Review Article

Facilitators of and Barriers to Caregiver Adherence to Home Therapy Recommendations for Infants and Children With Neuromotor and Neuromuscular Diagnoses: A Scoping Review

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Importance: Caregiver-performed home therapy programs are essential to occupational therapy intervention for infants and children with neuromotor and neuromuscular diagnoses. Factors that facilitate or are barriers to caregiver adherence when making home therapy recommendations should be considered.

Objective: To identify facilitators of and barriers to caregiver adherence to home therapy recommendations for children with neuromotor and neuromuscular disorders.

Method: The review followed the five-step methodological framework developed by Arksey and O'Malley (2005) and was guided by the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

Data Sources: Searches with no language or date range limits were performed in MEDLINE, CINAHL Plus with Full Text, PsycINFO, and SocINDEX on the EBSCO platform, and Scopus on the Elsevier platform from database inception through January 24, 2023.

Study Selection and Data Collection: Study inclusion criteria included caregiver adherence to home therapy recommendations for children with neuromotor and neuromuscular diagnoses. Eight hundred seventy-five articles underwent title and abstract screening; 64 articles met the criteria for full review.

Findings: Twelve articles met the inclusion criteria. Four used qualitative measures, 7 used quantitative measures, and 1 used mixed methods. Qualitative thematic analysis revealed four facilitators: routine, efficacy of caregiver education, positive relationship with therapist, and perceived benefit of treatment. The analysis revealed three barriers: lack of time, lack of confidence, and caregiver stress.

Conclusions and Relevance: The facilitators and barriers identified are central to best-practice occupational therapy. Therapists can use expertise in analyzing routines and context to maximize the fit between family needs and home therapy recommendations.

Plain-Language Summary: Home therapy for children with a neuromotor and neuromuscular diagnosis is common and uses some form of caregiver-performed movement activities or techniques. To support caregivers, occupational therapists need to understand what factors facilitate or serve as barriers to following home therapy recommendations. The review found three barriers: lack of time, lack of confidence, and caregiver stress. The review provides strategies to support home therapy based on core principles of occupational therapy practice. It also identifies the need for more research to support home therapy recommendations that fit within the child's and family's routine, that can be taught in a way that meets the child's and family's learning needs, that facilitate self-efficacy and confidence, and that reflect the values and motivators of all participants.

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Home therapy programs that complement direct occupational therapy services are a common intervention for infants and children with neuromotor and neuromuscular diagnoses, including cerebral palsy (CP), brachial plexus birth injury (BPBI), muscular dystrophy, and other disorders affecting movement. These home therapy programs often include activities performed by caregivers to facilitate active movement and functional range of motion, strengthen weak muscles, and promote motor development to prevent or decrease known sequelae, such as joint contractures or impaired joint integrity because of spasticity or decreased active movement associated with neuromotor and neuromuscular conditions (Brown et al., 2015; McNeely et al., 2021; Michel & Collins, 2020; Novak et al., 2017; Yilmaz et al., 2018).

For example, infants with BPBI are recommended to receive caregiver-performed passive range of motion (PROM) as early as possible after birth (Coroneos et al., 2017; Muhlestein et al., 2024; Smith et al., 2018) and as frequently as every diaper change (Yang, 2014). In a pilot study, Wingrat and Elrick (2023) found that infants with BPBI whose caregivers consistently adhered to daily PROM during the first year of life were less likely to develop shoulder contractures than those whose caregivers were inconsistent in adhering to daily PROM. To support caregivers in adhering to these and similar home therapy recommendations, and to provide the best outcomes for infants with neuromotor and neuromuscular diagnoses, therapists need to understand the factors that facilitate or serve as barriers to adherence to home therapy recommendations.

The purpose of this scoping review was to examine the literature to identify facilitators of and barriers to caregiver compliance with home therapy recommendations for infants and children with neuromotor and neuromuscular disorders and diagnoses. Although we initially set out to review the literature specifically related to infants and children with BPBI, the inclusion of neuromotor and neuromuscular disorders and diagnoses was chosen because we found limited research specifically on the diagnosis of BPBI; in addition, home therapy recommendations are likely to be similar for infants and children with any of these diagnoses in which caregivers are expected to carry out some form of passive movement activity.

Method

In this scoping review, we followed the five-step methodological framework developed by Arksey and O'Malley (2005) to (1) identify the research question(s); (2) identify relevant studies; (3) select studies; (4) chart the data; and (5) collate, summarize, and report the results. This process was guided and reported through the use of the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA–ScR) checklist (Page et al., 2021; Tricco et al., 2018). Institutional review board approval was not needed for this scoping review.

Identifying the Research Questions

This scoping review was guided by the following research questions:

1. What factors serve as facilitators of caregiver adherence to home therapy program recommendations for children with neuromotor or neuromuscular disorders?
2. What factors serve as barriers to caregiver adherence to home therapy program recommendations for children with neuromotor or neuromuscular disorders?

Identifying the Relevant Studies

The initial search was carried out by a research librarian with guidance and input from the primary investigator regarding search terms and parameters. The search included concepts for caregivers, home or home-based, and rehabilitation. The searches were run on MEDLINE, CINAHL Plus with Full Text, PsycINFO, and SocINDEX simultaneously through the EBSCO platform, as well as Scopus on the Elsevier platform, from database inception through January 24, 2023. The search strategies can be found in Table A.1 in the Supplemental Material (available online with this article at https://research.aota.org/ajot). The search was limited to peer-reviewed publications. No limits to language or date range were applied.

Study Selection

The initial search yielded 1,247 results that were uploaded to Rayyan (Ouzzani et al., 2016) for eligibility screening; 372 duplicates were removed, and 875 articles were considered for title and abstract screening, with 64 articles meeting the criteria for full review (12 articles met the inclusion criteria). Inclusion criteria included studies that focused on caregiver adherence to home-based therapy recommendations for infants and children from birth through age 18 yr with a neuromotor or neuromuscular diagnosis, including CP, BPBI, muscular dystrophy, and other motor disorders. Studies that examined adherence to home administration of medical procedures or medical management (e.g., insulin management for children with Type 1 diabetes) or home management of medical diagnoses (e.g., chest percussions for children with cystic fibrosis) were excluded because we determined that adherence to these interventions is likely influenced by the high-stakes nature of managing a serious medical condition. Studies that included caregivers of adults were also excluded because our focus was strictly on caregivers of infants and children.

All study designs were considered for inclusion. Two reviewers, Jennifer Wingrat and Tess Wright, screened 875 relevant titles and abstracts using the

predetermined search criteria and discussed disagreements to collaborate on a final decision regarding inclusion or exclusion. The two investigators subsequently completed full-text reviews of 64 included articles and discussed and collaborated on decisions for further exclusion when necessary.

Charting the Data

Data were extracted and charted in a Microsoft Excel table to organize and facilitate efficiency in reviewing and extracting themes. Charted categories included topic or main idea, population, results and conclusions, limitations, connection to other reviewed studies, and relation to the research questions. Wright performed the initial charting process, and Wingrat reviewed and screened the extracted data to ensure that all recorded data met the inclusion criteria and addressed the research question.

Collating, Summarizing, and Reporting the Data

Researcher triangulation (Patten & Newhart, 2018) was used throughout the qualitative thematic analysis process, which was performed by Wingrat and Wright. Initial qualitative thematic analysis was performed with open coding and handwritten visual mapping to extract two sets of common themes from the selected studies: one set for facilitators and one for barriers. The thematic analysis revealed four themes related to facilitators: routine, efficacy of caregiver education, positive relationship with therapist, and perceived benefit of treatment. The analysis revealed three themes related to barriers: lack of time, lack of confidence, and caregiver stress.

Results

As shown in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart (Figure 1; Page et al., 2021), 64 abstracts were screened on the basis of the inclusion criteria; 41 did not meet the inclusion criteria, leaving 23 articles that were duly screened by two independent reviewers (Wingrat and Wright). Eleven of the 23 articles read in full were excluded because they did not address the research question, resulting in 12 articles remaining for full data extraction (see Table A.2 in the Supplemental Material). Of the 12 articles, 4 used qualitative measures, including semistructured interview or focus groups; 7 used quantitative measures, primarily surveys ($n = 10$); and 1 used a mixed-methods design for data collection. The 12 studies were conducted in a variety of locations: 3 in the United States; 3 in Spain; and 1 each in Canada, India, Israel, Turkey, Saudi Arabia, and the United Kingdom. The studies were published in a variety of journals; the majority ($n = 8$) were published in rehabilitation or physical therapy–focused journals, 2 in developmental medicine journals, 1 in a public health journal, and 1 in the *Indian Journal of Physiotherapy and Occupational Therapy*.

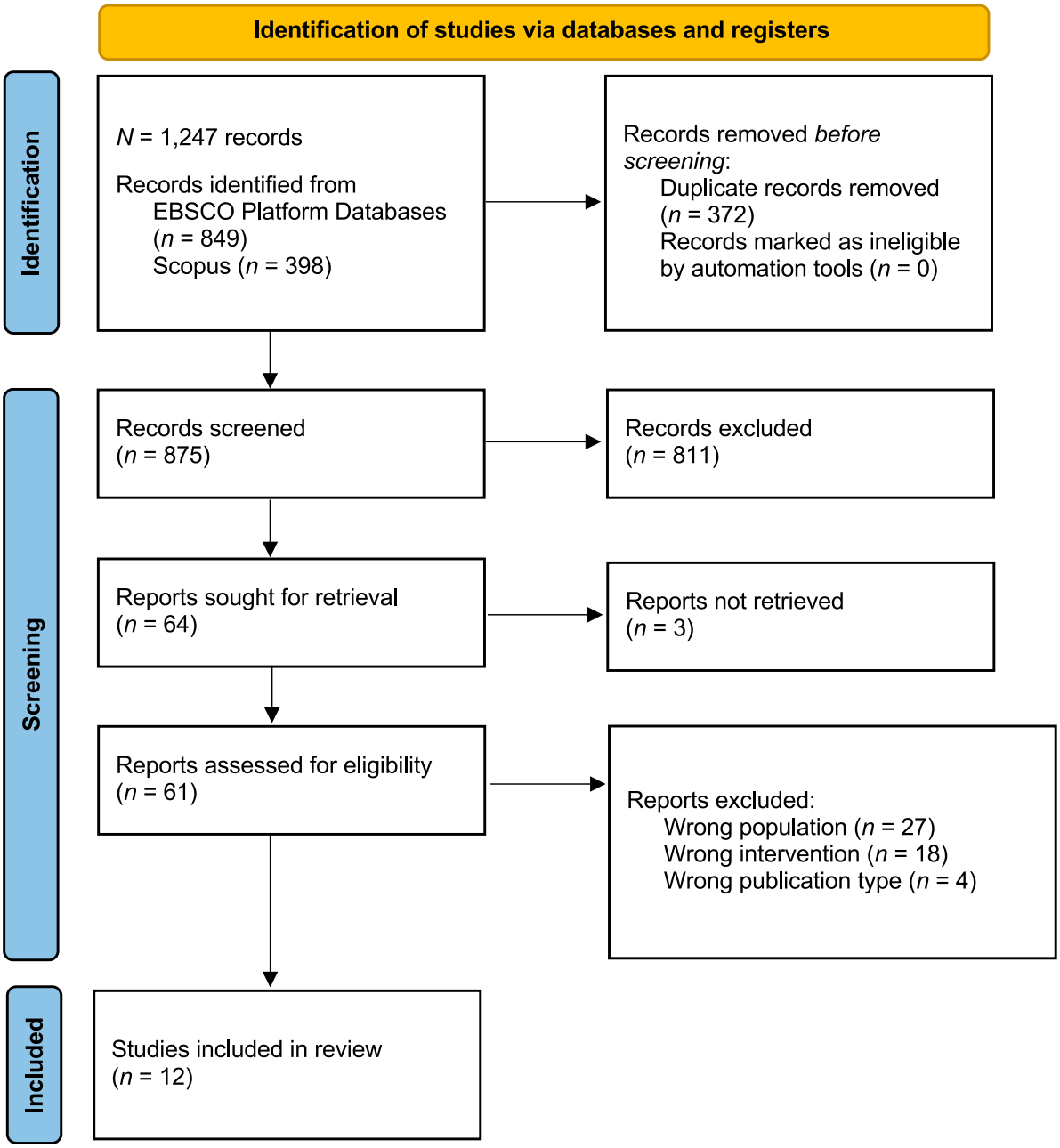
Study sizes varied from 28 to 538 participants; 8 of the studies included ≥100 participants. Home therapy programs had been prescribed by both occupational therapy practitioners and physical therapists in 7 of the 12 studies, by occupational therapy practitioners in 1 of the 12 studies, and by physical therapists in the remaining 4 studies. The participants in all of the studies were caregivers of children with disabilities, including varying neuromotor disabilities and motor delays ($n = 8$), CP ($n = 2$), BPBI ($n = 1$), and joint hypermobility ($n = 1$). Among the studies that included a variety of disabilities, types of disability included BPBI, CP, muscular dystrophy, motor delay, motor impairment, and other non-motor–based conditions. The decision was made to include the articles with some nonmotor conditions as long as their samples also included a motor-based diagnosis. The study on caregivers of children with joint hypermobility was included on the basis of the rationale that the goals of home therapy programs for these children focus on outcomes similar to those for children with neuromotor and neuromuscular diagnoses (e.g., facilitating motor development for improved participation in occupations).

Themes Related to Facilitators

As stated previously, the thematic analysis revealed four themes related to facilitators: routine, efficacy of caregiver education, positive relationship with therapist, and perceived benefit of treatment. Of the 12 studies, 6 described the importance of making a home therapy program fit within the family's or caregiver's routine as a facilitator of adherence (Alwhaibi et al., 2022; Birt et al., 2014; Gmmash et al., 2021; Lillo-Navarro et al., 2015; McConnell et al., 2015; Medina-Mirapeix et al., 2017). Lillo-Navarro et al. (2015) noted that therapists should consider the number of exercises they recommend to make fitting them into the family's routine manageable. Gmmash et al. (2021) and McConnell et al. (2015) recommended considerations of the family context, whereas Alwhaibi et al. (2022) noted the importance of fitting recommendations into routines because of increased demands on mothers in Saudi Arabia, specifically in regard to role expectations related to Saudi women. The concepts of routines, contexts, and roles are all considerable parts of occupational therapy's domain and practice, yet none of the studies n occupational therapy journal. Occupational therapy practitioners can play a considerable role in facilitating caregiver adherence using their expertise in identifying and understanding the impact of each family's unique routines, contexts, and roles when developing and making home therapy recommendations.

The theme of *efficacy of caregiver education* as a facilitator of adherence was noted in 5 of the 12 studies (Gmmash et al., 2021; Lillo-Navarro et al., 2015, 2019; Medina-Mirapeix et al., 2017; Murphy et al., 2012). In

Figure 1. Flow diagram for inclusion and exclusion of peer-reviewed studies in the scoping review.



Note. Figure format from "The PRISMA 2020 Statement: An Updated Guideline for Reporting Systematic Reviews," by M. J. Page, J. E. McKenzie, P. M. Bossuyt, I. Boutron, T. C. Hoffmann, C. D. Mulrow . . . D. Moher. (2021). *International Journal of Surgery, 88,* 105906. https://doi.org/10.1016/j.ijsu.2021.105906

the studies by Gmmash et al. (2021) and Lillo-Navarro et al. (2015, 2019), caregivers attributed adherence to home therapy to the educational methods used by their child's therapists, such as coaching, providing information about their child's diagnosis, and modeling reviewing exercises and activities with them. Medina-Mirapeix et al. (2017) found that caregivers reported improved adherence when education and training were scaffolded, allowing them to evolve in their understanding and expectations. Murphy et al. (2012) examined the efficacy of a specific caregiver education technique, specifically the use of a training DVD, and found this method to successfully facilitate efficacy in implementing home therapy recommendations. These findings highlight the importance of considering caregiver learning styles and learning preferences when providing home therapy recommendations.

Somewhat related to efficacy of caregiver education, *positive relationship with therapist* was noted as a facilitator to adherence in 4 of the studies (Alwhaibi et al., 2022; Lillo-Navarro et al., 2015, 2019; Medina-Mirapeix et al., 2017). Alwhaibi et al. (2022) found that adherence was affected by how the mother perceived the therapist's treatment of her. Similarly, caregivers noted that they were more adherent when they had positive

interactions with their child's therapist (Medina-Mirapeix et al., 2017) and were made to feel confident in their ability to carry out the home therapy recommendations (Lillo-Navarro et al., 2015, 2019).

The final theme related to facilitating adherence was the *perceived benefit of treatment*, as noted directly in 2 studies (Başaran et al., 2014; Birt et al., 2014) and conversely in a 3rd study (Galil et al., 2001). In the studies by Başaran et al. (2014) and Birt et al. (2014), adherence to therapy recommendations was greater for children with greater levels of functional impairment and when caregivers perceived that the home therapy was of considerable benefit. Conversely, in their study comparing adherence of Israeli and Bedouin mothers of children with physical disabilities, Galil et al. (2001) found that Bedouin mothers believed that their child's disability was their destiny, so there was no perceived benefit to intervention. On the basis of these findings, it seems that therapists can facilitate adherence by considering caregivers' values, volition or motivations, and understanding related to their child's condition.

Themes Related to Barriers

The data analysis revealed three themes related to barriers, each of which is related to and can likely be overcome by implementing the previously described facilitators. The identified barriers were lack of time, lack of confidence, and caregiver stress. Four studies described issues related to lack of time as barriers to adherence (Birt et al., 2014; Gmmash et al., 2021; Lillo-Navarro et al., 2015; McConnell et al., 2015). Gmmash et al. (2021) specifically noted that lack of adherence is affected by a poor fit with family routines and contexts, whereas McConnell et al. (2015) noted that caregivers might feel that they must sacrifice in other areas to fit in the daily home therapy recommendations. Lillo-Navarro et al. (2015) suggested that therapists should consider the number of exercises they recommend so that adherence is more manageable. These examples provide further support for the importance of considering the family routines, roles, and context to facilitate adherence to home therapy recommendations.

Lack of confidence was noted in 3 articles (Alwhaibi et al., 2022; Birt et al., 2014; Lillo-Navarro et al., 2015). Birt et al. (2014) noted that adherence was poorer when caregivers did not understand how to perform, or the value of, the recommendations. Lillo-Navarro et al. (2015) reported that the degree of confidence therapists convey can determine a caregiver's adherence to exercise guidelines. Because adherence is facilitated by efficacy of caregiver education and having a positive relationship between caregiver and therapist, therapists should use strategies to facilitate learning that meet the caregiver's learning needs and preferences and ensure the development of a strong therapeutic rapport.

The third theme related to barriers was caregiver stress, as discussed in 4 of the 12 articles (Başaran et al., 2014; Galil et al., 2001; Jeevannavar et al., 2018; Rone-Adams et al., 2004). Başaran et al. (2014) noted that the emotional exhaustion associated with caring for a child with physical disabilities (e.g., CP) leads to burnout and thus becomes a barrier to adherence. Rone-Adams et al. (2004) noted that "stress is one of the most cited characteristics of families caring for a disabled child" (p. 141); they subsequently found a significant correlation between reported stress and nonadherence to home therapy among caregivers of children with muscular dystrophy. Similar to addressing the barrier related to lack of time, therapists need to consider the family's contextual factors, including stress, to ensure that home therapy recommendations fit the family's routines and roles without becoming an increased stressor.

Discussion

The purpose of this scoping review was to identify facilitators of and barriers to caregiver adherence with home therapy recommendations for infants and children with neuromotor and neuromuscular disorders and diagnoses in which home therapy is common and uses some form of caregiver-performed movement activities or techniques. Findings indicate that adherence is facilitated by concepts that are integral to occupational therapy practice: providing recommendations that fit with a family's routine, using client-centered caregiver education that meets the learning needs and preferences of and thus builds confidence and self-efficacy for individual caregivers within their unique context, facilitating a positive therapeutic relationship to ensure trust and understanding, and considering the values and motivations associated with therapeutic intervention so that caregivers find the interventions to be beneficial. These identified facilitators can be used to overcome the primary barriers we identified: lack of time, lack of confidence, and caregiver stress. Creating home therapy recommendations that consider a caregiver's and family's routines, roles, and context, as well as using preferred learning styles and methods, may increase self-efficacy and decrease caregiver stress, making adherence less of a burden and more manageable.

Only 1 of the 12 studies in our review exclusively included infants and children with BPBI (Murphy et al., 2012), which was our initial intended focus. Although the findings of that study demonstrated that adherence and caregiver learning are facilitated by use of an external support, they used a DVD, which is now an outdated technology. More research is needed to examine whether current forms of external supports, such as text message reminders or an app, are beneficial in facilitating adherence for caregivers of children with BPBI and other neuromotor and neuromuscular diagnoses. Among the 4 other studies that specifically noted inclusion of caregivers of children

with BPBI in their samples (Galil et al., 2001; Lillo-Navarro et al., 2015, 2019; Medina-Mirapeix et al., 2017), 3 of the 4 noted the importance of efficacy of caregiver education and facilitating self-efficacy and confidence among caregivers as facilitators of adherence. These factors might be particularly important for caregivers of children with BPBI in which home therapy programs typically begin within the first few weeks of life and require caregivers to perform PROM on their child's injured arm, a proposition that likely seems scary to caregivers after what is often a traumatic birth.

Limitations

This study is limited by the small number of articles that met the inclusion criteria. The decision to exclude articles that did not include caregivers of children with neuromotor and neuromuscular diagnoses limited the number of articles reviewed; however, it was important because the types of home therapy recommendations for children with other diagnoses, such as cystic fibrosis or sensory processing disorders, are unlikely to resemble the recommendations for children with motor impairments. Similarly, the implications for adherence to a medical-based regimen, such as insulin management for a child with Type 1 diabetes, can be the difference between life and death; thus, factors affecting adherence are likely to be different. Although 7 of the 12 studies used samples that included caregivers of children both with and without neuromotor and neuromuscular diagnoses, the sample sizes in 6 of the 7 ranged from 100 to 538; therefore, the findings should be generalizable to our intended population. However, the generalizability of the findings might be limited by differences in cultural and contextual factors because the studies we reviewed were conducted in seven different and varying countries, with 4 in North America, 5 in Europe, 2 in the Middle East, and 1 in India.

The generalizability of our findings might also be limited by the variety of ages of the children included in the studies that we reviewed, although none of the studies noted the child's age as a factor affecting caregiver adherence. Variability in the home therapy recommendations, such as frequency or duration, might also affect the generalizability, although these factors were not identified as facilitators or barriers in our thematic analysis. Thematic analysis as a qualitative methodology limits the ability to interpret data because it does not account for relationships among multiple variables and can lead to incomplete or inaccurate conclusions. Finally, although we identified facilitators and barriers from the 12 studies that were included, we did not evaluate the rigor of the included studies, so our results should be considered cautiously.

Future Research

The results of this scoping review indicate several gaps that should be addressed in future research. Although our primary population of interest was infants and children with BPBI, only 1 of the 12 studies directly addressed this population; because home therapy programs are an integral part of therapeutic management to improve functional outcomes for infants and children with BPBI, additional studies are needed to identify facilitators of and barriers to adherence for caregivers of these children. In future studies, researchers should examine how home therapy programs are developed, taught, and supported.

Another gap that was uncovered in this scoping review was the paucity of research on caregiver adherence to home therapy recommendations for caregivers of children with neuromotor and neuromuscular disorders in the occupational therapy literature. Whereas 5 of the 12 studies we reviewed noted inclusion of an occupational therapy practitioner in developing or prescribing the home therapy programs, only 2 studies had at least one author who was an occupational therapy practitioner (Gmmash et al., 2021; Murphy et al., 2012). Moreover, although the study by Jeevannavar et al. (2018) was published in the *Indian Journal of Physiotherapy and Occupational Therapy,* none of the authors were occupational therapy practitioners. Home therapy programs are used in all areas of occupational therapy practice, so research is needed to ensure that occupational therapy practitioners are providing therapy recommendations that facilitate adherence for all populations. Because the transactional relationship among people with their routines and context is a foundational tenet of best practice in occupational therapy (American Occupational Therapy Association, 2020), occupational therapy practitioners are uniquely qualified to understand and evaluate individual contexts to develop home therapy programs that best support the relationship among person, environment, and occupation to facilitate participation.

Implications for Occupational Therapy Practice

In addition to the future occupational therapy research noted earlier, this scoping review has implications for occupational therapy practice in general and for practice with infants and children with neuromotor and neuromuscular disorders. Occupational therapy practitioners who recommend home therapy programs should consider the facilitators and barriers identified here to support client adherence. Home occupational therapy programs should be designed to fit within the child's and family's routine, be taught in a way that meets the child's and family's learning needs, facilitate self-efficacy and confidence, and reflect the values and motivators of all participants. These facilitators all rely on the effective therapeutic use of self to develop a positive and successful rapport and should serve to decrease the common barriers of lack of time, lack of self-efficacy, and overall stress.

To maximize functional outcomes for children with neuromotor and neuromuscular diagnoses, occupational therapy practitioners can use their expertise in analyzing and understanding routines and context to maximize the fit between the needs of a family and recommendations for daily home therapy programs. Occupational therapy practitioners are uniquely qualified to develop intervention plans that fit into a family's routines while considering the family context to reduce potential barriers to complying with demanding or time-consuming home therapy recommendations.

Conclusion

The purpose of this scoping review was to identify the factors that facilitate or are barriers to adherence to home therapy recommendations for infants and children with neuromotor and neuromuscular disorders. We identified four themes related to facilitators: fitting the home therapy into the caregiver's or family's routine, efficacy of caregiver education, having a positive relationship with therapist, and the caregiver's perceived benefit or value of treatment. We also identified three themes related to barriers: lack of time, lack of confidence, and caregiver stress. These facilitators and barriers are all areas that are central to best practice in occupational therapy. However, although home therapy recommendations are a commonly used modality in pediatric occupational therapy practice, our results reveal minimal research in the occupational therapy literature addressing adherence by caregivers of children with neuromotor and neuromuscular diagnoses. On the basis of our findings, more occupational therapy–based research is needed because occupational therapy practitioners are uniquely qualified to create home therapy recommendations that consider and support the relationship among person, environment, and occupation to facilitate participation with the ultimate goal of improving functional outcomes.

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