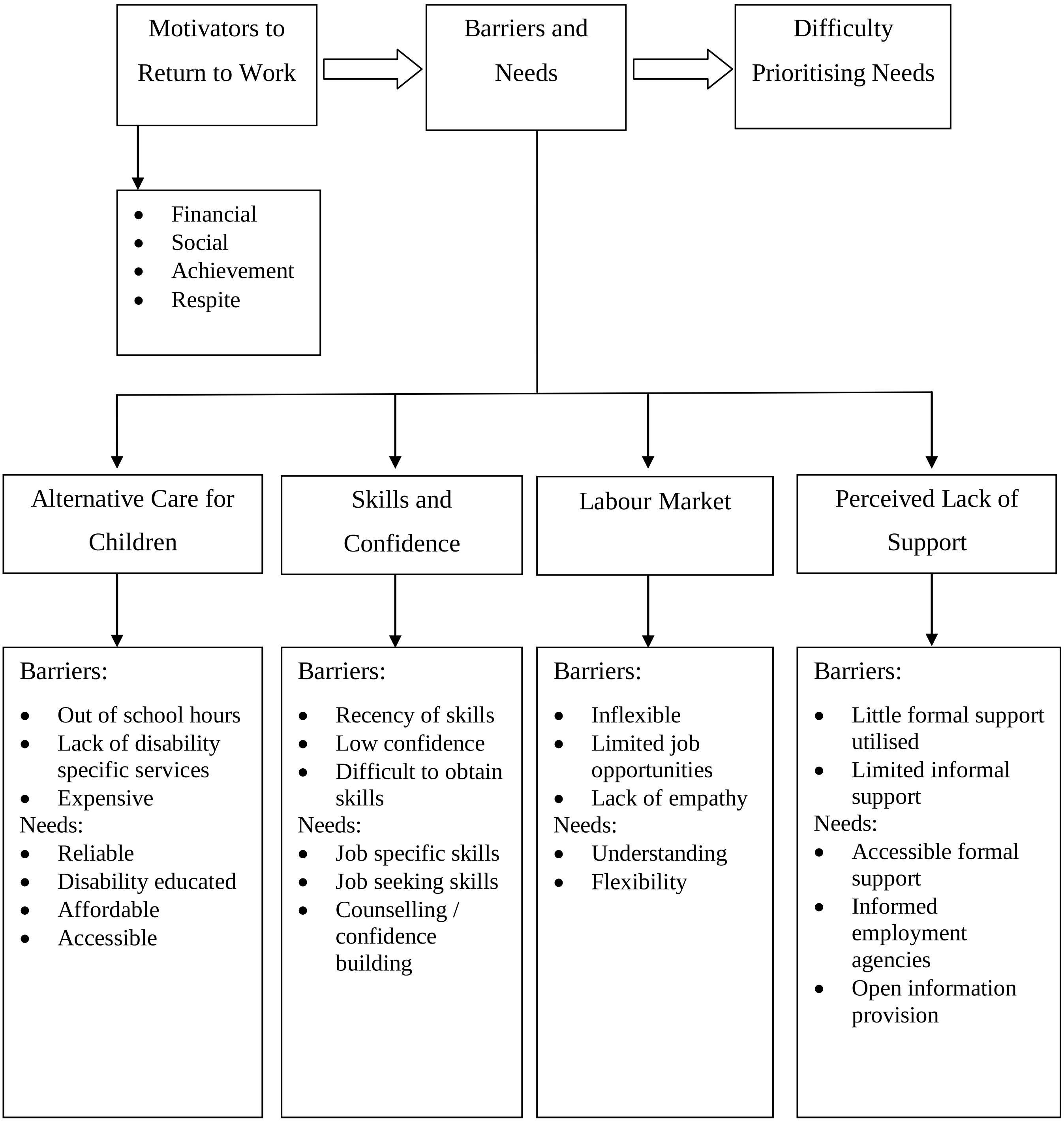
[a] = Australian female primary caregiver population (Cummins et al., 2007)

[b] = Australian female non-caring population (Cummins et al., 2010)

*= indicates statistically significant result

Appendix E

Flowchart of Main Qualitative Findings



Appendix F

MOHO Concepts and Related Themes

MOHO Concept	Related Research Themes
Volition **(Motivation)**	• Intrinsic motivation to RTW • Need confidence building • Need assistance prioritising
Habituation **(Routines)**	• Need a match between personal routines and work arrangements
Performance Capacity **(Abilities)**	• Need job specific, job seeking, and negotiation skills
Occupational Settings **(Environment)**	• Need greater support in child care • Need supportive employers • Need government funding and agencies

Appendix G

Proposed Intervention Outline Based on the Australian Workplace Rehabilitation Service Delivery Continuum

Stage 1	**Stage** 2	**Stage** 3	**Stage** 4
Assessment of Need	**RTW Planning**	**Active Implementation & Review**	**Durable RTW**
Individual: • Assessment of vocational skills, barriers, interests, values, routine related needs, other requirements (e.g. location, hours, time frame)	**Individual:** • Setting vocational goal (short term and achievable) • Confidence building / counselling • Job seeking skills development • Practice interview (in full attire) and feedback	**Individual:** • Job canvassing: Match job seeker with potential employer (congruent with assessed needs and goals) and facilitating job search • Work experience: 'Test out' job, with potential job guarantee	**Individual:** • Maintain support (telephone contact) to problem solve issues • Monthly meetings to review progress (over 4 months) and review goals
Group: • Group discussion and brainstorming to generate ideas during individual Assessment of Need phase.	**Group:** • Confidence building • Peer support • Job seeking skills development • Role play (e.g. interviews, negotiation skills, assertive communication)	**Group:** • Peer support	**Group:** • Peer support (to continue problem solving once formal assistance withdrawn)

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