Parent-to-Parent Support for Parents With Children Who Are Deaf or Hard of Hearing: A Conceptual Framework

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Background: Parent-to-parent support for parents with children who are deaf or hard of hearing (D/HH) is identified as an important component of Early Hearing Detection and Intervention (EHDI) programs for children with hearing loss.
Purpose: The specific aim of this review was to identify the constructs and components of parent-to-parent support for parents of children who are D/HH.
Research Design: An extensive scoping literature review identified 39 peer-reviewed articles published from 2000 to 2014. Studies were selected and reviewed based on standardized procedures.
Results: Data were identified, extracted, and organized into libraries of thematic and descriptive content. A conceptual

framework of parent-to-parent support for parents of children who are D/HH was developed and presented in a comprehensive, bidirectional informational graphic. The constructs and components of the conceptual framework are (a) well-being: parent, family, and child; (b) knowledge: advocacy, system navigation, and education; and (c) empowerment: confidence and competence.
Conclusion: The findings from this scoping review led to the development of a structured conceptual framework of parent-to-parent support for parents of children who are D/HH. The conceptual framework provides an important opportunity to explore and clearly define the vital contribution of parents in EHDI programs.

*P*arent-to-parent support, described as parents with lived experiences providing support to each other, is recognized as a distinctive and important type of support system. A growing body of evidence documents that parent-to-parent support groups provide positive assistance in managing the needs of parents with children who have disabilities and their families as they seek service for their child (Banach, Iudice, Conway, & Couse, 2010; Hoagwood et al., 2010; Ireys, Chernoff, Stein, DeVet, & Silver, 2001; Jackson, Wegner, & Turnbull, 2010; Mathiesen, Frost, Dent, & Feldkamp, 2012; McHugh, Bailey, Shilling, & Morris, 2013; Olin et al., 2014; Shilling et al., 2013; Wright & Wooden, 2013).

Research comprising parental perspectives and experiences of parents with children who are deaf or hard of hearing (D/HH) documents the pressing need for parental support (DesGeorges, 2003; Eleweke, Gilbert, & Bays,

2008; E. Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; Glanemann, Reichmuth, Matulat, & Zehnhoff-Dinnesen, 2013; Hardonk et al., 2013; Jackson, 2011; Jackson et al., 2010). Existing evidence indicates that, for parents with children who are D/HH, parent-to-parent support is a vital service not otherwise provided in formal support systems (Shilling et al., 2013). Organizations such as the Alexander Graham Bell Association for the Deaf and Hard of Hearing, Canadian Association of the Deaf, Hands & Voices, and VOICE for Hearing Impaired Children have provided service models of parent-to-parent support, recognizing the importance of family well-being in servicing a child who is D/HH.

Many countries have actively implemented Early Hearing Detection and Intervention programs (EDHI) in which newborn screening identifies children with or at risk for hearing loss and follow this with evidence-based approaches to secondary hearing tests when necessary, appropriate intervention within a timely fashion, and information to assist families with decision making (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). Relevant and timely support and intervention are important for families of children identified with hearing loss because the majority of these children will be born to parents with normal hearing who were not expecting the diagnosis.

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Supporting the evidence, the Joint Committee on Infant Hearing (JCIH, 2007, 2013) identifies parent-to-parent support as an important component of EHDI programs for children with hearing loss. The JCIH supports the development and implementation of guidelines of family-to-family support (JCIH, 2013). In addition, a recent international consensus statement for children who are D/HH identified family access to parent-to-parent support as a central tenet in family-centered principles (Moeller et al., 2013). Panels of experts in EHDI draw attention to the unique attributes of peer parental support as it pertains to social and emotional well-being for families and calls for provision of ingress, that all families have access to peer parental support systems (JCIH, 2013; Moeller et al., 2013).

A synthesis of evidence specific to parent-to-parent support from leading researchers indicates that parent-to-parent support is a necessary part of the whole health care system and ought to be provided or supported by a formalized entity (Eleweke et al., 2008; E. Fitzpatrick, Angus, Durieux-Smith, Graham, & Coyle, 2008; Jackson, 2011; Jamieson, Zaidman-Zait, & Poon, 2011; JCIH, 2013; Moeller et al., 2013; Poon & Zaidman-Zait, 2014).

Yet despite the benefits of peer parental support, very few syntheses of studies have been conducted. In fact, to the best of our knowledge, this is the first scoping review study to analyze thematic content centered on ideas central to parent-to-parent support of parents with children who are D/HH. The purpose of the review was to identify themes and ideas (constructs) and determine the key elements or specific parental needs of peer support (components).

Method

A scoping review of the literature was the appropriate method to meet the objectives of this study. *A scoping review* is defined as "a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge" (Colquhoun et al., 2014, pp. 2–4). A key strength of a scoping review in health-related practice is "its ability to extract the essence of a diverse body of evidence and give meaning and significance to a topic that is both developmental and intellectually creative" (Davis, Drey, & Gould, 2009, p. 13). This may explain why health-related research has increasingly adopted the scoping review as a method of digesting research evidence. This evidence may be neglected through a formal systematic review of the literature, which, on the other hand, aims to answer a particular research question through the critical appraisal of studies with specific methodological characteristics and may exclude less rigorous research material that may offer valuable evidence. Scoping reviews differ from literature reviews in that scoping reviews require critical interpretation of the research (Levac, Colquhoun, & O'Brien, 2010).

Similar to formal systematic reviews, scoping reviews use standardized and replicable procedures (Davis et al., 2009; Grant & Booth, 2009). Arksey and O'Malley (2005) developed a six-stage methodological framework for conducting scoping reviews. This framework was clarified and enhanced by Levac et al. (2010), who identified the six stages as (a) identification of the research questions; (b) identification of relevant studies; (c) study selection; (d) charting of the data; (e) collation, summary, and reporting of the results; and (f) consultation. Unlike Arksey and O'Malley, Levac et al. contend that consultation should be an essential component of scoping study methodology. As such, the present study is the first stage of a two-phase scoping review. The present study is intended to report collated results from the literature; the consultation process is currently underway and will be reported in a future publication.

Identifying the Research Question

Our scoping review addressed the following question: For parents of children who are D/HH, what thematic content is central to the constructs and components of a conceptual framework of parent-to-parent support?

Identifying Relevant Articles

The search strategy used the CINAHL, Scopus, MEDLINE, and Embase electronic databases between 2000 and 2014. The initial search revealed 120 articles in CINAHL, 434 in Scopus, 397 in EMBASE, and 289 in Medline. Key words were broad to capture the components of parents and families, peer parental support systems, and children who are D/HH. Subject headings were defined and adapted for each database to limit the search to parental support systems. Citation tracking from salient articles was also conducted. See Table 1 for search terms.

Study Selection (Inclusion/Exclusion Criteria)

Peer-reviewed studies, regardless of their design, met the inclusion criteria if they focused on (a) ideas central to parent-to-parent support for parents and families with a child who is D/HH, including children with comorbidities; (b) children aged 0–18 years (although most studies concentrated on children ages 0–6 years); and (c) parental support provided by professionals or peers and if they were (d) limited to the years 2000–2014 and (e) full articles written in English. Studies were excluded if they focused on adolescents and/or grandparent perspectives.

For this scoping review, the inclusion criteria included articles from professional and parental perspectives of parental support needs. We included articles of professional–parent support and professional perspectives when parental support needs were outside the scope of professional practice. The year 2000 was chosen as a cutoff point for study inclusion, as this represents a point in time during which universal newborn hearing screening had been widely implemented in the United States. Furthermore, this provides us with research articles that more accurately

Table 1. Search terms.

Category	Search term
Parent	Parents of disabled children
	Parent
	Family
	Extended family
	Mother
	Father
Support	Program development
	Program
	Patient centered/centered care
	Family centered/centered care
	Professional family relations
	Caregiver support
	Support groups
	Peer counseling
	Early childhood intervention
	Early intervention
	Parent-to-parent support
	Social support
	Peer support
	Education
	Neonatal screening
	Universal neonatal hearing
	Screening
	Early diagnosis
	Health services needs and demands
	Early hearing detection and intervention programs
Child who is deaf or hard of hearing (D/HH)	Infant
	Newborn
	Child, children
	Preschool
	Adolescent
	Hearing loss, conductive
	Hearing loss, sensorineural
	Hearing loss, functional
	Hard of hearing
	Deaf
	Hearing loss
	Hearing impairment
	Hearing disorder
	Hearing aid

reflect the current needs of families in a contemporary, diverse, and global society.

The lead author reviewed titles and abstracts of articles identified by the above-described searches and obtained full-text copies of articles believed to meet the inclusion criteria. The research team reviewed the articles and confirmed the final selection of papers through consensus.

Results
Charting the Data

Data extracted from the research papers included study design or method, purpose or objective of the study, study outcomes or findings, components of parent-to-parent support, number and sex of participants (parents), country, and future research directions outlined in the manuscript. Components of parent-to-parent support were extracted from parental experiences, semistructured interviews, focus groups, consultancy with clinicians, surveys, and questionnaires. The components were organized into tables of data. Supplemental Table 1 identifies the articles in this scoping review and charts the constructs and components.

We collectively compared and discussed the tables of charted information. The tables of thematic and descriptive data were derived from quotes, testimonials, themes, recollections, and expert opinions. We then interpreted the findings and organized the thematic and descriptive data into components, refining the language chosen to label each component throughout the process. Next, we grouped components according to similar themes. Groups of components were organized under constructs, and appropriate labels were derived for the constructs. Through consensus, we were able to determine the organization of the constructs and components.

Results of the thematic and descriptive data were organized into a conceptual framework and were depicted as an informational graphic. The informational graphic is a visual representation of evidence extracted in the scoping review and is intended to present complex information quickly and clearly.

Collating, Summarizing, and Reporting Results

As shown in Figure 1, 1,240 articles were located. Of the screened articles, 29 met the inclusion criteria. We further found 10 articles through citation tracking for a total of 39 articles included in this scoping review. Approximately half of the articles were quantitative (18), followed by qualitative (11) and review (seven) and, finally, mixed-method studies (three). Of the 39 articles, 26 articles focused on parental perspectives of family needs in relation to parent-to-parent support or professional-to-parent support.

Figure 1. Summary of search results.
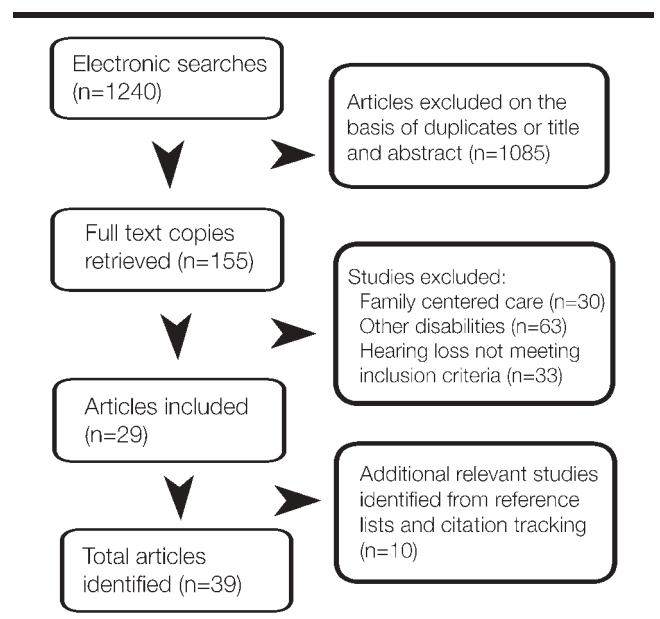
One article addressed parental or family support needs solely from a professional perspective. One study considered parental and family needs from both professional and family perspectives. We have classified the remaining eight articles as review papers. The studies' sample sizes for families ranged between nine and 456. Excluding review articles, 18 studies or 60% had a sample size between nine and 50 families. The two studies researching professionals had 27 and 35 participants.

The purpose of this review was to identify thematic concepts (constructs) through key elements (components) of parent-to-parent support for parents of children who are D/HH and design an evidence-based conceptual framework. Table 2 provides an overview of the number of studies identified through the literature review for each construct or component of the framework. The conceptual framework is illustrated in Figure 2.

The constructs and components are presented in a closed helix visual design with the supporting and learning parents at opposite curves. The "learning parent" is characterized as having a child recently identified as D/HH. The "supporting parent" has the lived experience of having a child with hearing loss. The helix represents the exchange of information between the parents. Two descriptive words—"connectedness" and "mutuality"—describe the underpinnings of the relationship. There are several layers of data available. Three overarching themes (constructs)—knowledge, well-being, and empowerment—are mirrored in the roles of the supporting and learning parents. In the flexure of the learning parent, arrows indicate that relationships exist between the defining constructs, namely that knowledge and well-being promote empowerment and empowerment and knowledge increase well-being. Under each construct, broad descriptive elements (components) are found on the supporting parent's spiral. Finally, specific key elements (components) itemize specific parental needs by the learning parent. The remainder of this article provides detail about each component or construct illustrated in the diagram and included in the framework.

Mutuality and Connectedness

The relationship between the supporting parent—defined as a parent with lived experience—and a learning parent in the parent-to-parent support dynamic requires mutuality and connectedness. Parent-to-parent support can be cyclical in nature when the learning parent transitions into the supporting parent role. Building a community of mentors and role models of thoughtful and supportive parents of children who are D/HH is becoming increasingly important for sustainable parent-to-parent support.

Mutuality. Mutuality is an important component of parent-to-parent support. Parents have expressed that a mutual exchange of information, thoughts, and resources benefits both the supporting and learning parents. In this model, parents require access and meaningful interaction with role models and mentors. In addition, studies report that supporting parents indicate giving support was as important as receiving it and that the learning parent may feel

motivated to help other parents who have a similar social identity (Bradham, 2011; Jackson, 2011; Meinzen-Derr, Lim, Choo, Buyniski, & Wiley, 2008; Moeller et al., 2013; Muñoz, Blaiser, & Barwick, 2013; Poon & Zaidman-Zait, 2014; Porter & Edirippulige, 2007; Sorkin & Zwolan, 2008; Yucel, Derim, & Celik, 2008; Zaidman-Zait, 2007).

Connectedness. A parent-to-parent support system creates a sense of social identity, social connectedness, affirmation, and belonging, which contributes greatly to parental well-being (Åsberg, Vogel, & Bowers, 2007; Dalzell, Nelson, Haigh, Williams, & Monti, 2007; DesGeorges, 2003; Eleweke et al., 2008; Glanemann et al., 2013; Hardonk et al., 2013; Hintermair, 2006; Jackson, 2011; JCIH, 2013; Meinzen-Derr et al., 2008; Uus, Young, & Day, 2012; van der Spuy & Pottas, 2008; Zaidman-Zait, 2007).

The common experience of raising a child who is D/HH is an intangible, vital quality, and a shared social identity fosters a sense of belonging, acceptance, and support from others. Awareness of a social identity may act as a buffering effect against stress and safeguard parents from negative psychological and physical health impacts. Evidence of shared social identity as a buffer for parents of children with disabilities outside of children who are D/HH is well documented (Banach et al., 2010; Barlow & Ellard, 2006; Dunst, 2011; Hoagwood, 2013; Kerr & McIntosh, 2000; Law, King, Stewart, & King, 2001; Mathiesen et al., 2012; McHugh et al., 2013; Resch et al., 2010; Sartore, Lagioia, & Mildon, 2013; Shilling et al., 2013; Wright & Wooden, 2013).

Connectedness refers to a welcoming and cordial atmosphere and experiencing social kinship with other families. Connectedness may involve building parental and family relationships, participating in community partnerships, engaging in political initiatives, reaching out to families who have children who are D/HH, and volunteering together. Sharing experiences reassures parents about their family's and child's future, and parents of children who are D/HH attribute a sense of belonging to better well-being, especially during stressful events. Parents describe deeper connections over a shared experience. Matching parents whose child has a similar diagnosis on the spectrum of hearing loss may also help. For example, parents considering cochlear implantation are likely to have different peer parental support needs than the parents of a child with a mild hearing loss.

Affirmational support is sharing and validating experiences. Parents describe affirmational support as being understood and appreciated. Meeting parents with similar experiences, such as a shared diagnosis, care requirements, or life circumstances (e.g., living in a rural community) was important to feeling understood. Benefits of relational support are described as having a sense of belonging in the group, understanding and learning from the experience of others, and having a safe environment for support.

Evidence Related to Well-Being

For parents and families of children who are D/HH, the evidence indicates that the key predictors of well-being

Table 2. Number of papers pertaining to each component and construct.

| Component and construct | Well-being | | | | | | Knowledge | | | | | | | | | Empowerment | | | | | Relation | |
| | Child | | | Family | | | Education | | | System navigation | | | Advocacy | | | Confidence and competence | | | | | | |
	Participation	Goals	Autonomy	Relational	Emotional	Adaptational	Resources	Information	Skills	Professionals	Services	Transitions	Legal rights	Funding	Representation	Problem solving	Parenting	Self-awareness	Engagement	Decision making	Mutuality	Connectedness
Well-being (n = 36)	23	26	15	33	33	27																
Knowledge (n = 36)							21	29	17	29	22	16	8	17	10							
Empowerment (n = 32)																20	13	14	19	18		
Relation (n = 21)																					12	13

Figure 2. Parent-to-parent support for parents of children who are deaf or hard of hearing: A conceptual framework.
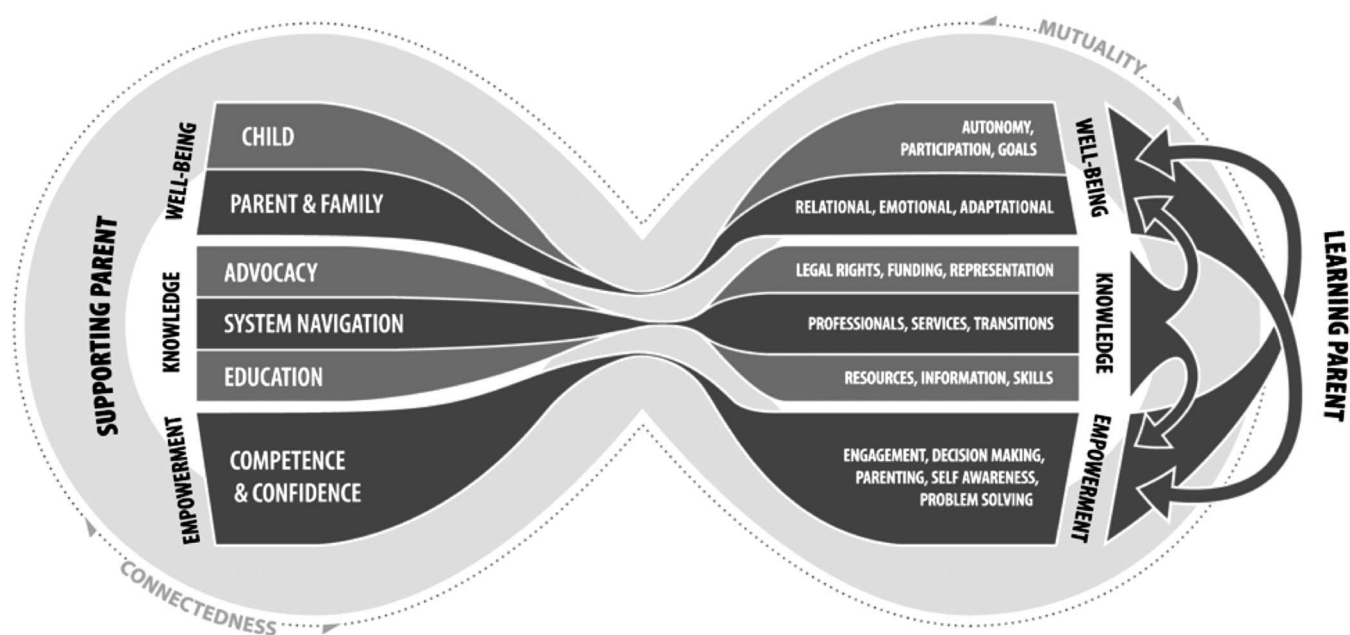
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for parents and families are (a) emotional support, (b) adaptational support, and (c) relational support. For the child who is D/HH, key predictors of well-being are (a) participation, (b) goals, and (c) autonomy (Åsberg et al., 2007; Brown, Abu Bakar, Rickards, & Griffin, 2006; Brown & Remine, 2008; Dalzell et al., 2007; DesGeorges, 2003; Eleweke et al., 2008; E. Fitzpatrick, 2010; E. Fitzpatrick et al., 2008; E. Fitzpatrick et al., 2007; E. M. Fitzpatrick & Durieux-Smith, 2011; Hintermair, 2006; Holzinger, Fellinger, & Beitel, 2011; Ingber, 2009; Jackson et al., 2010; Jamieson et al., 2011; JCIH, 2013; Larsen, Muñoz, DesGeorges, Nelson, & Kennedy, 2012; Lederberg & Golbach, 2002; Marriage, 2013; Meinzen-Derr et al., 2008; Moeller et al., 2013; Poon, Jamieson, Buchanan, & Brown, 2008; Porter & Edirippulige, 2007; Quittner et al., 2010; Sipal & Sayin, 2012; Zaidman-Zait, 2007).

Well-Being for Parents and Families

Emotional support. Parents require emotional support, and many articles indicate parent-to-parent support positively influences emotional well-being. Emotional priorities (and concerns) are key attributes of wellness and affect a parent's ability to cope with his or her own needs to support the child. The most common emotional concerns researchers have ascribed to parents include emotional distress, low self-esteem, grief, unpredictability, loneliness, incompetence, vulnerability, lack of fulfillment, and perceived stigma. Many of these negative emotions arose after the child's diagnosis with hearing loss and/or at periods of transition. Parent support groups offered psychological benefits, including

self-reliance, less isolation, autonomy, positive identity, self-worth, confidence, readiness to engage, and bravery. Leading researchers have documented evidence that parent-to-parent support may increase parental emotional well-being.

Adaptational support. Studies link well-being to adaptation, adjustment, and acceptance. Examples of important components of how parent-to-parent support assists with adaptation to the child's hearing loss include developing personal strategies, assisting in resolving grief, helping to accept a child's hearing loss, understanding around the unpredictability associated with a diagnosis, and coping with change. Positive emotions associated with adaptation include motivation, relief, increased sense of power, resilience, gratitude, learning, persistence, hopefulness, peacefulness, sense of safety, and optimism. Adaptational support assists the parent in developing an awareness and the skills necessary to create an optimal environment for language and literacy development, such as changing routines or learning sign language.

Relational support. Overall, 30 studies indicate relational support as a key attribute of parent-to-parent support. *Relational support* refers to relationships and well-being between the members of the immediate and extended family. Relational support in this framework is identified as bonding with the child, family functioning, family and marital cohesiveness, interaction, and communication between family members. Parent-to-parent support systems recognize that family members cope better when they have a sense of togetherness. For children who are D/HH, the impairment may affect language development, which can affect family

members' ability to communicate with the child and the child with his or her family. Parent support groups can help all members understand hearing loss and boost positive interactions between parent and child, grandparent and child, extended family and child, and siblings.

Well-Being for the Child

Participation. Twenty-three studies indicate that parents of children who are D/HH identify child participation in hearing and the Deaf community as a priority. Parents want their children to fully experience leisure or extracurricular activities, day care or school, and ventures with their siblings and friends. Parent support groups may identify solutions to full participation barriers, such as recommendations for community-based accommodations. Sometimes a child who is D/HH may have language or social–emotional delay, which may complicate peer acceptance and relationships, and parent support groups can support parents to improve their child's well-being.

Autonomy. Parents who have children with disabilities have indicated that their overprotectiveness may limit their child's autonomy (Anaby et al., 2013). Peer parental support provides an opportunity for parents to encourage and provide strategies for other parents who may feel unsure or uncertain about when and how to support autonomous behavior in their children. Autonomous children perceive greater control over decision making and exhibit persistence, curiosity, and stress-related coping strategies (Morrison, Dashiff, & Vance, 2013; Poulsen, Rodger, & Ziviani, 2006). All of these skills are important for parents to assist children with developing so that they become active participants in their hearing health care, education, and social environments as early as possible in life.

Goals. Twenty-eight studies report the positive influence of parent-to-parent support on reassuring parents about their child's short- and long-term goals. Parents are concerned about language achievement and communication outcomes and have expressed hopes and fears regarding their child's educational success and employment opportunities. Peer parental support systems boost parental morale and confidence when looking toward the future and at points of transition. Parents are better positioned to support the goals chosen by the child through meaningful collaboration.

Evidence Related to Knowledge

Thirty-six studies highlighted the need for parental access to accurate and unbiased knowledge. Given the magnitude of information on hearing loss, parents may find it difficult to ascertain quality information. Our informational graphic of parent-to-parent support for hearing parents of children who are D/HH depicts how knowledge leads to parental empowerment and well-being. Defining components of knowledge are (a) advocacy, (b) system navigation, and (c) education (Åsberg et al., 2007; Bradham, 2011; Brown & Remine, 2008; DesGeorges, 2003; Eleweke et al., 2008; E. Fitzpatrick, 2010; E. Fitzpatrick et al., 2008; E. Fitzpatrick et al., 2007; Hardonk et al., 2013; Hardonk et al., 2011;

Ingber, 2009; Ingber & Dromi, 2010; Jackson, 2011; Jackson et al., 2010; Jamieson et al., 2011; JCIH, 2013; Larsen et al., 2012; Lederberg & Golbach, 2002; Luterman, 2004; Marriage, 2013; Meinzen-Derr et al., 2008; Moeller et al., 2013; Porter & Edirippulige, 2007; Sorkin & Zwolan, 2008; Yucel et al., 2008; Zaidman-Zait & Jamieson, 2007). Adolescents and adults who are D/HH may provide enhanced cultural and linguistic experiences and help build family networks, perhaps through no other means than giving a reassuring example of successful aging with a hearing loss.

Advocacy

Legal rights. In many countries, positive attitudes toward disability and inclusion are reflected in policy and legislation. Yet stigma and barriers continue for children who are D/HH. In eight studies, parents wanted clear and accurate information about laws, entitlements, and rights for their children, especially regarding special education laws. Parent-to-parent support may provide parents with information on federal legislation and regulation and keep families apprised of changes to laws.

Representation. Parent-to-parent support can guide parents on how to advocate on behalf of their child who is D/HH at the local, state, and federal levels. Parental consultants may provide strength and advice at medical, professional, and educational appointments. Learning parents indicate feeling inadequate and lacking confidence at difficult decision-making meetings and would benefit from a peer advocate. Peer consultants may represent families and collaborate with governments, organizations, and initiatives.

Funding. Parents with children who are D/HH may have increased financial strain. Developing knowledge and skills related to accessing financial assistance and entitlements through private insurance, government funding, and not-for-profit supplements may reduce stress. Supporting parents can assist learning parents with developing strategies to obtain assistance with expenses related to private speech therapy, time off work for medical appointments and travel, and expenses related to technological equipment (e.g., hearing aids, earmolds, and batteries).

System Navigation

Services. Children who are D/HH require services to meet their needs, and their parents require assistance maneuvering through health care, school, legal, and community systems. Parent-to-parent support can assist parents with children who are D/HH by (a) identifying services, (b) accessing services, and (c) navigating services. Parents require assistance in identifying programs available in the community for today or in anticipation of a future or potential need. Peer parental support can assist parents with locating programs, determining eligibility criteria, navigation of the application process, and accessing appropriate programs. To illustrate, parents need to know about available community services, such as supports beyond the preschool years. If parents are unaware of a service, it cannot be

accessed. Further, parent-to-parent support may help families create a program if one does not meet a child's needs.

Professionals. Parents require a road map and care coordination in order to best work with their child's professionals. Twenty-nine studies refer to parents receiving inadequate support navigating the process from referral to hearing aid or cochlear implant provision and understanding the roles of the professionals they may encounter. Within our framework, parents seen as supporting parents can help explain to the learning parents how to coordinate efforts, book appointments, and determine timely service. Further, parents may not know the jobs and roles of their child's specialists. Parent-to-parent support can inform parents how speech-language pathologists, audiologists, and otolaryngologists work together and perform different tasks in their child's habilitation. Parent-to-parent support can also connect parents with skilled professionals, such as optometrists, dentists, or child-care workers who understand hearing loss.

Transitions. Sixteen articles indicate that maneuvering through these complex systems, processes, and stages can be frustrating periods, especially when unexpected barriers are presented. Support and informational needs increase at periods often referred to as transitional, such as when a child enters day care or school, becomes an adolescent, or begins to explore careers. Parents have suggested that educational components to prepare for transitional stages be part of pediatric habilitation for children who are D/HH to better support parents and children. Further, parents need ongoing support, not just when entering the school system. Parents express stress around educational concerns, such as learning supports, technological needs, policies, and specialized educational programs.

Education

Resources. Parent-to-parent support can provide parents with resources in the community. Recognized affiliations with national and local agencies and referrals to those organizations are an important component of peer parental support. Peer parental support can suggest volunteer networks, not-for-profit organizations, community partners, and support programs for parents at the point of diagnosis. The literature indicates that parents who have the lived experience of raising a child who is D/HH are more knowledgeable than many professionals about resources available for families in the communities in which they live.

Skills. Mastering new skills can be both rewarding and challenging for parents of children who are D/HH. Endeavoring to best support their child's language and educational needs, many parents receive instruction in sign language, speech training, and technological skills from experts in these fields. As a supplement to professional support, parents indicate they want skills-based instruction in peer parental support groups. Skills-based instruction pertaining to sign language may include workshops and opportunities to practice. Peer parental support recognizes the parent's effort and dedication to acquiring new skills.

Information. Parents require "information that is accurate, well-balanced, comprehensive, and conveyed in an unbiased manner" (JCIH, 2013, p. 5). For parents, quality information is critical and informs decisions at diagnosis and during their child's early development. Parents indicate they have received inadequate, outdated, biased, and incomplete information from their child's specialists. Parent-to-parent support creates an environment of shared information in which parents can learn about best practices, industry protocols, technological advancements, the latest research, amplification options, and communication choices. Twenty-nine research studies indicate parents would benefit from improved information.

Evidence Related to Empowerment

Thirty-two research articles provide evidence for the positive influence of parent-to-parent support on parental empowerment. Empowerment is a construct that is a social process, influenced by well-being and knowledge, which fosters power through confidence and competence in people's lives. We define the components of competence and confidence as (a) problem solving, (b) parenting, (c) self-awareness, (d) engagement, and (e) decision making (Brown et al., 2006; DesGeorges, 2003; Eleweke et al., 2008; E. Fitzpatrick et al., 2008; Hardonk et al., 2013; Hardonk et al., 2011; Ingber, 2009; Jamieson et al., 2011; JCIH, 2013; Marriage, 2013; Moeller et al., 2013; Porter & Edirippulige, 2007; Quittner et al., 2010; Yucel et al., 2008; Zaidman-Zait, 2007).

Confidence and Competence

Parenting. The exchange of parenting knowledge learned through the experience of raising a child who is D/HH is a vital component of peer parental support in 13 studies. Parents are eager to learn practical parenting skills, such as teaching their child to safely cross the street and how to anticipate their child's needs at a birthday party. Beyond the early years, peer parental support may offer parenting advice to improve child–parent interactions and guidance when parenting a child who may require behavioral or social supports.

Decision making. Peer parental support offers parents the opportunity to access knowledge, information, and resources and to cultivate ideas and opinions for informed decision making. Further, emotional support provided in parent-to-parent structures helps parents develop the capacity and confidence to make decisions. Families fully engaged in decisions about their child's options and care with specialists can find validation in their peer support group.

Self-awareness. Several studies indicate peer-to-peer support may provide a sense of self-awareness by helping hearing parents respond with intention to their child's diagnosis. Supporting parents' emotional and educational needs empowers parents to be more self-efficacious in orienting to the present and setting goals for the future. Self-awareness is a process; parents build on areas of strength, acknowledge areas to learn, and become confident to act in line with personal and family values. Finding clarity with

parent-to-parent support empowers parents to rediscover their personal strengths and resilience to support their child who is D/HH.

Problem solving. Parent-to-parent support may empower parents to trust their innate problem-solving and coping abilities. Unable to rely on specialists in daily living, parents must acquire skills and confidence to improve problem-solving abilities. Parent-to-parent support can help parents acquire problem-solving skills specific to raising a child who is D/HH and enhance the process together.

Engagement. Confidence and competence equip parents to play an active and engaged role in the management of their child's daily life. Parents' ability and readiness to assume their expert parental role with their child's specialist team to foster their child's development is related to the parents' willingness and ability to fully engage. Peer parental support can provide positive support and help parents actively engage in their child's habilitation process.

Discussion

The specific objective of this scoping review was to provide a synthesis of the existing peer-reviewed knowledge regarding clinical and parental experiences relating to parent-to-parent support for parents of children who are D/HH. The key finding to emerge is the development of a conceptual framework of parent-to-parent support for parents of children who are D/HH.

The 2013 Supplement to the JCIH and Moeller et al.'s (2013) International Consensus Statement indicate that parent-to-parent support has an appreciable quality that cannot be reproduced by clinicians and that this specific support is recommended for the social and emotional well-being of families. In order for parents to function effectively on behalf of their child who is D/HH, the panels of experts recommend the development and implementation of guidelines for best-practice parent-to-parent support (JCIH, 2013; Moeller et al., 2013). The JCIH and International Consensus Statement served as the catalyst for this scoping review. Prompted by these recommendations, this scoping review sought to determine the constructs and components of this specific type of support. The conceptual framework, developed through this scoping review, may serve as a foundational tool in the development of these guidelines.

The assessment and assimilation of a diverse body of evidence across developed nations in Africa, Australia, Europe, and North America has identified central themes and ideas relating to peer parental support needs and has the potential to standardize content of parent-to-parent support for parents of children who are D/HH.

In addition to establishing parent-to-parent guidelines, leading researchers suggest that strengthened peer parent support programs may complement existing services and have a sequential effect, such as augmenting EHDI programs (Åsberg et al., 2007; Eleweke et al., 2008; E. Fitzpatrick et al., 2008; Jackson, 2011; Poon & Zaidman-Zait, 2014).

Limitations of the Study

We did not complete a quality appraisal of the studies, which is not required in the methodological process of a scoping review of the literature. In addition, although gray material, such as what is produced on all levels of government, business, and industry, is permissible in scoping reviews, we chose to limit our search to academic literature. Therefore, we did not use parent-to-parent support material from not-for-profit organizations that may work daily with parents of children who are D/HH. Further, the interpretive nature of developing the conceptual framework may be a limitation. Although the scoping review adhered to the methodological standards of a scoping review, the development of the conceptual framework may not be replicable due to authors' interpretations, creative allowances, and subjectivity of assigning significance.

Conclusion

There is increasing evidence regarding the vital and beneficial role of parent-to-parent support. To the best of our knowledge, this is the first conceptual framework of parent-to-parent support for parents of children who are D/HH. This conceptual framework provides a comprehensive overview of the literature and in doing so addresses recommendations from the JCIH and the International Consensus Statement on best practices in family-centered early intervention for children who are D/HH.

The conceptual framework was developed with the intent to be of service to parents, policy makers, clinical practitioners, and researchers. It has the potential to influence the development and implementation of family support guidelines, policy, legislation, and practice.

This review concludes that parent-to-parent support is a central tenet in family-centered care for families with children who are D/HH, that it must be provided by experienced parents, and that it cannot be replicated by health care professionals. Evidence indicates parent-to-parent support is necessary and adjunctive to professional services. High priority must be given to ensure parent-to-parent support is incorporated within but complementary to EHDI programs and that professionals serving parents are informed of peer parental programs.

This research has the capacity to refine the content and type of support offered by institutions and organizations. Parents have already emerged in this health care role, but they must be widely recognized as integral providers of this service.

Most important, this new information may improve health outcomes for children who are D/HH by fully supporting their parents and families.

Future Directions

This is a dual-phase scoping review. The initial conceptual framework was developed based on diverse peer-reviewed literature in the field. However, as per scoping

review methodology, we recognize leaders in this field may be able to provide additional insights beyond the literature, and we will seek stakeholder involvement. Therefore, the next stage for this program of research will be to present the framework to professionals and parents with expertise in the area of parent-to-parent support to gather additional evidence to support and or direct revisions for the framework.

Additionally, we appreciate how context and environment influences and impacts best practice parent-to-parent support. Conditions affected by "who," "where," and "how" will impact potential implementation of the conceptual framework. Future research directions may consider strategies for best environmental context to complement this conceptual framework. The findings from the parent-to-parent support conceptual framework contextualized in an evidence-based peer parental support environment would be depicted in an interactive 3-D model. A 3-D model would best represent the interaction and merging of the conceptual framework and the environment to support it.

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