

Review of Parental Activation Interventions for Parents of Children with Special Healthcare Needs

The U.S. Maternal and Child Health Bureau defines children with special healthcare needs (CSHCN) as children with chronic physical, developmental, behavioral, or emotional conditions who require health and related services of a type or amount beyond that required by most children (McPherson et al., 1998). CSHCN share the following common characteristics: (1) one or more chronic clinical conditions, (2) mild to severe functional limitations, (3) high healthcare resource utilization including medical specialists, special therapies, mental health care, and special education services, and (4) substantial family-identified needs (McPherson et al., 1998).

Currently, 20%, or approximately 15 million, U.S. children are identified as CSHCN (Child & Adolescent Health Measurement Initiative, 2012). Given rising numbers and the complexity of healthcare needs, improving healthcare services and outcomes for CHSCN is a priority area identified by Healthy People 2020 (U.S. Department of Health and Human Services, 2010).

Despite their central role in managing their child's needs, many parents report difficulties in navigating bureaucratic service systems, finding information related to their child's condition, and accessing healthcare providers that can assist them in making care choices (Golden & Nageswaran, 2012; Lutenbacher, Karp, Ajero, Howe, & Williams, 2005). These tasks call for complex cognitive and social skills, such as understanding medical terminology; evaluating potential treatment options; communicating and advocating with healthcare providers; locating community-based resources; and problem-solving barriers across healthcare, educational, and social service systems (Mathiesen, Frost, Dent, & Feldkamp, 2012). The label 'patient activation' describes the process of developing and utilizing these skills to become an effective and informed manager of ones' health (Hibbard, Mahoney, Stock, & Tussler, 2006).

In adult healthcare, there is a growing emphasis on interventions that ‘activate’ patients by increasing their knowledge, skills and confidence to self-manage their health problems, to be more involved in provider and treatment choices, and to navigate the healthcare system (Hibbard et al., 2006). Research studies, including systematic reviews, have demonstrated that patient activation interventions have been successful in helping adult patients with complex chronic conditions achieve better health outcomes (Hibbard & Green, 2013; Bolen et al., 2014). Similar to adult patients with chronic illnesses, caregiving for a CSHCN requires skills to navigate multiple healthcare services and be a more informed healthcare consumer and advocate. However, the analogous concept *parental* activation, is currently understudied. To the authors’ knowledge, no existing systematic reviews have addressed this topic. Thus, knowledge about relevant interventions and their relative effectiveness is limited. For the purpose of this review, parental activation interventions were defined as those that strive to ‘activate’ parents to increase their knowledge, skills and confidence in managing and advocating for their child’s healthcare needs, to improve parental quality of life, and ultimately improve their child’s outcomes. The term ‘parents’ was defined to include biological parents, adopted parents, step-parents, and other primary caregivers, such as grandparents.

Methods

A detailed protocol describing the methods for this review is published elsewhere (CITATION BLOCKED FOR BLINDING). The following electronic databases were searched: MEDLINE, EMBASE, PsycINFO via ProQuest, PubMed, Cumulative Index to Nursing and Allied Health (CINAHL) via EBSCO, Education Resources Information Center (ERIC) via ProQuest, The Cochrane Library (Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, Cochrane Methodology

tables of contents of the following journals: *Child: Care, Health and Development*, *Children's Health Care*, *Early Child Development and Care*, *Infants and Young Children*, *Journal of Pediatric Psychology*, and *Pediatric Nursing*. These journals were selected because they are commonly publish intervention research with the same population.

Search Strategy

The PICO (patient/client, intervention, comparator, outcome) model guided identification of search terms (Aslam & Emmanuel, 2010). Examples of search terms describing the patient/client group included: special healthcare needs, chronic health condition, chronic illness, developmental disability, parent, and caregiver. The authors initially used the search term “parental activation” to describe the intervention. However, preliminary searches retrieved minimal literature. Subsequently broader search terms were used, including phrases such as psychoeducation, coordinating care, parent training, parent coaching, parent support, and systems navigation. No search terms were specified for the comparator in order to retrieve studies with and without control or comparison groups. Examples of search terms describing outcomes included: self-efficacy, confidence, parent role, stress, well-being, service needs, service utilization, health status, school attendance.

Initial searches were conducted between December 15, 2014 and January 15, 2015. Automatic monthly reruns of searches in each database identified additional studies indexed since the original search was conducted and until manuscript development. CITATION BLOCKED FOR BLINDING provides a sample search strategy for one of the databases.

Inclusion and Exclusion Criteria

Studies were included if they met the following criteria: (1) recruited parents of a CSHCN; (2) evaluated an intervention that, either in part or whole, focused on educating parents to manage their child's health and social service needs, and (or) navigate pediatric

providers, and (or) locate and utilize community resources; (3) the intervention was delivered in community settings since most CSHCN receive long-term services in the community. Studies with disease- specific training were included only if this training was part of a multilayered intervention that emphasized the inclusion criteria listed above.

This review comprised experimental studies only, including randomized and non-randomized designs to broaden the scope of intervention research considered under this emergent topic (Kaminski, Valle, Filene, & Boyle, 2008). Studies that recruited parents of adult children (age: 18+) and those that only recruited children but not parents were excluded. Studies were excluded if the intervention was delivered during short-term inpatient encounters or if they focused exclusively on (1) providing parents with psychosocial support for acceptance of child's disease/disability, (2) training parents in home-based treatment for symptomatic control, (3) improving generic parenting skills or parent-child interactions unrelated to managing healthcare.

Procedure for Selecting Studies

The first two authors independently screened articles against eligibility criteria. Screening began with title review followed by abstract and full-text review. At each stage, articles were excluded only if both reviewers agreed that the article met at least one of the exclusion criteria. Inter-rater reliability was high (Cohen's kappa=0.93). Disagreements were resolved in consultation with a third reviewer (MS). Additional studies were located by manually searching bibliographies of selected articles and by tracking forward citations through Web of Science, Scopus, and Google Scholar.

Data Extraction and Quality Appraisal

The first two authors independently extracted data and assessed the quality of selected studies. To guide data extraction, a standardized form was adapted from existing

(2) sample characteristics; (3) intervention content, frequency, duration, delivery format, and implementation barriers; (4) type of comparator; (5) outcome measures and data collection method; (6) study results.

The review team used a second standardized form adapted from multiple sources (Hawker, Payne, Kerr, Hardy, & Powell, 2002; MacDermid, 2004; Shilling et al, 2013; Yates, Morley, Eccleston, & de C Williams, 2005) to guide the quality appraisal process. In assessing risk of bias and quality of evidence, the reviewers considered intervention characteristics (e.g. training of interventionists, monitoring fidelity) and study design characteristics (e.g. presence of a control or comparison group, blinding, selection bias). Reviewers gave each item a score of 0, (study authors did not address this item), 1, (study authors addressed this item insufficiently), or 2, (study authors addressed this item adequately). For some items, such as treatment manualization, only a 0 or a 1 could be awarded, as an intervention was either manualized or not.

All studies were assigned a final grade for study design based on a grading scheme adapted from Sackett, Straus, Richardson, Rosenberg, and Haynes (2000) and Logan, Hickman, Harris, and Heriza (2008). Data extraction and quality assessment was compared for concordance and discrepancies were resolved through discussion, joint re-reviewing of the article, and reaching a consensus between the two reviewers. Accuracy of data extraction and quality appraisals was verified for 20% of the articles by a third reviewer (SM or a research assistant).

Results

Participant and Study Characteristics

Twenty studies met the inclusion criteria. Most studies were RCTs (k =12). Five studies used quasi-experimental designs with non-equivalent comparison groups while

Table 1 summarizes participant characteristics. Of 17 studies that provided caregiver data, six (Chernoff, Ireys, DeVet, & Kim, 2002; Ireys, Chernoff, DeVet, & Kim, 2001; Pilon & Smith, 1985; Silver et al., 1997; Sullivan-Bolyai et al., 2010; 2004) targeted mothers; one (Sullivan-Bolyai et al., 2011) focused on fathers; five included either parent (Jerram, Raeburn, & Stewart, 2005; Kieckhefer et al., 2014; Picard, Morin, & De Mondehare, 2014; Singer et al., 1999; Swallow et al., 2014); two included parent dyads (Delve et al., 2006; Schultz et al., 1993); three included grandparents along with biological, adopted or step parents (Farber & Maharaj, 2005; Ireys, Sills, Kolodner, & Walsh, 1996; Kutash, Duchnowski, Green, & Ferron, 2011). Seven studies focused on children with a variety of chronic health conditions (Chernoff et al., 2002; Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Hixson, Stoff, & White, 1992; Ireys et al., 2001; Jerram et al., 2005, Kieckhefer et al., 2014; Pless & Satterwhite, 1972); five focused on children with specific chronic conditions such as juvenile rheumatoid arthritis (Ireys et al., 1996;), diabetes (Sullivan-Bolyai et al., 2011; 2010; 2004;) or chronic kidney disease (Swallow et al., 2014); five studies included children with developmental or intellectual disabilities (Farber & Maharaj, 2005; Picard et al., 2014; Pilon & Smith, 1985; Romer et al., 2002; Schultz et al., 1993); two studies included children with both chronic health conditions or developmental disabilities (Silver et al., 1997; Singer et al., 1999); and one study focused on youth with emotional disturbances (Kutash et al., 2011).

Of the 17 studies that reported sample demographics, 11 had a sample that was predominantly (75% or more) White or of European origin. Four studies (Chernoff et al., 2002; Ireys et al., 2001; Kutash et al., 2011; Silver et al., 1997) included a racially and ethnically diverse sample and two studies (Farber & Maharaj, 2005; Pilon & Smith, 1985) specifically targeted racial/ethnic minorities. In most studies, the intervention was

study was conducted (Dellve et al., 2006; Picard et al., 2014). Only one study (Pilon & Smith, 1985) targeted a language minority group of Spanish-speaking parents in the US.

Types of Intervention

Five intervention categories were identified based on the underlying theoretical framework or rationale for the intervention and the mechanism of intervention delivery (see Table 2 for details).

Parent-to-Parent Support Interventions. For nine studies (Chernoff et al., 2002; Ireys et al., 2001; Ireys et al., 1996; Kutash et al., 2011; Silver et al., 1997; Singer et al., 1999; Sullivan-Bolyai et al., 2011; 2010; 2004), the primary intervention mechanism was to link participating parents with parents of children with the same diagnosis who had successfully managed similar challenges. These interventions were informed by Ireys et al.'s (2001) social support framework, which emphasizes three types of social support: informational support, emotional support, and affirmational support (Ireys et al., 2001).

Mentors made one-on-one contact with families either in-person or by phone. Two studies also included monthly mailings and newsletters (Chernoff et al., 2002; Ireys et al., 2001), two studies included email contact (Sullivan-Bolyai et al., 2011; 2010), and four included optional recreational events in small groups (Chernoff et al., 2002; Ireys et al., 2001; Ireys et al., 1996; Kutash et al., 2011; Silver et al., 1997). Recommended intensity and duration of contact varied widely across studies.

Implementation barriers included disconnect between participating parents and mentors (Singer et al., 1999), contamination effects due to other social supports accessed by parents (Sullivan-Bolyai et al., 2011; 2010; 2004), and wide variation in intervention dose as some families were too busy to meet with mentors (Chernoff et al., 2002; Ireys et al., 2001; Kutash et al., 2011; Silver et al., 1997; Sullivan-Bolyai et al., 2011; 2010; 2004).

Psychoeducational Groups Focusing on Family Stress and Coping. Four studies

evaluated psychoeducational group-based interventions based on theories of family stress and coping (Barber, Turnbull, Behr, & Kerns, 1988; Lacharité, Éthier, & Couture, 1999; Schultz & Schultz, 1990). Interventions sought to improve parental coping by addressing skills such as parenting and family relationships (Jerram et al., 2005; Picard et al. 2014), coping (Jerram et al., 2005; Schultz et al., 1993), problem-solving (Farber & Maharaj, 2005; Schultz et al., 1993), accessing services and supports (Farber & Maharaj, 2005; Jerram et al., 2005; Picard et al., 2014; Schultz et al., 1993), and advocacy (Farber & Maharaj, 2005; Jerram et al., 2005).

These interventions were delivered through didactic input from facilitators, group discussions, and group activities such as role playing. Either study investigators (Jerram et al., 2005; Picard et al., 2014; Schultz et al., 1993) or experienced parents (Farber & Maharaj, 2005) facilitated the groups. Inconsistent attendance at weekly sessions was a common barrier (Farber & Maharaj, 2005; Picard et al., 2014).

Diagnosis or Content-Specific Educational Groups with Multilayered

Information. Three studies (Dellve et al., 2006; Hixson et al., 1992; Pilon & Smith, 1985) included interventions that focused on educational groups addressing topics such as managing the child's medical condition, utilizing medical and social services, and accessing community resources. Content experts provided lectures. Additional components included fostering mutual sharing (Pilon & Smith, 1985) and practicing communication and advocacy skills (Hixson et al., 1992). None of these studies identified an underlying conceptual framework nor were interventions standardized through structured manuals, curricula, or provider training.

Challenges varied according to the duration and intensity of the intervention. Some

longer interventions, spanning up to 14 months (e.g. Pilon & Smith, 1985), struggled with inconsistent attendance of participants.

Community Health Worker Model. Two studies focus on support services delivered by community workers. In Pless and Satterwhite (1972), experienced mothers served as ‘counselors’ for families with children with chronic illnesses. Families received psychosocial counseling, parenting advice, care-coordination, and support with finding services. In Romer et al. (2002), lay persons from the targeted geographical community who had personal, professional or volunteer experience with children with disabilities, delivered similar services. Factors deemed critical for successful implementation included community workers’ personality, their ability to meet per family convenience, and families having a clear understanding of the community workers’ role.

Self-Management and Self-Efficacy Based Interventions. Two studies employed interventions grounded in Bandura’s (2004) social learning theory. Kieckhefer and colleagues (2014) developed a family-centered, group-training curriculum based on a pediatric adaptation of the Chronic Disease Self-Management Program (Helmer & Stenzel, 2000). Curriculum content addressed daily management of childhood chronic illness, networking with other parents and sharing resources, and working with service providers. Swallow et al.’s (2014) study offered similar content and supports via an interactive health communication application. Both studies reported barriers to parent engagement due to preoccupation with other issues.

Outcomes and Results

Main study outcomes are available in Table 3.

Parental Activation. Nine studies examined outcomes relevant to parental activation. Kieckhefer et al. (2014) found that intervention participants had higher post-

Similarly, Dellve et al. (2006) found a significant improvement in parent's perceived competence. No significant changes were observed in 'active coping', which was defined as parents being prepared for healthcare appointments.

Four studies reported on measures of parental confidence in managing their child's healthcare. Two (Sullivan-Bolyai et al., 2010; 2004) found no observable effects, one (Pilon & Smith, 1985) found a modest average increase of 2%, and the fourth (Sullivan-Bolyai et al., 2011) found significant positive effects. Findings of these latter two studies need to be interpreted with caution owing to small sample size. A fifth study (Swallow et al., 2014) examined parent's perceived ability and effort toward managing their child's needs. No significant effects were observed in either domain, although results favored intervention parents for condition management ability.

Three studies examined changes in parents' overall sense of empowerment related to meeting their child's needs and advocating for services. One study (Swallow et al., 2014) reported no observable differences between groups at post-trial, one study (Kutash et al., 2011) showed small positive effects and the third study (Farber & Maharaj, 2005) showed significant within group improvement.

Two studies examined empowerment in specific areas. For example, Jerram et al. (2005) found significant improvement in parent report of inclusion in clinical decisions, getting needed health information, and advocating with healthcare professionals. Kutash et al. (2011) reported small positive effects in parents' efficacy for service advocacy, with effects found to be accentuated for a subgroup of highly strained parents.

Parent Psychosocial Outcomes. A variety of parent psychosocial outcomes were examined in 14 of the 20 studies. Evidence was most consistent for measures of parent coping. For example, Kieckhefer et al. (2014) found post-intervention coping scores to be

al. (2005) found significant positive effects in favor of the intervention group on four subscales of the COPE inventory. While Singer et al. (1999) found no significant effects for their overall sample, coping scores were significantly better for intervention parents with low coping levels at baseline.

Evidence for other psychosocial outcomes was mixed. Of five studies that reported on depression-related outcomes, three (Chernoff et al., 2002; Ireys et al., 1996; Picard et al., 2014) found no observable effects. Kieckhefer et al. (2014) found significantly lower depression scores among intervention parents. Similarly, Farber and Maharaj (2005) found parents to be more hopeful about themselves and the future from baseline to post-intervention.

Seven studies examined stress, worry or anxiety. Three studies (Ireys et al., 1996; Picard et al., 2014; Sullivan-Bolyai et al., 2010) found no observable differences between groups, while a fourth study (Sullivan-Bolyai et al., 2011) found that intervention fathers had higher post-trial worry scores. Two studies (Ireys et al., 2001; Jerram et al., 2005) found significant positive effects on measures of anxiety in favor of the intervention group. A fifth study (Silver et al., 1997) found follow-up anxiety scores to be significantly better for the intervention group but only in a subgroup of parents with high baseline stress.

Findings were also mixed for measures of caregiver strain. Kutash et al. (2011) reported small positive effects for their overall sample, and large positive effects for a subgroup of highly strained parents. Dellve et al. (2006) reported that caregiver strain improved among full-time working mothers and among fathers of young children but declined among single mothers.

There was inconsistent evidence related to parental need for social support (Kutash et al., 2011), perceived availability of social support (Ireys et al., 1996), size of support

(Picard et al., 2014). Only Dellve et al. (2006) found significant improvement in social integration and attachment, but only among mothers.

Positive effects were also noted for parent quality of life (Kieckhefer et al., 2014), functioning ability (Schultz et al., 1993), and management of day-to-day activities (Farber & Maharaj 2005). Only one study (Dellve et al., 2006) examined parents' overall health and found a decline in health of both mothers and fathers.

Family Life and Functioning. Three studies (Sullivan-Bolyai et al., 2011; 2010; Swallow et al., 2014) found no effects on measures of perceived impact of child's illness on the family while a fourth study (Sullivan-Bolyai et al., 2004) found that intervention parents perceived the impact of their child's illness as significantly less negative over the course of the study. Singer et al. (1999) reported significant positive effects on family closeness and adjustment to disability and Jerram et al. (2005) reported positive effects on family environment.

Child Outcomes. Three studies reported outcomes related to child psychological health. Chernoff et al. (2002) found no observable effects on depression, anxiety, and self-esteem. However, they found significant positive effects on psychosocial adjustment, especially for children with low baseline self-esteem. Similarly, Pless & Satterwhite (1972) found significant positive effects on a composite indicator of psychological status while Kutash et al. (2011) found only a small positive effect on psychosocial functioning.

Of the two studies that examined school-based outcomes, Kutash et al. (2011) found small positive effects on reading ability, disciplinary referrals, and school attendance for youth with emotional disturbances, while Pilon and Smith (1985) found an average decrease of 88% in number of school days missed for their small sample (n=5) of children with cerebral palsy.

Service Utilization. Evidence related to use of acute care services was mixed. Sullivan-Bolyai et al. (2004) found no observable differences in number of emergency room visits or acute care visits. Conversely, Pilon and Smith (1985) found an average decrease of 28% in number of emergency room visits for children with cerebral palsy.

Evidence was more consistent for use of community-based services. Two studies (Picard et al., 2014; Sullivan-Bolyai et al., 2004) reported a significant or near significant increase in use of support services and community resources among intervention parents. Similarly Kutash et al. (2011) reported that youth with emotional disturbances in their intervention group accessed more school-based mental health services. The only exception was Romer et al.'s (2002) study of a community guide intervention. Families satisfied with their guides did not differ from 'no guide' families in terms of finding specific support services. However mean ratings of extent to which various service needs were met were highest for satisfied families.

Discussion

This review identified 20 studies that document the effectiveness of intervention programs intended to support parents in active management of their children's healthcare needs, while also addressing other parent and child outcomes.

Direct comparisons and meta-analyses of studies is precluded by methodological constraints of individual studies. First, many studies had small samples and possibly carried the risk of type II error. Sample size adequacy was difficult to ascertain as only one study (Kieckhefer et al., 2014) explicitly reported their a priori power estimation.

A second methodological consideration pertains to choice of outcome measures. Authors of two studies (Dellve et al., 2006; Sullivan-Bolyai et al., 2010) questioned the responsiveness and conceptual congruence of their main outcome measures. Four studies

qualitative or anecdotal data in support of the intervention despite tepid quantitative results.

These data underscore the need for better selection of outcome measures. Many studies used measures of parental self-efficacy, parental confidence, and parental empowerment. Previous research suggests that while the construct of parental activation encompasses all of these, there is a need for further theoretical and psychometric development of this construct (Pennerola et al., 2011).

A third methodological consideration is the possible dilution of intervention effects from parents' exposure to other forms of support. Only three studies (Sullivan-Bolyai et al., 2011; 2010; 2004) explicitly monitored parents' receipt of supports outside the intervention being investigated and found that parents in both groups were accessing other sources of support thus hindering isolation of intervention effects. A fourth study (Singer et al., 1999) specifically excluded parents who were participating in other support programs and found significant positive effects of the intervention on three of four outcomes.

A final methodological factor is participants' exposure to the intervention. In eight of nine studies involving one-on-one support from an experienced parent, authors reported wide variation in participants' engagement in the intervention or that a substantial proportion of participants was either unengaged or received less interaction with their parent mentor than was originally planned. Similarly, three of six studies (Farber & Maharaj, 2005; Picard et al., 2014; Pilon & Smith, 1985) that used a group-based intervention format reported inconsistent attendance at group sessions. Thus several studies reported variability in dosage, of which only two explored a dose-response relation (Chernoff et al., 2002; Ireys et al., 2001) and found no evidence in this regard.

Overall, while most studies showed positive trends in favor of the intervention, the evidence was inconsistent for parent outcomes such as self-efficacy, confidence,

functioning. Evidence was more consistent in showing improvement in parent coping and in use of community-based services and resources, the latter being an important indicator of parental activation. The evidence also showed positive intervention effects on psychosocial and school-based outcomes for children.

Limitations

Some studies did not adequately report on their methods and outcomes thereby limiting our ability to compare studies (Schultz et al., 1993; Dellve et al., 2006). This review only included studies that were published in English and were experimental in design. Therefore it is likely that the search team missed relevant studies using observational designs and published in other languages. It is also likely that the search team missed program descriptions and evaluations published in the grey literature.

Implications for Practice and Research

Despite limited evidence, several implications emerged. For example, studies that used a non-categorical approach and included children with a variety of diagnoses reported more positive outcomes than studies that focused on a single diagnostic category. In general, studies found improvements in parent mental health and competency regardless of diagnostic category (emotional disturbances, developmental disabilities, or chronic health conditions). This trend comports with the idea that despite diagnostic variations, families must navigate the same service systems and therefore experience similar challenges in everyday management of their children's health (Kieckhefer et al., 2014; Shilling et al., 2013; Stein & Jessop, 1982).

Effectiveness of interventions did not appear to vary by intervention format, whether one-on-one or group-based. However, implementation barriers for one-on-one interventions suggest that perceived usefulness of these interventions was contingent on the

& Satterwhite, 1972; Romer et al., 2002; Singer et al., 1999), thereby rendering such interventions difficult to standardize. Notably, four of nine studies (Ireys et al., 2001; Kutash et al., 2011; Silver et al., 1997; Singer et al., 1999) that examined interventions involving one-on-one support from an experienced parent mentor reported greater effectiveness for parents who were doing poorly at baseline (more anxious, less able to cope). These high need parents would therefore be most suitable candidates for parent mentor interventions.

Child age and time since diagnosis might also be factors to consider in targeting specific families. Most studies in this review included children spanning a wide age range, and only three studies (Sullivan-Bolyai et al., 2011; 2010; 2004) focused on newly diagnosed children. Qualitative feedback from parents suggested that interventions might be most useful earlier in the lives of parents and soon after they have had a chance to accept their child's diagnosis (Picard et al., 2014; Sullivan-Bolyai et al., 2004).

As stated previously, parent engagement in interventions varied widely in studies. Three studies (Kieckhefer et al., 2014; Sullivan-Bolyai et al., 2011; 2010) reported that a third to nearly half the parents contacted were not enrolled mostly because they were unable to make the commitment. A related factor was attrition risk. Six studies (Dellve et al., 2006; Farber & Maharaj, 2005; Pilon & Smith, 1985; Singer et al., 1999; Sullivan et al., 2011; Swallow et al., 2014) reported attrition rates greater than 20%. In studies that did not report such problems, the intervention was delivered in a single block of time over one session (Hixson et al., 1992) or weekly sessions were scheduled on weeknights or weekends to encourage attendance (Schultz et al., 1993). Thus, creative scheduling of intervention delivery is an important consideration. Prescriptive intervention doses might be unrealistic and future research should consider titrating dosage to parents' 'real-world'

are unable to commit to the intervention to be enrolled as ‘non-joiners’ who contribute data without being randomized (Sullivan-Bolyai et al., 2011). Future studies might also benefit from adaptive trial designs, which allow modification of the intervention in response to participant behaviors, needs, and outcomes (Chen, Zhao, Cui, & Kowalski, 2012).

Future research and interventions might also benefit from minimizing the intervention burden on parents. Using information and communication technology to deliver some or most components might make the intervention more amenable. Portable and hand-held technologies can be especially practical, allowing parents to engage in the intervention per their convenience. Large-scale consumer surveys in the U.S. indicate widespread use of information and communication technologies, particularly cellular phones (Anderson, 2015). Moreover, historically underserved groups such as African Americans and Latinos have comparable, if not higher, cell phone usage compared to the general population (Smith, 2010). Prior research also indicates high parental acceptance of technology-based interventions to enhance children’s access to and use of primary care (Hoffstetter, Vargas, Kennedy, Kitayama, & Stockwell, 2013), specialist care (Glynn, O’Duffy, O’Dwyer, Colreavy, & Rowley, 2013), as well as community supports specific to CSHCN (Parette, Meadan, Doubet, & Hess, 2010). Surprisingly, despite this evidence, only one study in this review investigated a technology-based intervention (Swallow et al., 2014). While the health communication application was found to be useful and acceptable by parents, authors also reported parental expectations for direct engagement with the study team. Therefore, designing innovative technology-based interventions and comparing effectiveness and parent adherence for these interventions alone and in combination with in-person supports is an essential area for research.

Another area for further consideration is development of targeted interventions for

experiencing poverty, limited education, and limited proficiency in the dominant language. Research in the U.S. shows that African American and Hispanic families with CSHCN are significantly more likely to report difficulties with services use compared to White families (Ngui & Flores, 2006). Only two studies (Farber & Maharaj, 2005; Pilon & Smith, 1985) specifically targeted low-income families from these racial and ethnic groups. Three studies (Ireys et al., 2001; Sullivan-Bolyai et al., 2010; Swallow et al., 2014) reported higher dropout rates for ethnic minority parents or those from low socioeconomic backgrounds. Therefore there is a need for interventions that strive to include and retain these families.

Conclusion

Interventions examined in this review showed positive effects on parent coping and on family use of community-based services. The evidence was mixed for outcomes relevant to parental activation such as self-efficacy, confidence, and empowerment. Thus there is a need to boost active ingredients of interventions that specifically target enhancing parent skill sets relevant to these areas. There is also a strong need for future studies that creatively adapt intervention and study design to recruit and retain socioeconomically vulnerable families.

Key Messages

- There is a need for interventions that “activate” parents of children with special healthcare needs to increase their knowledge, skills and confidence in managing, coordinating, and advocating for their child’s needs.
- Five intervention categories were identified: parent-to-parent supports, psycho-educational groups, content-specific groups, community health worker model, and self-management-based interventions.

- Evidence was inconsistent for outcomes such as self-efficacy, confidence, caregiver strain, depression and perceived social support.
- Evidence was more consistent in showing improvement in parent coping and in use of community-based services, the latter being an important indicator of parental activation.
- There is a need to boost active ingredients of interventions that specifically target enhancing parent skill sets and for future studies that creatively adapt intervention and study design to recruit socioeconomically vulnerable families.

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