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SARGENT COLLEGE OF HEALTH AND REHABILITATION SCIENCES

Doctoral Project

THE CAREGIVER RESILIENCE EDUCATION (Ca.R.E.) PROGRAM

by

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Submitted in partial fulfillment of the

requirements for the degree of

Doctor of Occupational Therapy

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DEDICATION

I dedicate this work, first and foremost, to God, who used this endeavor to strengthen my faith and raise me up to stand on mountains. Second, I dedicate this to my parents and brother, my pillars of strength and biggest supporters. Finally, I dedicate this to the team and caregivers of the Handimachal Therapy Center in Kullu. Thank you for inspiring the Ca.R.E. program.

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THE CAREGIVER RESILIENCE EDUCATION (CA.R.E.) PROGRAM

GRACE ELIZABETH MUPPIDI

Boston University, Sargent College of Health and Rehabilitation Sciences, 2023

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ABSTRACT

Caregivers' involvement in therapy is integral to the child's engagement in therapy and their occupational performance outcomes (D'Arrigo et al., 2020b). Access to cost-effective, culturally relevant educational programs for caregivers of children with disability, who are oftentimes burdened with anxiety and stress due to society's stigma, are limited in low-income and -resource settings like rural India (Angelin et al., 2021). Also compounding the problem are caregiver personal factors, environmental and contextual factors, and health care system factors (Brassart et al., 2017; Vadivelan et al., 2020). Caregiver Resilience Education (Ca.R.E.) is a group-based program comprising five modules that include approaches such as role-modeling, coaching, group discussions, collaborative goal-setting, and therapist modeling. The Ca.R.E. program culminates in the demonstration and formation of a caregiver support group to be facilitated by an occupational therapy practitioner. The mission of the Ca.R.E. program is to improve caregiver engagement and self-efficacy. Through the Ca.R.E. program, the author envisions empowered caregivers coming together to advocate for their children and themselves to combat occupational injustice in a community with the odds stacked against them.

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LIST OF ABBREVIATIONS

AIOTA .... All-India Occupational Therapy Association

AOTA .... American Occupational Therapy Association

Ca.R.E. ....Caregiver Resilience Education (program)

CINAHL .... Cumulative Index of Nursing and Allied Health Literature

Cog-Fun .... cognitive-functional

CSR .... corporate social responsibility

CHAPTER ONE – Introduction

Problem Definition and Outcomes

Occupational therapy is a constantly evolving evidence-based profession, and the tenet of bridging gaps to enhance the quality of life of the clients they serve is particularly inspiring. Due to growing workforce demand, occupational therapy practitioners often manage multiple roles. In a developing country like India, where the client–professional ratio is high, it is difficult or impossible to provide therapy and training one-to-one or daily (Kurani et al., 2009). For example, the author previously worked in rural India, where the occupational therapist: child ratio is 1:55, leaving the occupational therapist treating 10 to11 children per day. This high caseload and lack of ability to provide one-to-one intervention laid a foundation for inviting caregivers' engagement, education, and motivation to participate in their children's occupational therapy services a.

Caregiver involvement and engagement are essential to building advocacy skills. Increasing knowledge is vital for caregivers to be more involved in their child's occupational therapy at the clinic and home (Gafni-Lachter & Jacobs, 2015). Research has shown that caregivers' participation in their child's therapy can improve communication with the occupational therapist, a better understanding of their child's diagnosis, and information to support self-decision-making (Lin et al., 2018). Families and caregivers of children with disabilities are an essential support system, and their active involvement potentially lays the foundation for their children's inclusion in society (Adithyan et al., 2017). Helping caregivers of children with disabilities move from passive observers to more key, active, equal partners in the early intervention process is

vital to consider (Harrison et al., 2007; World Health Organization, 2012).

The intended outcome of this doctoral project is to develop and create an evidence-based, affordable, and effective group education program for caregivers that encourages active engagement in their children's occupational therapy sessions. This program aims to improve caregivers' self-determination, motivating higher caregiver engagement (D'Arrigio et al., 2017).

Problem Scope and Consequences to Clients

There is a lack of evidence on the best ways to support caregivers of children with disabilities, especially in limited resource settings (Smythe et al., 2020). Children with disabilities living in low and middle-income counties are one of the most marginalized groups in the world (UNICEF, 2020). In low and middle-income countries with the complicated legacy of colonialism, the exclusion of children with disabilities is prominent (Rahman et al., 2018). Rural India, which is the setting where the author previously worked, is a classic example of an environment with infrastructural barriers, lack of government funding, cultural stigma, low income, and low resources (Janardhana et al., 2015). This provides an opportunity to view the problem and try to bridge the gap through the lens of occupational injustice (Rabaey et al., 2021). An essential step toward filling that gap could be encouraging caregiver engagement and involvement as active partners in their children's occupational therapy process. There is also a need for occupational therapy practitioners to move from child-centered care to family-centered care (World Health Organization, 2012). Families are socio-culturally diverse units. Each family needs to consider their differences to understand the optimum style of learning,

communication, and support required by practitioners (Edwards et al., 2003). This could empower and motivate them to be actively engaged.

Caregiver engagement is crucial for caregiver-mediated interventions' effectiveness. *Caregiver engagement* can be broadly defined as involvement in treatment and behaviors that promote their children's participation in treatment (Haine-Schlagel et al., 2020). While caregiver engagement is essential, community-based practitioners may need more training, time, or resources to focus on developing engagement in their child's therapy programming. Along with the stressors faced by caregivers, practitioners report limited frequency and confidence in working with caregivers, revealing a disconnect between recommended practices and implementation (Sawyer & Campbell, 2012). Occupational therapy practitioners need to identify the barriers leading to the lack of engagement of caregivers and overcome them, using evidence-based strategies in their treatment approach.

The engagement of caregivers in their child's occupational therapy at the clinic, home, and school can be viewed through the Occupational Therapy Practice Framework 4th edition (American Occupational Therapy Association, 2020) as the dynamic relationship between domains: context, environments, and occupation. Several environmental and contextual factors influence caregiver participation, involvement, and engagement as an occupation.

Factors Contributing to This Problem

Factors contributing to the lack of caregiver involvement and engagement are specific to the environment and context. The factors identified based on a review of the literature are listed below:

Personal Factors

- Help-seeking attitudes, cultural expectations, lack of knowledge and awareness, lack of familial support, and lack of confidence (Edwards et al., 2003; Lin et al., 2018; Tully et al., 2017; Vadivelan et al., 2020).

Environmental and Contextual Factors

- Lack of accessibility and resources, social stigma, discrimination, unfavorable work environments, and timings (Edwards et al., 2003; Stargel et al., 2020; Vadivelan et al., 2020).

Therapist Factors

- Lack of cultural sensitivity and lack of parent/caregiver-therapist collaboration (Brassart et al., 2017; Edwards et al., 2003).

Proposal to Address the Problem

The intervention proposed to address the problem identified in this doctoral project is to create an evidence-based, cost-effective, and accessible caregiver education program. Initially, the program is intended to meet the needs of caregivers and children of India with the long-term goal of making it globally relevant. This includes the following steps: identifying existing approaches and programs and studying their core principles to create a culturally sensitive and appropriate program, deciding on a mode of

dissemination (virtual or in-person), determining a source of funding, and evaluating the program using appropriate outcome measures. The education program aims to encourage and improve caregiver engagement, involvement, and self-determination. The education program will be designed with sociocultural, linguistic, educational, and other contextual factors in mind, hoping to expand its dissemination to a global audience.

CHAPTER TWO – Project Theoretical and Evidence Base

Overview of the Problem

There is a rise in awareness of occupational therapy and other rehabilitation therapies (i.e., physical therapy, speech therapy, behavioral therapy) throughout India's rural, low-income, and -economic regions. This increases the demand for occupational therapists, leading to a high caseload ratio. A scoping review shows that pediatric occupational therapists face stressors such as high caseload, excessive administrative tasks, lack of time, constant interruptions, etcetera (Goffredo et al., 2022). With a stunning lack of education regarding the benefits of caregiver engagement and self-efficacy among caregivers and occupational therapists, this poses a bigger problem. In the explanatory model below, three major factors contribute to the lack of caregiver engagement and self-efficacy. These are personal caregiver, environmental, contextual, and therapist-related factors. Due to insufficient evidence from the Indian population, the factors listed are based on research from other countries.

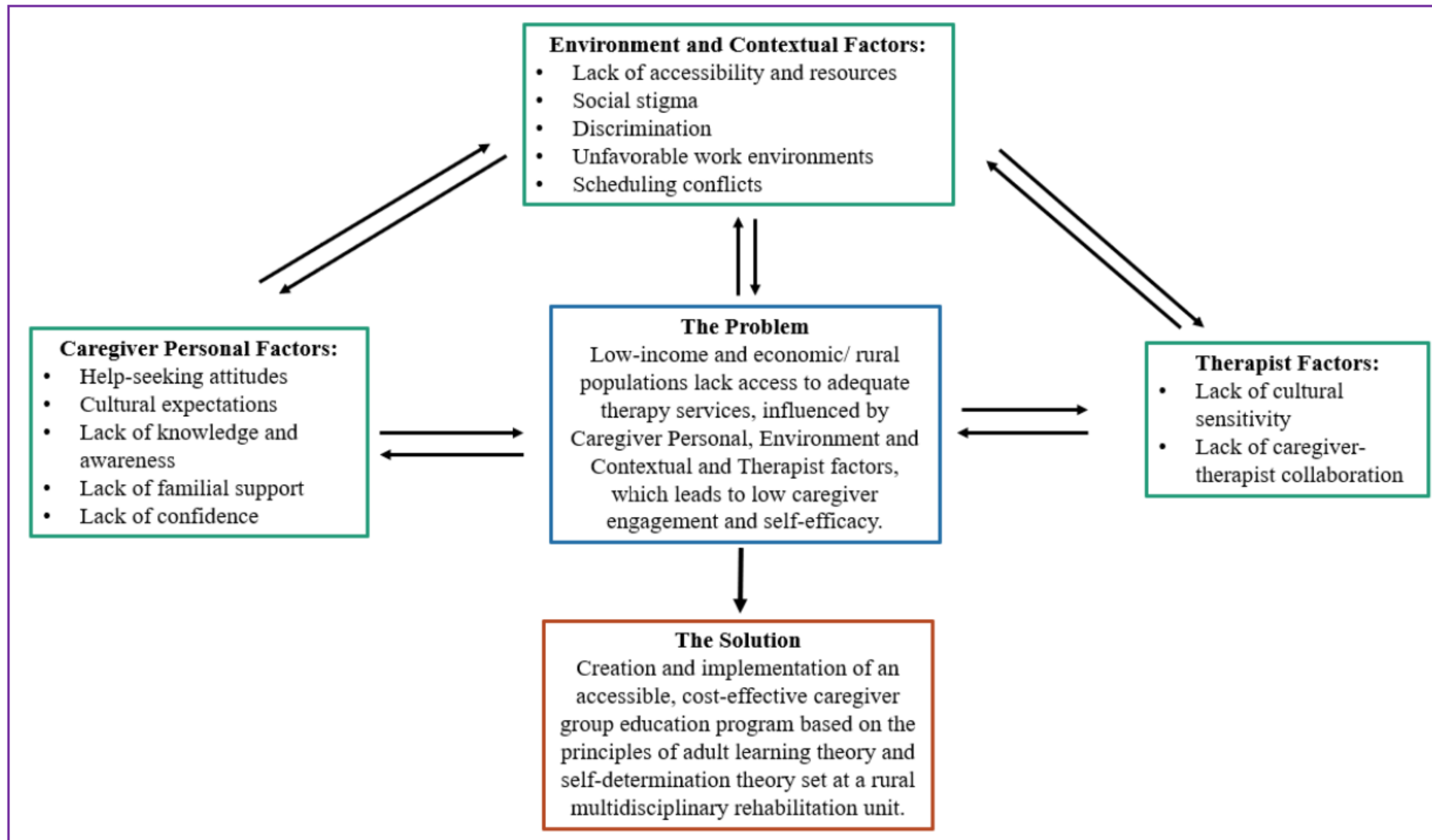
Personal factors of the caregiver contribute to the problem, such as lack of knowledge and awareness, low levels of confidence, help-seeking behavior, cultural expectations, as well as lack of familial support (Edwards et al., 2003; Lin et al., 2018; Tully et al., 2017; Vadivelan et al., 2020). Environmental and contextual factors include lack of access to public and private transportation options, rough terrain/geography, social stigma, discrimination, scheduling conflicts, and unfavorable workplace environments (Edwards et al., 2003; Stargel et al., 2020; Vadivelan et al., 2020). The practitioners can compound these issues due to a lack of cultural sensitivity and limited

caregiver-therapist collaboration (Brassart et al., 2017; Edwards et al., 2003).

The proposed solution is to create and implement an accessible and cost-effective group education program for caregivers of children with disabilities living in and receiving therapies in India's rural, low-income, and -economic regions. The education program will be based on the principles of self-determination theory, social cognitive theory, and adult learning theory. The Caregiver Resilience Education program aims to improve caregiver self-efficacy and engagement in therapy services. Figure 2.1 depicts the initial explanatory model.

Figure 2.1

Initial Explanatory Visual Model Depicting the Factors Contributing to a Lack of Caregiver Engagement



Theoretical and Evidence Base for the Problem

The theoretical basis behind the explanatory model of the problem is supported by self-determination theory (Deci & Ryan, 2000), social cognitive theory (Bandura, 1986), and adult learning theory (Knowles, 1984). Engagement is essential to efficient service delivery for therapists working with children, adolescents, and youth. It is an internal state influenced by internal and contextual factors. Self-determination theory explores that people's motivation requires a consideration of innate psychological needs such as autonomy, relatedness, and competence. When combined as a support, the three principles of autonomy, relatedness, and competence provide a foundation for engagement components: affective, behavioral, and cognitive (D'Arrigio et al., 2017). The author intends to apply the three principles and the components of engagement to the education program content in order to improve self-determination, efficacy, and caregiver engagement.

Social cognitive theory (Bandura, 1986) plays a role in adopting, initiating, and maintaining health behaviors (Luszczynska & Schwarzer, 2005). Engagement in therapy services is considered a behavior of health for children and their caregivers. This theory states that an individual's behavior influences three factors that affect each other: sociocultural norms, cognitive, and actions of the individual (Zhou & Fan, 2019). When influenced by sociocultural facilitators, barriers, and outcome expectations, this theory states that self-efficacy leads to goal-setting and behavior change (Luszczynska & Schwarzer, 2005). These factors influence caregiver engagement, as depicted in the explanatory models. Caregiver self-efficacy is the confidence and capability caregivers

carry into collaborative goal-setting, involvement, and engagement in therapy sessions. The author reviews the factors contributing to the problem of low caregiver engagement and self-efficacy through the lens of social cognitive theory.

Engagement in their children's therapies, regardless of discipline (i.e., occupational therapy, physical therapy, speech therapy, behavioral therapy), requires a degree of new learning and acceptance on behalf of the caregivers. Working with and teaching adults (in this case, caregivers) requires a different approach than working with and teaching children. The author will apply the principles of adult learning theory, such as active participation, group interaction, goal-oriented learning, autonomous and self-directed learning, and relevant practical approaches (Knowles, 1984), to the education program. These three theories provide a foundation for understanding the facilitators, barriers, and motivators for caregiver engagement in occupational therapy.

Evidence Bases for the Problem

Occupational therapy is an inspiring profession, with the unique ability to merge client-centered care with evidence-based practice to bridge the gaps between what clients receive and deserve. There is a growing awareness of the profession's capacity throughout developing low-income and economic countries like India. This awareness leads to a growth in the demand for occupational therapy practitioners. Due to this demand, the practitioner-to-caseload ratio is high, especially in rural areas with few rehabilitation-equipped centers or hospitals. There is a need for caregivers of children with disabilities to bridge the gap and ensure their children receive the therapeutic services necessary to succeed. Helping caregivers of children with disabilities move from

passive observers to more key, active, equal partners in the early intervention process is essential to consider (Kurani et al., 2009; World Health Organization, 2012). Active engagement of caregivers is an essential component of effective intervention (Angelin et al., 2021). Caregiver engagement and involvement increase the child's participation in daily routines (Shoen et al., 2019). Caregiver engagement and participation in occupational therapy interventions help improve the quality of children's learning, improve parent-child interactions, improve developmental and functional skills children's gross motor, fine motor, and social skill development, and establish a communication bridge between caregivers and professional therapists, proving knowledge and facilitating decision-making (Lin et al., 2018).

Literature Search Strategy

Many factors can impact caregiver engagement. The author searched the literature using CINAHL, APA PsycInfo, Embase, and PubMed to identify these factors. The terms used for the search were caregiver OR parental involvement OR parent engagement OR parent participation AND occupational therapy OR occupational therapist AND children. Criteria for selection included peer-reviewed articles published after 2010 and published in English. This search revealed about forty-five related articles, of which, after critical analysis, twenty-five are included in this review. Due to the dearth of evidence from India, the author included research articles from other countries.

Five of the twenty-five articles pertain to education and school settings. The remainder pertains to studies in developed and developing countries' rehabilitation therapies, occupational therapy, and health care settings.

Literature Search Questions

1. Is there evidence that a lack of caregiver engagement and self-efficacy contributes to the deterioration of children with disabilities' well-being?
2. Is there evidence that sociocultural, personal, and therapist factors influence caregiver engagement in their children's therapies?
3. Is there evidence that caregivers of children with disabilities have limited access to occupational therapy/rehabilitation services or education programs?

Based on the research questions and literature search, the author synthesized the results of the following findings.

Synthesis #1: Evidence of Lack of Caregiver Self-Efficacy and Caregiver Engagement

Identifying Information

Individual generated by the writer.

Clinical Question

Is there evidence that a lack of caregiver engagement and self-efficacy contributes to the deterioration of children with disabilities' health and well-being?

Summary of the Evidence Base

The author searched the literature using CINAHL, APA PsycInfo, Embase, and PubMed to identify these factors. The terms used for the search were caregiver OR parental involvement OR parent engagement OR parent participation AND occupational therapy OR occupational therapist AND children. Criteria for selection included peer-reviewed articles published after 2010 and in English.

Clinical Bottom Line

Lack of Caregiver Engagement. There has been a shift from the traditional medical model to a more client and family-centered approach. In comparison, this has been accepted widely in Western contexts, yet developing countries that follow Eastern philosophy find it challenging to adopt. This shift requires active participation unaligned with traditional cultural roles, where caregivers follow whatever health care professionals say (An, 2017). Caregiver involvement has improved children's independence and caregiver's confidence and knowledge (Schoen et al., 2019). In developing countries like India, mothers are the primary caregivers of children with disabilities, are not allowed to have a say in decision-making, and are often blamed for their child's condition (Angelin et al., 2021). Without proper familial or therapist support, caregivers lose motivation to care for their children beyond their basic needs, leaving them unattended throughout the day, causing greater dependency, higher self-stimulatory behavior, poor social skills, low sitting endurance, poor posture, and decreased interpersonal interactions (Kurani et al., 2009). Often caregivers must also navigate multiple responsibilities inside and outside the house, leading to stress, reducing the willingness to participate in interventions, thus causing negative impacts on the children (Lin et al., 2018). Lack of caregiver involvement leads to a decrease in the autonomous behaviors of children, compounding into reduced engagement in social situations and with peers (Pereira et al., 2016).

Parents are critical facilitators of their children's social skills. A lack of involvement due to negative parenting practices and child symptom severity can contribute to poor social skills in children (Wilkes-Gillan et al., 2016). Interventions will

have limited benefits and impact if they fail to effectively engage the target population: caregivers of children with disabilities (Hackworth et al., 2018). The benefits of the treatment program need to outweigh the costs for caregivers to choose to be more engaged (D'Arrigo et al., 2020a).

Lack of Caregiver Self-Efficacy. Caregiver self-efficacy can be heavily influenced by the child's health status, leading caregivers of children with disabilities at risk for low self-efficacy. Caregivers who are more involved in promoting their child's development have higher levels of self-efficacy (Avrech et al., 2016). Community-based early intervention providers may lack the training and expertise to involve and engage caregivers effectively, leading to caregivers' decreased sense of competence and self-efficacy (Haine-Schlagel et al., 2020). Parents' sense of competence or self-efficacy can significantly improve children's independence (Lin et al., 2018).

Caregivers with higher levels of self-efficacy show more acceptance and warmth toward their children, which leads to a sense of satisfaction for the children, as opposed to lower self-efficacy. Higher caregiver self-efficacy has a rippling effect (Soref et al., 2012). Higher caregiver self-efficacy leads to more children participating in daily activities, which leads to higher caregiver satisfaction. Conversely, low self-efficacy and social support can snowball into depression and stress for the caregivers and less than optimal care for their children (Vadivelan et al., 2020).

Synthesis #2: Evidence of Factors Influencing Caregiver Engagement

Identifying Information

Individual generated by the writer.

Clinical Question

Is there evidence that sociocultural, personal, and therapist factors influence caregiver engagement in their children's therapies?

Summary of the Evidence Base

The author searched the literature using CINAHL, APA PsycInfo, Embase, and PubMed to identify these factors. The terms used for the search were caregiver OR parental involvement OR parent engagement OR parent participation AND occupational therapy OR occupational therapist AND children. Criteria for selection included peer-reviewed articles published after 2010 and in English.

Clinical Bottom Line

There are numerous factors contributing to caregiver engagement in their children's therapies. Based on the review of the literature, the author organized the factors into three main categories: (a) personal caregiver factors, (b) environment and contextual factors, and (c) therapist and health care factors. These factors act as both barriers and facilitators to caregiver engagement.

Personal Caregiver Factors. The literature search revealed that personal caregiver factors are the most reported barriers to caregiver engagement. Caregivers who are immigrants or whose native language is not English struggle to build and foster therapeutic relationships with their child's clinicians due to the language barrier (Al Khateeb et al., 2015; Brassart et al., 2017; Hackworth et al., 2018). These culturally diverse families represent the minority population and find opposing or differences in cultural beliefs surrounding disability a barrier (Al Khateeb et al., 2015; Angelin et al.,

2021; Brassart et al., 2017). They also face social stigma and discrimination in the community (Janardhana et al., 2015; Vadivelan et al., 2020). Eastern traditional practices still follow the medical model, wherein the caregiver follows the practitioner's instructions without collaborative input. This leads to a lack of knowledge regarding the caregiver's right to decide on their child's health and treatment (Al Khateeb et al., 2015; An, 2017; Angelin et al., 2021; Brassart et al., 2017; Pitt et al., 2013).

Caregivers often balance multiple roles (Brassart et al., 2017; Lin et al., 2018; Stargel et al., 2020; Wilkes-Gillan et al., 2016; Vadivelan et al., 2020). Juggling multiple roles can lead to scheduling conflicts and time constraints to be engaged with their children's therapies (Bramesfeld et al., 2013; Hackworth et al., 2018; Shepherd et al., 2018; Stargel et al., 2020; Vadivelan et al., 2020). If not balanced well, work commitments or other priorities can take up the caregivers' energy and focus (Bramesfeld et al., 2013; Hackworth et al., 2018; Lin et al., 2018; Tully et al., 2017; Stargel et al., 2020; Van Niekerk & Ismail, 2013). Families with multiple children leads to a division of attention and care (Al Khateeb et al., 2015; Lin et al., 2018; Vadivelan et al., 2020; Van Niekerk & Ismail, 2013; Wilkes-Gillan et al., 2016). Financial constraints also add to caregiver burden (Bramesfeld et al., 2013; D'Arrigo et al., 2020a; Shepherd et al., 2018; Vadivelan et al., 2020; Van Niekerk & Ismail, 2013). Due to multiple stressors, and lack of familial support, caregivers often face domestic issues and struggle with dysfunctional family dynamics (D'Arrigo et al., 2020a; Vadivelan et al., 2020; Van Niekerk & Ismail, 2013).

Literature has shown that parent-child relationships and parenting styles impact caregiver engagement (Pereira et al., 2016; Van Niekerk & Ismail, 2013; Wilkes-Gillan et al., 2016). Depending on the caregiver's education levels (Angelin et al., 2021; Pitt et al., 2013), they may have a lack of knowledge regarding the child's diagnoses and possible treatments (Bramesfeld et al., 2013; Brassart et al., 2017; Solish & Perry, 2008; Solish et al., 2015; Tully et al., 2017; Vadivelan et al., 2020). This can lead to a lack of caregiver self-efficacy and confidence (Angelin et al., 2021; Avrech et al., 2016; Schoen et al., 2019; Solish & Perry, 2008; Solish et al., 2015; Soref et al., 2012; Wilkes-Gillan et al., 2016). Research also indicates that to be engaged and involved, caregivers must believe in the intervention their children receive (Solish & Perry, 2008; Solish et al., 2015).

Environment and Contextual Factors. Developing countries are beginning to understand the importance of implementing rehabilitation models in various settings. However, resources are significantly lacking (Pitt et al., 2013). Government funding is insufficient to maintain rehabilitation centers (Shepherd et al., 2018; Vadivelan et al., 2020). Families living in remote areas cannot access the few established rehabilitation centers (Brassart et al., 2017; Shepherd et al., 2018; Teleman et al., 2021; Vadivelan et al., 2020). Limited transportation options, coupled with geographic distance and travel time, add on to the difficulties faced by caregivers (D'Arrigo et al., 2020a; Vadivelan et al., 2020; Van Niekerk & Ismail, 2013).

There are a higher number of adult-centered rehabilitation centers than for the pediatric population (Teleman et al., 2021). Sometimes, health insurance does not offer

coverage for adolescents with disabilities after a certain age (Shepherd et al., 2018). There are also limited caregiver support groups, which would help caregivers build peer relationships and gain the motivation to engage in their children's therapies (Al Khateeb et al., 2015; Vadivelan et al., 2020). All these deficiencies in the health care system lead to the need to support caregiver engagement.

Practitioner and Health Care Factors. Caregivers of children with disabilities from diverse cultural backgrounds face a lack of cultural sensitivity from practitioners and the health care team (Al Khateeb et al., 2015; Brassart et al., 2017; D'Arrigo et al., 2020a). In remote areas with limited access to health care, there need to be more human resources like qualified practitioners (Pitt et al., 2013). Caregivers who are balancing multiple roles often find that health care systems need to be more flexible to suit their needs for scheduling and emergencies (Brassart et al., 2017). A lack of communication and collaborative efforts from the therapists toward the caregivers leads to further resistance to caregiver engagement (An, 2017; Bramesfeld et al., 2013; D'Arrigo et al., 2020a; Haine-Schlagel et al., 2020; Tully et al., 2017; Van Niekerk & Ismail, 2013; Willoughby et al., 2019). Clinicians and practitioners who do not communicate effectively with each other also contribute to the problem (Willoughby et al., 2019).

The factors listed above have been shown in the literature to contribute to the barriers and facilitators of caregiver engagement. Authors of these studies have attempted to identify these factors and provided a foundation for future researchers, educators, and occupational therapists to consider these factors when developing their caregiver education program. The factors have been summarized in Table 2.1.

Table 2.1

Review of the Literature on Factors Contributing to Caregiver Engagement

Factor	Evidence from the literature
Personal caregiver	• English language proficiency or language vulnerability (Al Khateeb et al., 2015; Brassart et al., 2017; Hackworth et al., 2018) • Cultural barriers and beliefs about disability (Al Khateeb et al., 2015; Angelin et al., 2021; Brassart et al., 2017) • Lack of knowledge of caregiver's right to make decisions regarding their child's treatment (Al Khateeb et al., 2015; An, 2017; Angelin et al., 2021; Brassart et al., 2017; Pitt et al., 2013) • Balancing multiple roles (Brassart et al., 2017; Lin et al., 2018; Stargel et al., 2020; Vadivelan et al., 2020; Wilkes-Gillan et al., 2016) • Other children at home require caregiver presence and attention (Al Khateeb et al., 2015; Lin et al., 2018; Vadivelan et al., 2020; Van Niekerk & Ismail, 2013; Wilkes-Gillan et al., 2016) • Parenting style and parent-child relationships (Pereira et al., 2016; Van Niekerk & Ismail, 2013; Wilkes-Gillan et al., 2016) • Domestic issues and family dynamics (D'Arrigo et al., 2020a; Vadivelan et al., 2020; Van Niekerk & Ismail, 2013) • Social stigma and discrimination (Janardhana et al., 2015; Vadivelan et al., 2020) • Self-efficacy and confidence levels (Angelin et al., 2021; Avrech et al., 2016; Schoen et al., 2019; Solish & Perry, 2008; Solish et al., 2015; Soref et al., 2012; Wilkes-Gillan et al., 2016) • Knowledge about the diagnosis and intervention (Bramesfeld et al., 2013; Brassart et al., 2017; Solish & Perry, 2008; Solish et al., 2015; Tully et al., 2017; Vadivelan et al., 2020) • Education levels (Angelin et al., 2021; Pitt et al., 2013) • Belief in the intervention (Solish & Perry, 2008; Solish et al., 2015) • Time constraints (Bramesfeld et al., 2013; Hackworth et al., 2018; Shepherd et al., 2018) • Financial situation (Bramesfeld et al., 2013; D'Arrigo et al., 2020a; Shepherd et al., 2018; Vadivelan et al., 2020; Van Niekerk & Ismail, 2013) • Scheduling issues (Stargel et al., 2020; Vadivelan et al., 2020) • Work commitments and other priorities (Bramesfeld et al., 2013; Hackworth et al., 2018; Lin et al., 2018; Stargel et al., 2020; Tully et al., 2017; Van Niekerk & Ismail, 2013)
Environmental/ contextual	• Resource limitation (Pitt et al., 2013) • Limited access to rehabilitation facilities (Brassart et al., 2017; Shepherd et al., 2018; Teleman et al., 2021; Vadivelan et al., 2020) • Health care insurance coverage is not offered after a certain age (Shepherd et al., 2018)

	• Lack of government funding (Shepherd et al., 2018; Vadivelan et al., 2020) • More adult-centered rehabilitation versus pediatric rehabilitation (Teleman et al., 2021) • Limited access to accessible transportation and transportation time (D'Arrigo et al., 2020a; Vadivelan et al., 2020; Van Niekerk & Ismail, 2013) • Lack of caregiver support groups (Al Khateeb et al., 2015; Vadivelan et al., 2020)
Therapist/ health care	• Cultural sensitivity (Al Khateeb et al., 2015; Brassart et al., 2017; D'Arrigo et al., 2020a) • Lack of flexibility in the health care system (Brassart et al., 2017) • Human resource limitation (Pitt et al., 2013) • Lack of therapist-caregiver collaboration and communication (An, 2017; Bramesfeld et al., 2013; D'Arrigo et al., 2020a; Haine-Schlagel et al., 2020; Tully et al., 2017; Van Niekerk & Ismail, 2013; Willoughby et al., 2019) • Lack of communication between clinicians (Willoughby et al., 2019) • Lack of trust in therapists' skills (Brassart et al., 2017; Teleman et al., 2021; Tully et al., 2017)

Synthesis #3: Evidence of Limited Access

Identifying Information

Individual generated by the writer

Clinical Question

Is there evidence that caregivers of children with disabilities have limited access to occupational therapy/rehabilitation services or education programs?

Summary of the Evidence Base

The author searched the literature using CINAHL, APA PsycInfo, Embase, and PubMed to identify these factors. The terms used for the search were *caregiver* OR *parental involvement* OR *parent engagement* OR *parent participation* AND *occupational therapy* OR *occupational therapist* AND *children*. Criteria for selection included peer-reviewed articles published after 2010 and in English.

Clinical Bottom Line

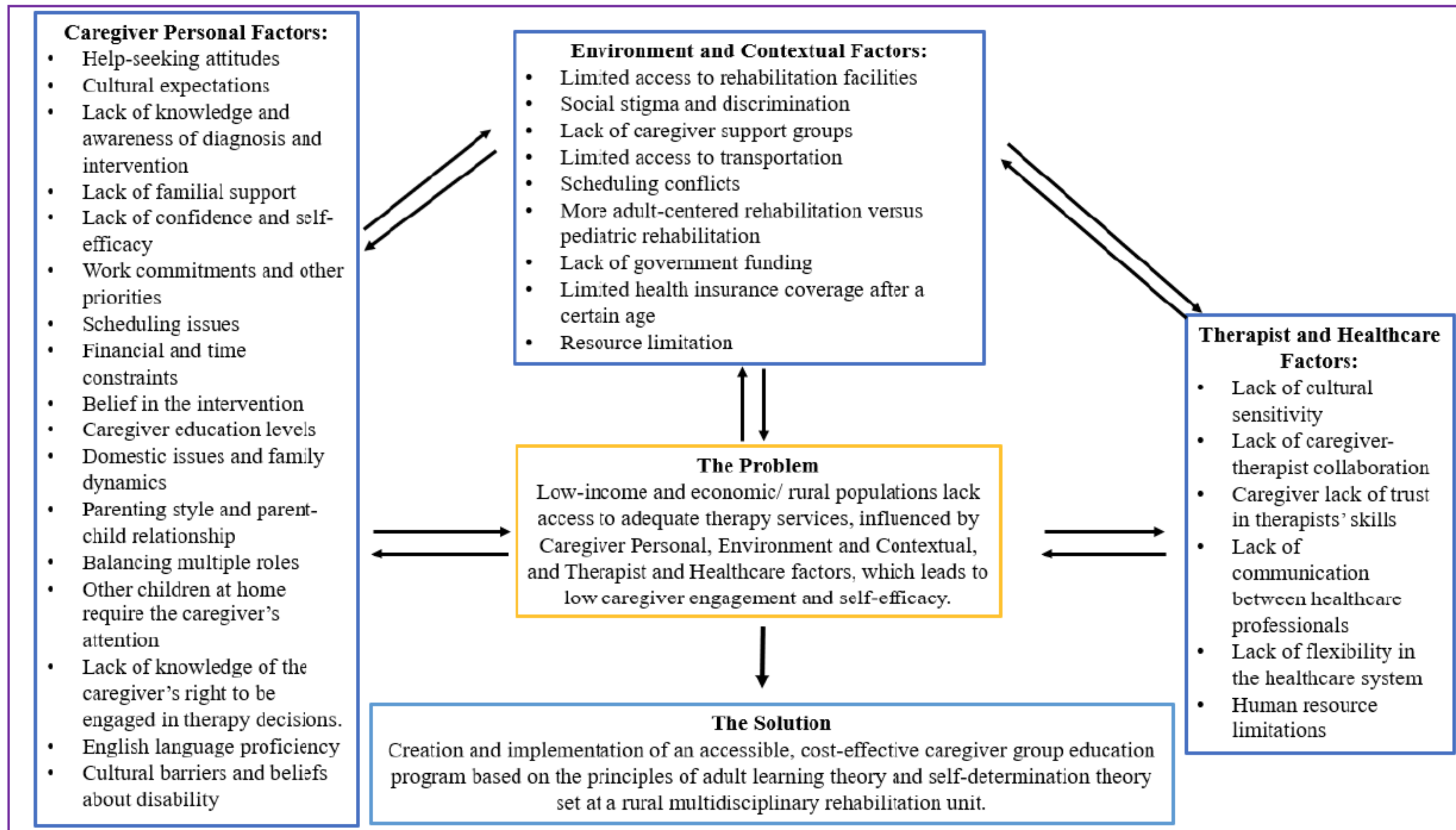
Parent support groups, caregiver education and training programs, and family-centered practice settings are essential to providing caregivers with the knowledge and tools they require to raise children with disabilities (An, 2017). However, such programs are limited in developing countries like South Korea, India, and South Africa or remote areas of countries like New Zealand and Australia (An, 2017; Angelin et al., 2021; Janardhana et al., 2015; Lin et al., 2018; Pitt et al., 2013; Shepherd et al., 2018). Even in developed Western countries like the United States, there is a lack of culturally sensitive intervention programs for caregivers of children with disabilities from minority groups and immigrant populations that consider language and communication barriers (Al Khateeb et al., 2015; Brassart et al., 2017; Hackworth et al., 2018). Despite improving health care systems in developing countries like India, the lack of access to proper rehabilitation centers for people living in rural, remote, and low socioeconomic areas continues (Janardhana et al., 2015; Hackworth et al., 2018). While some countries' health care systems expand their reach by establishing more rehabilitation centers in rural areas, quality remains an issue due to a lack of infrastructure, space, and human resources (Pitt et al., 2013). There is limited access to transportation for many to reach these rehabilitation centers (Hackworth et al., 2018; Pitt et al., 2013; Shepherd et al., 2018; Teleman et al., 2021), and adult-centered rehabilitation services are concentrated, leaving limited access and availability for the pediatric population (Teleman et al., 2021).

Revised Visual Model

After reviewing the literature, some additions were made to the visual explanatory model. First, numerous factors were added to personal caregiver factors based on the literature reviewed. For example, the addition of financial and time constraints, parenting styles, scheduling issues, and family dynamics. Second, factors were added to the second category, environment and contextual, such as more adult rehabilitation centers than pediatric ones and transportation frequency. Finally, more factors were added to the therapist and health care category. All three categories of factors influence one another and contribute to the problem: a lack of caregiver engagement and self-efficacy.
Figure 2.2 depicts the revised model with these additional factors.

Figure 2.2

Revised Visual Model With Additional Factors



Conclusion

Caregiver engagement is essential for children's independence, development, and caregiver confidence and knowledge (Schoen et al., 2019). There is sufficient evidence that a lack of caregiver engagement and self-efficacy contributes to the deterioration of children with disabilities' well-being. Based on the literature review of factors contributing to the lack of caregiver engagement, low self-efficacy is among them (Angelin et al., 2021; Avrech et al., 2016; Schoen et al., 2019; Solish & Perry, 2008; Solish et al., 2015; Soref et al., 2012; Wilkes-Gillan et al., 2016). Low caregiver self-efficacy can lead to stress and depression in caregivers, leading to sub-optimal care for their children (Vadivelan et al., 2020).

Numerous factors influence caregiver engagement. There is an overlap between certain factors, where one can fall under two or more categories. However, the author decided to categorize these into three categories: (a) personal caregiver factors, (b) environment and contextual, and (c) therapist and health care related factors. Personal caregiver factors outnumber the other two categories. There is mounting evidence that caregivers lack awareness of their right to be involved in the decision-making process (Al Khateeb et al., 2015; An, 2017; Angelin et al., 2021; Brassart et al., 2017; Pitt et al., 2013) and knowledge about the diagnosis and intervention (Bramesfeld et al., 2013; Brassart et al., 2017; Solish & Perry, 2008; Solish et al., 2015; Tully et al., 2017; Vadivelan et al., 2020).

While targeting personal caregiver-related barriers through interventions is vital, it is worth noting that therapist and health care related factors have been under-

represented in literature. Factors such as a lack of cultural sensitivity (Al Khateeb et al., 2015; Brassart et al., 2017; D’Arrigo et al., 2020a) and lack of communication and collaboration between therapists and caregivers (An, 2017; Bramesfeld et al., 2013; D’Arrigo et al., 2020a; Haine-Schlagel et al., 2020; Tully et al., 2017; Van Niekerk & Ismail, 2013; Willoughby et al., 2019) can addressed by practitioners in their clinical practice settings.

Finally, there is evidence that limited access to appropriate, fully equipped rehabilitation settings, frequent transportation, and caregiver support groups contribute to the problem. The low availability of human resources, quality, and lack of infrastructure and space (Pitt et al., 2013) only compounds the difficulty in developing countries. This literature review and revised visual model of the problem and its contributing factors lay a foundation for the need to create an accessible and evidence-based intervention for caregivers, to improve the quality of life of themselves and their children.

CHAPTER THREE – Overview of Current Approaches and Methods

Introduction

Education programs for caregivers of children with special needs that are accessible and cost-effective are in short supply in low-income and economic countries. When they are available, personal, environmental, and sociocultural barriers may prevent caregivers from participating in them. An impactful education program needs to be based on evidence from literature and includes strategies targeting caregiver engagement and empowerment.

Literature Search Questions

These research questions with resulting evidence were used to gather information to create an efficacious group-based caregiver education program called Caregiver Resilience Education (Ca.R.E.). The questions are:

- What interventions exist for improving engagement and self-efficacy for caregivers of children with disabilities, and what is the evidence of their effectiveness?
- Is there evidence about what features of the available interventions are most associated with positive outcomes?

Synthesis #1: Evidence and Effectiveness of Existing Interventions to Improve Engagement and Self-Efficacy of Caregivers

Identifying Information

Generated by writer.

Clinical Question

What interventions exist for improving engagement and self-efficacy for caregivers of children with disabilities, and what is the evidence of their effectiveness?

Summary of the Evidence Base

The author searched the literature using CINAHL, APA PsycInfo, Embase, and PubMed to identify the interventions used for improving engagement and self-efficacy in caregivers of children with disabilities. The terms used for the search were caregiver OR parental involvement OR parent engagement OR parent participation AND occupational therapy OR occupational therapist OR education OR intervention OR program AND children. Criteria for selection included peer-reviewed articles published after 2010 and written in English.

Clinical Bottom Line

Parents' involvement in therapy is integral to the child's overall engagement in therapy and their occupational performance outcomes (D'Arrigo et al., 2020b). Providing caregivers with the appropriate program and valuable strategies is essential to help their children's coping competence and confidence levels (D'Elia et al., 2013). A literature review identified twelve existing intervention programs to improve caregiver engagement, self-efficacy, and child outcomes. Of the twenty articles reviewed, only one study targeted caregivers of children with disabilities in India, which will be discussed below.

Occupational performance coaching is a process where caregivers are guided by trained occupational therapists in problem-solving to achieve self-identified goals.

Occupational performance coaching is intended to engage caregivers in skill improvement to resolve children's difficulties and not to tell them what to do but to guide and support them (An, 2017). Coaching helps caregivers find strategies to intervene with their children, thus helping with improving their participation and competence and reducing their distress (Dunn et al., 2012). Occupational performance coaching effectively improves caregiver self-efficacy, confidence, and engagement, improving children's performance (Angelin et al., 2021). Three other articles mention caregiver coaching as an effective intervention strategy to improve self-efficacy and engagement (Dunn et al., 2012; Schoen et al., 2019; Soref et al., 2012). Based on this review, coaching has effectively trained caregivers of children with disabilities and will be a valuable addition to the Ca.R.E. program.

It is understood that occupational performance coaching can potentially change the attitude toward disability in the Indian population (Angelin et al., 2021). This intervention was mentioned in two articles for caregivers of children diagnosed with autism spectrum disorder. One was conducted in Korea and used occupational performance coaching in individual sessions with the caregiver-child dyad (An, 2017). The other was conducted in India and used the same approach, except it was administered over ten group sessions (Angelin et al., 2021). Both showed improved caregiver efficacy and engagement (An, 2017; Angelin et al., 2021). It is important to understand that caregivers of children with disabilities in India are burdened with anxiety and stress due to society's stigma, sociocultural factors, and family-related problems. Despite the impact of the factors mentioned above, Angelin et al. (2021) reported that in their study,

caregivers' self-competence and children's outcomes improved due to occupational performance coaching. Therefore, the author intends to create the Ca.R.E. program modules to be scheduled and planned to overcome some barriers caregivers face in attending sessions, such as scheduling conflicts and daycare for their other children.

Another approach mentioned in the literature is therapist modeling, which is helpful in improving caregiver self-efficacy (Hahn-Markowitz et al., 2018; Soref et al., 2012; Wilkes-Gillan et al., 2015). Caregivers learn therapeutic strategies along with their children while engaging in their sessions. They are taught to model the therapists' method of communication and learn to provide adequate support, leading to a higher sense of self-efficacy (Hahn-Markowitz et al., 2018). In such behavioral modeling programs, caregivers are more likely to engage in interventions that they feel are appropriate for their child's needs. For example, when the therapist modeled an intervention with the children, the caregivers could appreciate its effectiveness and appropriateness, thus encouraging them to engage in and adhere to the program (Wilkes-Gillan et al., 2015). In Pitt et al. (2013), the authors model and demonstrate the activities for the caregivers to do and learn themselves. Similarly, the Ca.R.E. program will include therapist modeling to aid caregiver learning.

Group-based caregiver workshops or education programs effectively provide health-related knowledge and a safe space for caregivers to share their experiences, learn from one another, and provide support. It was found that caregivers' sense of competence improved after a group workshop versus an individual clinic appointment (Collis et al., 2020). The Calm Child Program is an example of a group caregiver education program

targeting caregivers of children with anxiety, autism spectrum disorder, and intellectual disabilities that has proven effective in elevating parent self-efficacy, confidence, and involvement (Gobrial & Raghavan., 2018). Using a developmental approach and various engagement strategies, a group-based caregiver workshop conducted in South Africa helped overcome the challenges associated with a low socioeconomic context (Pitt et al., 2013). Another group caregiver education program was conducted there to target child safety issues in the community (Van Niekerk & Ismail, 2013). Hence, the author will implement the Ca.R.E. program as a group-based education program to improve efficiency, cost-effectiveness, and feasibility, as well as a way to improve caregiver peer support.

The literature review also revealed targeted, individual interventions, such the TEACCH program (D'Elia et al., 2013), a video-modeling program to help improve social skills in children with attention deficit hyperactive disorder (Wilkes-Gillan et al., 2017), and the cognitive-functional (Cog-Fun) intervention (Hahn-Markowitz et al., 2018). The Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) is a global approach based on multidisciplinary collaboration among professionals and families of children with autism spectrum disorder. With regard to providing effective caregiving training, the TEACCH program goals were based on individual education plan goals, and intervention was provided in both home and school settings for two consecutive years in the D'Elia et al. (2013) study. The intervention included a collaborative team meeting and assessment with each family every three months. D'Elia et al. reported an improvement in child and caregiver outcomes, including

an improvement in autism rating scores and parental stress and efficacy. Based on this, the author will discuss multidisciplinary collaboration between the rehabilitation professional team and caregivers in the Ca.R.E. program to ensure all perspectives are voiced and heard in a safe and respectful environment. This strategy will help improve team collaboration and transparency.

Wilkes-Gillan et al. (2017) used a video modeling program as an intervention to improve social functioning and play skills. The video modeling was based on the social learning theory, where caregivers and children could benefit from observational learning. The intervention included a series of pre-recorded video modeling play and social skills, and caregivers led the children through this parent-mediated intervention. In this study, Wilkes-Gillan et al. reported that caregivers found this intervention effective; however, they noticed a decline in motivation for the children to engage in the intervention over time. This led to the recommendation to regularly update video content and follow up with caregivers to ensure continued engagement. The Ca.R.E. program will include technology in the program in form of demonstrations and informational videos. However, the author will keep in mind the availability and feasibility of the technology in rural, low-income communities.

The Cog-Fun intervention is an occupational therapy intervention for children with attention deficit hyperactive disorder focusing on executive functioning skills, administered by licensed occupational therapists certified in Cog-Fun interventions (Hahn-Markowitz et al., 2018). The Cog-Fun is based on family-centered practices, which aid in improving child outcomes and caregiver self-efficacy. Hahn-Markowitz

et al. (2018) reported that twelve occupational therapists administered Cog-Fun to caregiver-child dyads across three months, including home follow-ups. They reported an improvement in caregiver self-efficacy after the intervention period. Tully et al. (2017) reported that caregivers suggested an internet-based program as the preferred mode of education. This less intensive form of caregiver education was chosen to help address the barriers associated with participation in the program, such as childcare, transportation, and scheduling difficulties. The author planned the initial implementation of the Ca.R.E. program to be a series of in-person, group-based workshops. Based on the program evaluation and feedback, the author will make the Ca.R.E. program available on digital platforms to reach caregivers in similar settings on a larger scale.

The examined literature shows that multiple strategies and interventions can improve caregiver engagement and self-efficacy. However, it is necessary to build a program that reflects the recommendations for efficiency and impact made based on the review of evidence. Caregivers from India’s rural, low-income, and economic regions need an education program that is accessible, cost and time effective, and based on evidence-based strategies, considering sociocultural barriers (Angelin et al., 2021). A group education approach with coaching seems more feasible and easier to implement with limited health professionals than individual specialized approaches. The Ca.R.E. program will reflect strategies and approaches reflective of programs such as occupational performance coaching, treatment and education of autistic and related communication handicapped children, video modeling, group-based education programs, and Cog-Fun that benefit and empower caregivers, despite the numerous existing

barriers.

Synthesis #2: Evidence of Features of Existing Interventions Most Associated With Positive Outcomes

Identifying Information

Generated by writer.

Clinical Question

Is there evidence about what features of the available interventions are most associated with positive outcomes?

Summary of the Evidence Base

The author searched the literature using CINAHL, APA PsycInfo, Embase, and PubMed to identify interventions for improving engagement and self-efficacy in caregivers of children with disabilities. The terms for the search were *caregiver* OR *parental involvement* OR *parent engagement* OR *parent participation* AND *occupational therapy* OR *occupational therapist* OR *education* OR *intervention* OR *program* AND *children*. Selection criteria were peer-reviewed articles published in English after 2010.

Clinical Bottom Line

All studies reviewed include features of strategies and recommendations for positive outcomes of the available interventions. The author categorized these features into three categories: (a) caregiver features, (b) therapist features, and (c) program content features.

Caregiver Features. There are some features of the caregiver that, when added to the intervention program, lead to improved results. While it is important to design an

evidence-based program, it is also essential to ensure that caregivers are willing to participate in the activities of the training program (Pitt et al., 2013). This will lead to a willingness to engage and participate in play activities with their children (Schoen et al., 2019) and adhere to the advised activities at home (Wilkes-Gillan et al., 2015). Attending training sessions regularly will help caregivers build rapport with the health care workers involved in their child's care (Dunn et al., 2012). This build-up of rapport will inevitably open doors for collaboration and trust between caregivers and health care professionals (An, 2017). This is especially necessary for rural, low-income, and economic countries like India, where caregivers are used to following the medical model of health care and are unaware of their right to participate and collaborate (An, 2017; Angelin et al., 2021). Caregivers must also feel validated, supported, and respected to gain trust and empowerment from the intervention program (D'Arrigo et al., 2020b).

Barfoot et al. (2017) wrote that emotionally available caregivers could easily engage in the interventions and support their children when necessary. Caregivers who were not emotionally available tended to be more task-oriented and difficulty-focused rather than the implementation of strategies (Barfoot et al., 2017). Caregivers are more willing to participate in therapy when they have confidence in the therapists' knowledge and abilities (D'Arrigo et al., 2020b). These are the personal caregiver features associated with improved caregiver engagement and self-efficacy.

Therapist Features. It is not only the responsibility of caregivers to attend and actively participate in intervention programs. It is also up to occupational therapy practitioners and other health care professionals to ensure the intervention program is

facilitated and conducted in a way that encourages engagement and caregiver self-efficacy. Caregivers from diverse cultural backgrounds, like India, require consideration of their local ethnic and sociocultural needs for the program content to be relevant and relatable (Al Khateeb et al., 2015; Angelin et al., 2021). Not all people living in low-income countries are proficient in the English language. Delivering program content in the participant's native language adds value to the program as it encourages more understanding and engagement (Al Khateeb et al., 2015; Angelin et al., 2021; Van Niekerk & Ismail, 2013). Ensuring caregivers feel included in the team is crucial to caregiver engagement. This is achieved by connecting and communicating with all child caregivers regarding ongoing therapy sessions, workshops, and progress (D'Arrigo et al., 2020a; Tully et al., 2017). It is also the responsibility of therapists conducting the education program to actively listen, demonstrate and respond to caregiver concerns (D'Arrigo et al., 2020b).

Therapists are advised to communicate their training and expertise in their said profession before implementing a program (Tully et al., 2017) and continue to provide professional support to caregivers who have completed the program for long-term benefits (Wilkes-Gillan et al., 2017). Therapists must emphasize parental support and self-care while understanding that every family's situation is unique (Bryne et al., 2019). This adds important value to the program and makes caregivers feel supported and validated.

Program Content Features. Developing program content and planning its execution is essential in ensuring knowledge gets communicated effectively to the target

population. Developing evidence-based information resources (Al Khateeb et al., 2015), short-duration workshops in local languages (Pitt et al., 2013), and moving beyond bias and stereotypes (Al Khateeb et al., 2015; Van Niekerk & Ismail, 2013) all contribute to helping develop culturally sensitive content. Caregiver training programs that adopt culturally appropriate features encourage active caregiver engagement (An, 2017). Techniques such as demonstration, modeling, and coaching help caregivers prepare their children for school (Pitt et al., 2013). Expertise in the strategies taught in the education program improves caregiver competence and self-efficacy and helps decrease the burden on health care professionals in poorly resourced regions (Gobrial & Raghavan, 2018).

These effective tools help caregivers, and their children problem-solve in any context (Schoen et al., 2019). A contextual approach considers all aspects of the child's life, such as school, clinic, and home. This consideration helps caregivers achieve a sense of fulfillment as they can see differences in their children's performance in all contexts (Dunn et al., 2012). Incorporating technological innovations and media help keep up with current practices (Van Niekerk & Ismail, 2013). For example, Wilkes-Gillan et al. (2015) used video modeling and interactive DVD media sessions as the intervention for parent-mediated at-home sessions. Employing these techniques was shown to help improve the child's social functioning and play as well as caregiver competence. While it is important to study the immediate impact of the interventions, it is also salient to ensure the long-term benefits of the intervention. Wilkes-Gillan et al. (2017) studied the long-term impacts of the video modeling intervention. They found lasting improvements in the child's play levels and caregiver adherence to the program. However, caregivers also

stated the need for ongoing professional support and guidance.

Including a component of parent support and self-care in the intervention is beneficial (Byrne et al., 2019). Interventions focusing on implementing strategies and understanding the child's play cues, rather than the child's difficulties are understood to improve caregiver engagement and child outcomes (Barfoot et al., 2017). Group-based caregiver education workshops are more beneficial than individual clinic appointments in improving caregivers' sense of self-competence (Collis et al., 2020). Caregivers need a supportive environment and safe space to share and support one another (Angelin et al., 2021; Collis et al., 2020). Providing an information and resources pack to participating caregivers helps ensure the continued application of the strategies taught (Gobrial & Raghavan, 2018).

Intervention strategies that improve parenting practices in everyday life increase positive caregiver-child interactions, establish strategies for everyday interactions and establish a home routine to ensure generalization in all contexts (Gobrial & Raghavan, 2018; Hackworth et al., 2018). The features that have been reviewed and categorized above provide a foundation and guideline for the design and content of the Ca.R.E. program.

Conclusion

Evidence supports using educational programs and interventions to improve caregiver engagement and self-efficacy. There is also sufficient evidence outlining the features to be included in the Ca.R.E. intervention program to ensure positive outcomes for caregivers and their children with disabilities. Upon review of the findings and

summary of evidence of each of the questions noted above, several implications can be drawn for the design of the Ca.R.E. program.

The Ca.R.E. program content is based on strong evidence of the effectiveness of occupational therapy and other health care professions targeting caregiver engagement and self-efficacy. The author has chosen to deliver the Ca.R.E. program content as a group-based education program that is supported by literature (Collis et al., 2020; Gobrial & Raghavan, 2018; Pitt et al., 2013; Van Niekerk & Ismail, 2013). The program will contain modules encouraging collaborative goal setting (An, 2017; Angelin et al., 2021; D'Arrigo et al., 2020a; Dunn et al., 2012). As part of program design and implementation, the author will facilitate development of a caregiver support group in one of the modules to aid the long-term continued impact of the program (Barfoot et al., 2017). Based on the available literature, the Ca.R.E. program will incorporate a module or session of individual or group caregiver coaching to improve caregivers' self-efficacy and sense of competence and confidence. The Ca.R.E. program will also incorporate technology in implementing strategies, as caregivers have identified it as a preferred and effective mode of learning (Tully et al., 2017; Van Niekerk & Ismail, 2013; Wilkes-Gillan et al., 2015). This mode of delivery is more accessible and will help combat difficulties such as lack of transportation and scheduling conflicts (Tully et al., 2017). However, it will be important to keep in mind the availability of technological devices in the homes of caregivers living in rural, low-income communities. Last, consideration will be given to measuring the outcomes again 1 or 2 years after the program implementation to assess its long-term benefits (Wilkes-Gillan et al., 2017).

CHAPTER FOUR – Description of the Proposed Program

Basis of Proposed Program

The author's proposed program is a group-based education program. The program will be implemented at community-based rehabilitation centers in rural India. This program aims to educate caregivers of children with disabilities to engage in their children's therapies. The expected outcome is to increase their self-efficacy, leading to empowerment and caregiver peer support. The intervention, entitled the Caregiver Resilience Education (Ca.R.E.) program, will be delivered over 5 weeks as group education workshops to achieve its intended outcome. Along with learning from therapist-led information sessions, the Ca.R.E. program will utilize peer discussions, experiential learning through demonstrations, collaborative goal setting, and role-playing to achieve its goals. The author will deliver the pilot program at the primary office of the Handimachal Therapy Center building in Kullu, North India. The multidisciplinary rehabilitation team at Handimachal Therapy Center will assist with the implementation of the program with the intent to improve caregiver engagement and self-efficacy in their community-based clinical setting.

The Ca.R.E. program is created to address the dearth of and utilization of cost-effective, accessible, contextually appropriate group-based occupational therapy programs for caregivers in low-income and economic settings. The final explanatory model (Figure 2.2) depicts critical barriers to caregiver engagement in their children's education and therapies. The main categories of barriers are personal caregiver, environmental and contextual, and therapist and health care factors. In low-income and

economic countries like India, in the medical model of care, clients follow instructions and recommendations of health care professionals and are not active participants in their care (Angelin et al., 2021). This, and the factors listed in the final explanatory model (Figure 2.2), contribute to a lack of caregiver engagement and self-efficacy.

The author lays the foundation for understanding the problem and creating the education program using three theoretical frameworks. The frameworks are self-determination theory (Deci & Ryan, 2000), social cognitive theory (Bandura, 1986), and adult learning theory (Knowles, 1984). The self-determination theory is a theory of motivation that requires consideration of innate psychological needs such as autonomy, relatedness, and competence (D'Arrigo et al., 2017). If these three needs are unmet, the result is feelings of powerlessness, low self-efficacy, and lack of support (Ziviani et al., 2013). Caregivers often choose their children's activities based on their convenience or toys at home. Caregivers will benefit from learning to give their children autonomy of choice. Collaborative goal-setting and opportunities for children to choose their activities pave the way for autonomy. Building rapport and developing a therapeutic relationship with children and their caregivers meet relatedness needs. According to the self-determination theory, a sense of competence is attained when children and their caregivers see that a goal is achieved (D'Arrigo et al., 2017).

Caregiver self-efficacy is the confidence and capability caregivers carry into collaborative goal-setting, involvement, and engagement in therapy sessions. Research has shown that children having behavioral, physical, and emotional difficulties can increase caregiver stress (Gobrial & Raghavan, 2018). When caregivers engage in their

children's therapies, this leads to improvement in parenting skills and treatment knowledge, leading to positive child developmental outcomes and reduced caregiver stress (Lin et al., 2018). This engagement in their child's therapy services is considered a behavior of health for the child and the caregiver. The social cognitive theory states that an individual's behavior influences three factors that affect each other: environment, person, and behavior (Zhou & Fan, 2019). The person refers to individual cognitive factors, such as reasoning, judgment, executive functioning, attention, and literacy. The environment includes both physical and social environments such as living conditions, family cultural beliefs, and environmental systems, which can facilitate or inhibit the performance of a behavior (Conner, 2015). The behavior refers to an individual's actions (Zhou & Fan, 2019). The author reviews the factors contributing to the problem of low caregiver engagement and self-efficacy through the lens of social cognitive theory. Careful consideration of the barriers faced by caregivers will help make the Ca.R.E. program more culturally relevant and effective. As caregivers of children with disabilities are the target population for the Ca.R.E. program, the strategies for training and new learning include principles of adult learning theory (Knowles, 1984). The principles include active participation, group interaction, goal-oriented learning, autonomous and self-directed learning, readiness to learn, motivation, and transformational learning (Knowles, 1984). The first principle, active participation, refers to active, hands-on participation in learning activities versus being a passive observer. The second principle, group interaction, is important for adults to form peer relationships and support and encourage observational social learning. The activities must be goal-oriented, having a

focus and an outcome (Fairbanks, 2021). Adults need to choose the way they learn and their own pace of learning, which is self-directed and autonomous learning. Through transformational learning, adults can mentor each other, learn new perspectives, and shift world views. Finally, unlike children, adults are not required by school education to learn; hence they must have the internal motivation and be ready to learn (Fairbanks, 2021).

Two models of caregiver involvement are guiding posts for the development of the Ca.R.E. program, along with the three theoretical frameworks mentioned above. The Hoover-Dempsey and Sandler model of the parent/caregiver involvement process (Hoover-Dempsey et al., 2005) and Epstein's framework for six types of involvement (Epstein et al., 2018). The Hoover-Dempsey and Sandler model depicts five levels (Appendix A), beginning with parents' motivational beliefs, perception of invitations, and contextual factors, leading to student achievement at level five (Walker et al., 2010). In the first level, the three factors influencing the variety and frequency of involvement are personal motivators like self-efficacy, parents' perception of the invitation to be involved, and life context variables. In level 1.5, the model defines several forms of involvement: personal values, goals, aspirations and expectations, involvement activities at home, teacher-school communication, and school activities. Level two depicts the specific kinds of learning mechanisms employed by caregivers/parents during involvement activities. They are encouragement, modeling, reinforcement, and instruction. Level three states that the learning mechanisms in level two are pointless unless the students perceive them appropriately. This leads to level four, which describes

four student attributes for academic success. These are academic self-efficacy, intrinsic motivation to learn, self-regulatory strategy knowledge and use, and social self-efficacy in relating to teachers. All these levels lay a foundation for the ultimate goal, level five, the student's academic success. As aforementioned, caregiver/parent involvement and factors lay the foundation for a student's success (Walker et al., 2010). The author will only use the first three levels in the Ca.R.E. program, as they pertain to caregiver factors and self-efficacy.

Epstein's framework (Appendix B) discusses parental/caregiver involvement within the three contexts of school, family, and community, encompassing a child's development and learning (Mahuro & Hungi, 2016). In Epstein's framework, the first type is "parenting," which refers to helping families establish home environments conducive to their children's learning (Epstein et al., 2018). The author will include this concept in the Ca.R.E. program modules to help caregivers create a therapeutic atmosphere for play and development for their children at home.

The second type is "communicating," which, in this case, refers to appropriate modes and methods of communication between the school and caregivers about the child's progress and school programs. According to Tully et al. (2017), caregivers felt that they were not receiving invitations to communicate regarding events at their children's therapy center. This is an indication to ensure a proper communication channel is established for the Ca.R.E. program.

The third type is "volunteering," where the school recruits caregivers/parents for help and support. This can be introduced in the Ca.R.E. program modules. However, the

author feels this can happen after the program, where caregivers are encouraged to engage in and volunteer for various celebrations, fund-raising initiatives, and workshops conducted by the therapy center.

Fourth is “learning at home.” This is when teachers provide ideas and resources to caregivers and families on how to help their children with homework, planning activities, and other curriculum-related activities. The author will include this in the Ca.R.E. program’s learning activities through coaching and therapist–modeling so that caregivers will learn how to support their children’s outcomes at home.

Fifth is “decision-making,” where the school includes parents in the decision-making process to develop parent leadership and representation. This is crucial for developing self-efficacy and will be introduced as collaborative goal-setting in the Ca.R.E. program. Finally, the sixth type is “collaborating with the community,” where caregivers are encouraged to identify and integrate resources from the community to strengthen school programs and students’ learning experiences. The author foresees this as a long-term effect of the Ca.R.E. program, where the caregivers begin to advocate for their children in the community. Epstein’s model implementation in Uganda shows effective communication and regular school attendance to be essential for student achievement (Mahuro & Hungi, 2016). Though both models are rooted in school education, the principles are relevant to caregiver involvement in occupational therapy.

From a micro level, the individual stakeholders whose support will help ensure the success of the Ca.R.E. program are caregivers whose children receive multidisciplinary therapy at Handimachal Therapy Center, Kullu, India. Handimachal

Therapy Center's organizational board members, the multidisciplinary rehabilitation team, and support staff will also directly support the pilot program's implementation. They will act as key personnel for the Ca.R.E. program implementation, described in detail in Table 4.1. Meso-level stakeholders of the Ca.R.E. program include the community members who will have access to the therapy center and program. Other occupational therapists working within Himachal Pradesh in similar community-based settings will contribute to the Ca.R.E. program's success. They will offer feedback and an avenue to implement the program in their settings. On a more significant macro level, future stakeholders include the District Disability Welfare Office officials, the District Commissioner, the Ministry of Social Justice and Empowerment, and local hospital administrators. The Welfare officer and the Commissioner of the district of Kullu are in charge of implementing national and statewide policies for social justice and empowerment. A proposal for the Ca.R.E. program, along with the impact of the pilot program, will pave the way for large-scale caregiver advocacy and dissemination.

Table 4.1

Summary Table of Title, Role, and Duties of Caregiver Resilience Education (Ca.R.E.) Program Personnel

Title	Role	Duties
Occupational therapy practitioner (author)	• Course instructor/ administrator • Supervise support staff • Logistics of program implementation • Coordinate stakeholders and multidisciplinary rehabilitation team	• Deliver lectures • Facilitate group discussions, experiential learning activities, and peer-support groups • Demonstrate coaching • Supervise/delegate tasks to support staff • Coordinate with multidisciplinary team, administration, and remaining Ca.R.E. program stakeholders
Support staff (3)	• Course assistant	• One staff member assist the author during the workshop • Two staff members provide daycare services for children of caregivers attending the session • All three staff members assist with set up/clean up before/after workshop • Assemble/distribute educational handouts • Distribute refreshments
Multidisciplinary rehabilitation team (3 therapists + 3 community-based rehabilitation workers)	• Course assistants • Guest speakers	• Assist with delivering evidence-based Ca.R.E. program content specific to area of expertise • Note-taking during group sessions • Assist in facilitating parent support group breakout sessions
Social worker	• Course assistant • Public liaison	• Track caregiver attendance • Note-taking during group sessions • Coordinate stakeholder meetings • Program marketing • Referrals and recruitment • Social media and blog posts about the program on Handimachal Therapy Center's socials
Handimachal Therapy Center administrator	• Resource allocation	• Ensure space, resources, and time allocation for the program
Handimachal Therapy Center board of directors	• Resource allocation	• Permission for use of space/personnel

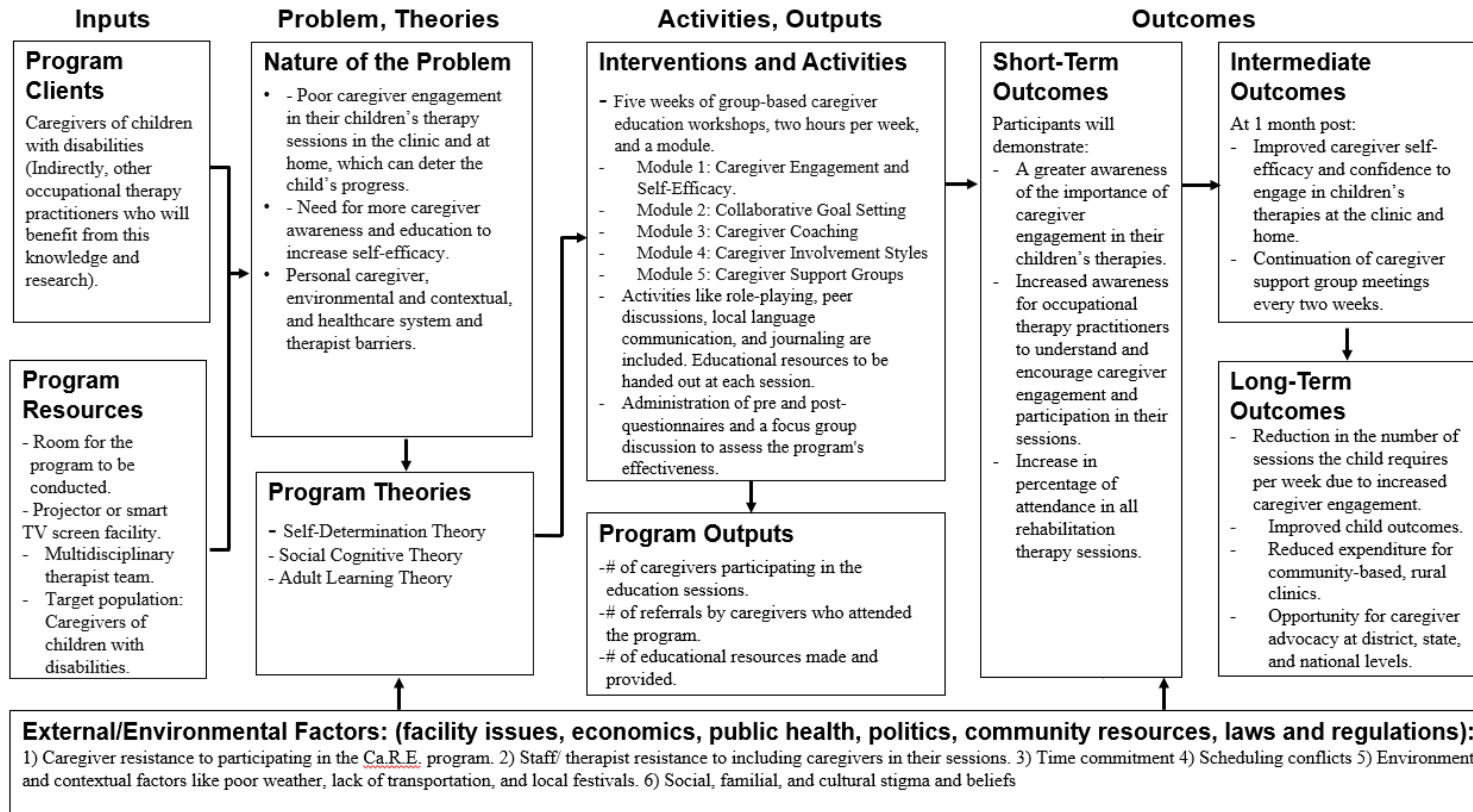
The main objective of the Ca.R.E. program is to improve caregiver engagement and self-efficacy in their children's occupational therapy and other rehabilitation therapy sessions in the therapy center and at home. This objective will be sought by implementing a group-based education program using strategies like therapist-led information sessions, coaching and demonstrations, peer support and discussions, and collaborative goal-setting. The long-term impact of the Ca.R.E. program is to empower caregivers to make connections, build a community of peer support and advocate for their children.

Full Logic Model

The complete logic model (Figure 4.1) will be utilized to communicate elements of the Ca.R.E. program and intended outcomes to the stakeholders. The model will be sent to stakeholders via WhatsApp, the primary mode of communication in this setting. Depending on the engaged stakeholder, the author will spend time elaborating on the model via video conferencing platforms that provide a secure option for communication such as WhatsApp, Google Meet, or Zoom. For example, the administrative board members will want to know how this program benefits their organization and the resources and cost required for its implementation.

Figure 4.1

Full Logic Model of the Caregiver Resilience Education (Ca.R.E.) Program, Depicting the Flow of Resources Required of the Program's Activities to Achieve Short-, Intermediate-, and Long-Term Goals



Program Clients and Resources

Several personnel will be required for the optimal delivery of the Ca.R.E. program. The author will be the primary instructor of the program and responsible for the information sessions, coaching, providing educational resources, facilitating caregiver peer discussions, delegating roles to the multidisciplinary therapist team, and supervising the program's logistics. The multidisciplinary therapist team (physical therapist, speech and language pathologist, special educator, and community-based rehabilitation workers) will be demonstration models for the coaching session and guest speakers when the subject matter falls within their area of expertise. Their input will be required for the collaborative goal-setting session as well. The support staff at Handimachal Therapy Center will assist the author with setting up the room with the required furniture and resources and handing out refreshments. One or two support staff will be allotted for child daycare during the workshop sessions. The Handimachal Therapy Center Board and its affiliated organizations will help fund the Ca.R.E. program. The social worker employed by Handimachal Therapy Center will assist in program marketing and referrals. A summary table of the Ca.R.E. program's resources is described in detail in Table 4.1.

The Ca.R.E. program will be delivered for 2 hours every Saturday for 5 weeks at the primary office of Handimachal Therapy Center. The building is wheelchair accessible, has accessible and adequate bathroom faculties, and is close to public transportation stops. The hall is well-lit, has sufficient space to seat up to twenty participants freely, and is equipped with a large television screen for screen casting the digital parts of the program. An adjacent room or space will be required to arrange and

serve the refreshments. The laptop required should be able to run PowerPoint and other necessary software. The television should have a sufficient visual and audio output for optimal participation and viewership.

The author will make every attempt to engage stakeholders in person. The stakeholders for the Ca.R.E. program are the caregivers of children with disabilities, the multidisciplinary rehabilitation team, the Handimachal Therapy Center's administration team and Board of Directors, the district welfare officer, and state government officials. Handimachal Therapy Center's Board of Directors will be contacted through video or phone, given their off-site locations. The author will engage with them as they are crucial for permissions, resource allocation, and funding. Once permission is obtained, the multidisciplinary rehabilitation and administration teams will be contacted via email, video, and phone. This communication will be more frequent due to the nature of their involvement in the program, as seen in Table 4.1. The support staff will be delegated their roles and responsibilities in person, the day before the program is to be implemented. The state and local government officials will be approached in person due to the uncertainty of online communication and the government system. They will be the last group of stakeholders to be contacted, as the communication will depend upon the success of the pilot of the Ca.R.E. program. The social worker will be contacted to assist with recruitment. Participants will be caregivers whose children are enrolled and receive therapies at Handimachal Therapy Center will be included in this.

Excluding the participants, the author will email the remaining stakeholders to set up meeting timings and agendas. Prior to the scheduled in-person or video conference

meeting, the author will send out the full logic model, along with the document highlighting the program outline, outcomes, and a brief description of the program evaluation research. The author will seek stakeholder feedback at every step of the process to ensure timely problem-solving and program quality improvement. The author will also email each stakeholder an outline of the meeting minutes and points for clarification, if any. The author foresees regular biweekly stakeholder meetings and frequent communication as the program implementation progresses.

Interventions and Activities

The Ca.R.E. program will be implemented through five sessions, each lasting 2 hours weekly. All program sessions will be delivered in-person, utilizing group-based sessions, experiential learning, coaching and peer discussions, and evidence-based information sessions led by the author. The topics of the five modules are:

1. Caregiver Engagement and Self-Efficacy
2. Collaborative Goal-Setting
3. Caregiver Coaching
4. Caregiver Involvement Styles
5. Caregiver Support Groups

The 120-minute sessions will be scheduled every Saturday for five consecutive weeks unless there is a local holiday. Each session will start with group attendance and introductions. The first module will outline the Ca.R.E. program and session agenda over the next few weeks. Each session after that will begin with a review of what was learned and discussed in the previous week’s session. Each module has a warm-up activity,

followed by a review of the previous session, then the author-led information session, followed by a question-and-answer session. There will be a small break for refreshments in between. The next part will be peer support groups of 3–4 caregivers in each group discussing the module content and their own experiences. These break-out groups will be led by a several open-ended questions developed by the author. The final part of the session is a large group discussion of the break-out groups and time for the caregivers to provide feedback, if any. The participants will also be given a journal prompt to reflect upon before the next session. Participants are expected to focus on building relationships with each other for peer support, as well as the module content's application to their circumstances. See Appendix C for a sample course outline (three program modules).

All Ca.R.E. program participants will receive a folder with the program outline, a journal, pen, and pencils at their first session. They will be given that week's module content to add to the folder every week. The module content will include slides, information resources, discussion points, and space to jot down their thoughts. Care will be taken to ensure the font is legible and the text is translated into the local language, Hindi, to accommodate all literacy levels. The author will ensure the slides are updated and accurately translated, leading each session, facilitating group discussions, and delegating and supervising the support team's tasks and key personnel's roles.

Program Outputs and Outcomes

The intended immediate output of the Ca.R.E. program is for 12 to 15 participants to attend all five sessions regularly and receive the resources being provided. Additionally, the participants should be independent enough to create their own support

group and continue meeting once the program is complete. With their consent, they will also be added to a WhatsApp group, including the author, and select key personnel for any updates regarding upcoming training, local opportunities, and evidence-based research and practice updates. This can also serve as a communication platform for further questions or feedback.

Short-term outcomes include the participants demonstrating a greater awareness of the importance of caregiver engagement in their children's therapies. Increased awareness for the multidisciplinary rehabilitation team to understand and encourage caregiver engagement and participation in their sessions. The author also anticipates an increase in the attendance of caregivers for all the therapy sessions they attend at Handimachal Therapy Center.

Intermediate outcomes include improved caregiver self-efficacy and confidence to engage and participate in children's therapies at the clinic and home. As the final module is about the benefits of forming and maintaining caregiver support groups, another outcome is the continuation of caregiver support group meetings once every 2 weeks. The frequency can be decided by the caregivers facilitating the session continuation. Long-term outcomes include fewer sessions the child requires per week due to increased caregiver engagement. This would help Handimachal therapy center administration and therapists accommodate the increasing demand for therapies with the current therapists and budget. This outcome then ripples into reduced expenditure for the community-based rural clinic. The author foresees improved child results from engaging caregivers in clinic sessions and at home. The successful pilot implementation of the Ca.R.E. program and

continuation of caregiver support groups will pave the way for caregiver advocacy and advocacy for occupational justice at a district, state, and national level.

Anticipated Barriers and Challenges

Possible barriers and challenges that the Ca.R.E. program might face include participants being unable to attend the sessions due to infrequent transportation availability and options, poor weather conditions, falling ill, or unavoidable family circumstances. Handimachal Therapy Center is located in a mountain terrain rural district, facing network issues that occur with poor weather. This may impede the progress of the program. The key personnel involved in the Ca.R.E. program's implementation may fall ill or take an unannounced leave of absence, which may cause challenges. Lastly, as the caregivers are from a wide range of literacy levels, the content and resources may be difficult to follow for some.

To overcome the aforementioned barriers, the author will utilize several strategies. Sessions will be scheduled when there are no major local festivals or events to encourage participation and attendance. Two of the support staff will be allocated to providing daycare services in an adjacent room for the children so that their caregivers may attend and participate in the session. The sessions are planned for Saturdays to accommodate caregivers who work in office or other types of jobs and are available only on weekends. The author will arrive early for each session to check and test the technology for the presentation. In case any key personnel take a leave of absence, the author will request help from the support staff and administrator if required. Finally, the author will ensure that the program content and materials are translated into the local

language and are prepared to accommodate all literacy levels.

Summary and Conclusion

The Ca.R.E. program is an evidence-based group education program designed to bridge the gap and provide a service that caregivers in rural, community-based settings in India need. There is a dearth of such programs, despite the percentage of children with disabilities requiring rehabilitation therapies in these remote areas. The program is designed based on theories and frameworks such as the Self-Determination Theory, Social Cognitive Theory, Adult Learning Theory, Hoover-Dempsey and Sandler Model of Caregiver involvement, and Epstein's Framework of the six types of involvement. Each theory contributes to the Ca.R.E. program's focus on improving caregiver engagement and self-efficacy, which will help them improve their peer support and child outcomes. Several evidence-based studies have been used to inform the content of the Ca.R.E. program. These include approaches such as coaching, caregiver support groups, peer discussions, involvement styles, collaborative goal setting, and therapist-led information sessions (An, 2017; Angelin et al., 2021; Dunn et al., 2012; Gobrial & Raghavan, 2018; Mahuro & Hungi, 2016; Pitt et al., 2013; Walker et al., 2010). The author designed the Ca.R.E. program with the long-term vision that it will be a steppingstone to caregiver empowerment and advocacy toward fighting for occupational justice for their children with disabilities rights in rural India. Its application for use in other developing nations is a longer-term goal to explore.

CHAPTER FIVE – Program Evaluation Research Plan

Program Scenario

Program Details

The Caregiver Resilience Education (Ca.R.E.) program is a group-based caregiver education intervention that aims to optimize caregiver engagement and self-efficacy. The program utilizes a combination of group discussions, learning, and coaching to develop participant engagement and self-efficacy skills. In its pilot implementation, the Ca.R.E. program will benefit caregivers of children with disabilities who attend rehabilitation therapies at Handimachal Therapy Center in Kullu, India. The program will also benefit multidisciplinary rehabilitation professionals employed at Handimachal Therapy Center. The improved caregiver engagement and self-efficacy skills will help their child's session performance, outcomes, caregiver involvement, and confidence. Handimachal Therapy Center is a community-based rehabilitation center based in the Kullu district at the foot of the Himalayan mountains. It is one of two multidisciplinary rehabilitation centers in the entire district. This means an extremely high child-to-therapist ratio leads to burnout, inefficient therapy services, and the inability to provide adequate therapy sessions for every child's weekly services. As a result, therapists are forced to treat children in groups, with only one individual session per week. Increased caregiver engagement and self-efficacy would help alleviate these difficulties and provide an opportunity for the children to receive the quality therapies they deserve.

Program Logistics

One of the features of the Ca.R.E. program is that the participants learn from and support each other through group discussions. Since this is essential to the success of the Ca.R.E. program, the program will be delivered in person. Various hands-on activities like journaling, coaching exercises, and role-play supplement the group sessions. The program will be implemented over 5 weeks, for 2 hours every Saturday, at the primary clinic of the Handimachal Therapy Center. Based on the author's experience working there, Saturdays are the preferred days for caregivers to attend education workshops as that is more convenient than weekdays.

The author will be the main instructor of the program. The multidisciplinary rehabilitation professional team, support, social worker, and administrative staff of Handimachal Therapy Center will be the key personnel assisting the author with the Ca.R.E. program implementation. The professional team will collaborate with the author for session lectures and group discussion facilitation. The support staff will assist the author with setting up, providing daycare services to the children, and in-session assistance. The administrative staff will ensure the smooth running of the Ca.R.E. program by providing resources and coordinating with the entire team. The social worker will assist with program marketing, social media, and caregiver recruitment. The Board of Directors of Handimachal Society will provide the permissions and fund allotment required.

Users of Program Evaluation Findings

The caregivers who participate in the program will be the main people interested in whether their self-efficacy and engagement levels improved after attending the program. They will also want to see an improvement in their child's outcomes. The multidisciplinary team will be interested in seeing an improvement in caregiver self-efficacy and engagement to help them with the challenges associated with the growing demand of their respective caseloads. In India, the Right to Education Act states that all children be treated equally and provided the educational experience they deserve. However, the schools are not accessible and do not provide many accommodations for the children they allow in. This, along with the distance between villages and the only disability — friendly school in the district, often prevents caregivers from sending their children to school. They choose to keep them at home. The administrative staff, social worker, and Board of Directors of Handimachal Therapy Center will want to see whether participation in the Ca.R.E. program increases session attendance, child outcomes, number of children integrated into school, and the ability to continue the services of Handimachal Therapy Center with the same budget, as it is a nonprofit organization. Finally, the author wishes to present the findings to local, district and state government officials to influence policy change and funding allotment toward the rehabilitation services of children with disabilities and caregiver empowerment.

Vision for Program Evaluation Research

The author will implement the Ca.R.E. program on her next on-site visit to Handimachal Therapy Center in India. Prior to this, the author will attain approval from

the Boston University Institutional Review Board to conduct the program evaluation research. The short-term vision for the program evaluation research is to

(a) Share summative program outcomes with funding and administrative stakeholders, the Board of Directors of Handimachal Therapy Center to demonstrate program effectiveness, justify funding, and allocate resources for the program's continuation.

(b) Provide the Ca.R.E. program participants with insights into the positive change in their self-efficacy, confidence, and engagement levels.

(c) Analyze and incorporate formative data to improve the Ca.R.E. program quality for further development, marketing, and dissemination.

(d) Formative data will also be shared with the multidisciplinary rehabilitation team, social worker, and support staff at Handimachal Therapy Center to discuss the knowledge gained, challenges faced, and lessons learned.

(e) Lastly, summative outcomes and qualitative formative feedback will be shared with other clinics or similar organizations within India to promote the Ca.R.E. program further and encourage referrals.

The long-term vision of the Ca.R.E. program is to

(a) To secure funding for research at a local level.

(b) Perform a research study with an experimental and control group to determine the program's effectiveness.

(c) To secure funding for program implementation in other clinics at a state or national level.

(d) To reduce the gap in the services and support caregivers of children with disabilities in these rural communities deserve and receive.

(e) Expand the program's reach beyond one local clinic to other clinics nationwide and make it available online for global reach.

Ultimately, the author envisions the Ca.R.E. program will address the issues that inspired the author to create the program in the first place. The personal caregiver, sociocultural, and therapist factors are barriers and facilitators to caregiver engagement. The lack of caregiver self-efficacy to get involved in their children's therapies due to the medical model being followed in rural India results in a lack of confidence. Finally, the lack of accessible and appropriate group-based education workshops for caregivers with disabilities is based in India's low-income and -economic regions.

Stakeholder Collaboration

The Ca.R.E. program requires the support of certain key individuals to ensure its successful implementation. They are the multidisciplinary rehabilitation professionals' team, the support staff, the social worker, the administrative staff, the Board of Directors of the nonprofit organization running the Handimachal Therapy Center, and last but not least, the caregivers of children enrolled at Handimachal Therapy Center. Initial attempts to meet with the key personnel will be via telephone, email, and WhatsApp. Given that the author used to work at Handimachal Therapy Center until November 2022, this will be most feasible and effective due to familiarity and distance. Once initial contacts are made, continued engagement with stakeholders will happen through email, WhatsApp, and phone conversations until the implementation of the Ca.R.E. program.

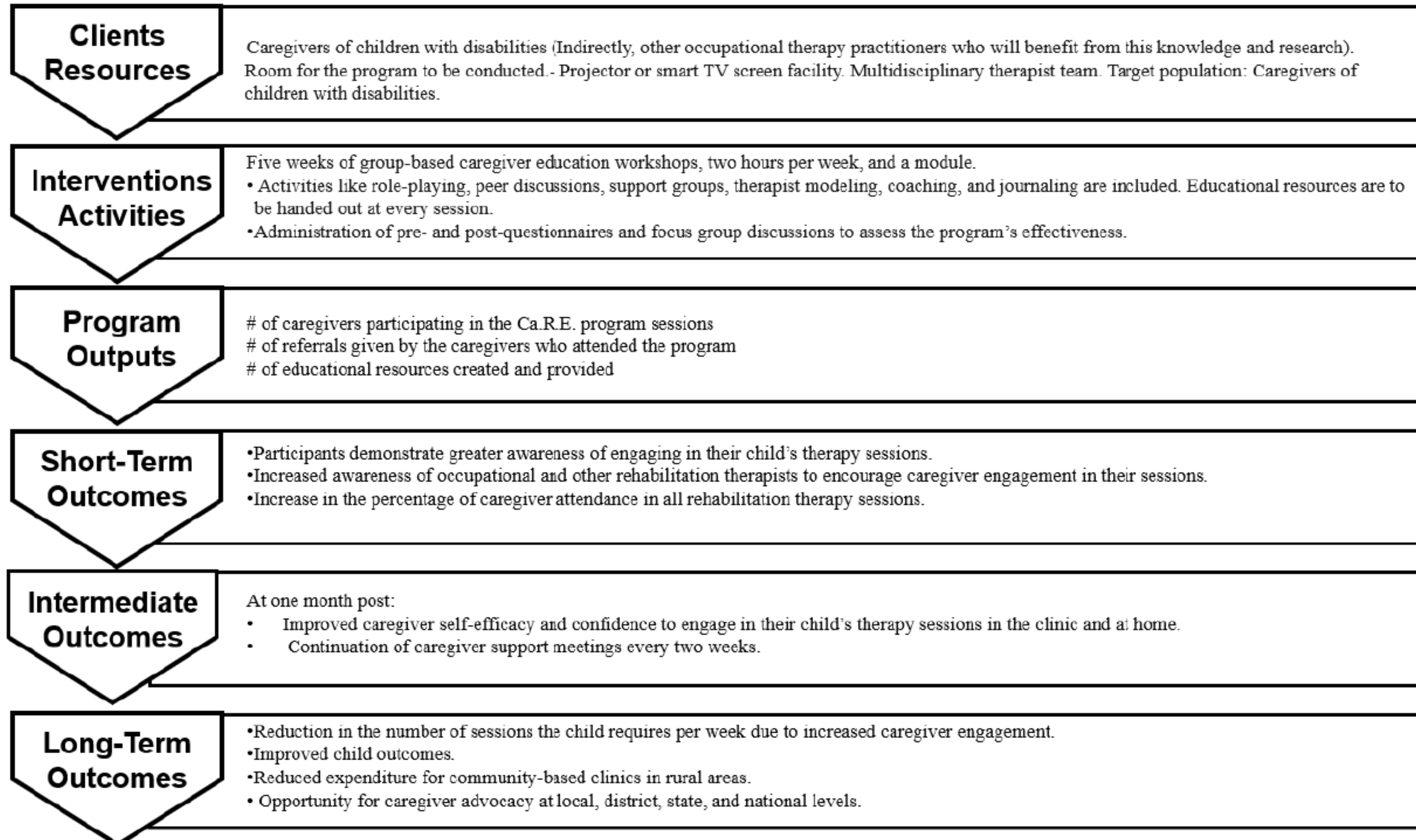
The caregivers whose children are enrolled at Handimachal Therapy Center will be engaged in recruitment and information about the program. Once the program is implemented, correspondence will be maintained in person and via WhatsApp. The multidisciplinary rehabilitation team, support staff, and administrative staff will be engaged with the program's content and outline via email and WhatsApp. Before the program implementation, the author will attempt to schedule in-person meetings with these stakeholders. The Board of Directors will be called initially but visited in-person prior to program implementation to answer questions, provide information on the program's effectiveness, and give accounts for the resource allocation.

Logic Model

The simplified logic model below (Figure 5.1) will be utilized to communicate the Ca.R.E. program outline and short-term and long-term goals to stakeholders. The author will share the simplified logic model via WhatsApp and email to provide an overview of the program implementation. The author will further elaborate on program plans and evaluation research plans with stakeholders depending on their level of engagement and area of interest and investment. For example, the Board of Directors will want to know more about the resources and funding required to ensure the success of the Ca.R.E. program. The logic model will be shared with program participants in the resource folder.

Figure 5.1

Simplified Logic Model Depicting the Flow of Resources and Activities of the Caregiver Resilience Education (Ca.R.E.) Program, Outputs, and Short-, Intermediate-, and Long-Term Goals



Confirmatory Process

The author will make every attempt to engage stakeholders in person and through digital means. These stakeholders include the caregivers of children with disabilities enrolled at Handimachal Therapy Center, the multidisciplinary rehabilitation team, the social worker, support staff, the administrative team, and the Board of Directors of the nonprofit organization that runs Handimachal Therapy Center. The Board of Directors will be engaged with and contacted first, as they are responsible for resource allocation and approval. Once permission is attained, the author will coordinate with the administrative staff to organize and schedule the pilot implementation of the Ca.R.E. program. The multidisciplinary team will then be sent an outline of the research plan along with details of their engagement. They will also be consulted for advice regarding the research design and implementation. The caregivers will be engaged throughout the process to help improve the program content and delivery quality.

The author will schedule a Zoom video conference with each stakeholder and support staff to walk through everyone's roles and answer questions before implementing the program. Before the scheduled meeting, the author will also email all involved parties the simplified logic model, a document of the evidence used to build the program, and a description of the research design. The author will acknowledge each member's unique contributions and perspectives upon meeting. The author will appreciate their valuable input and highlight their importance to the success of the Ca.R.E. program. After meeting with the stakeholder, the author will remain in touch with the stakeholders, including their feedback, and keep them updated on the program's progress.

Research Questions

A list of research questions specific to each stakeholder group is presented below in Table 5.1. Questions are both summative and formative, depending on the stakeholder group. Attempts will be made to answer all the research questions pertaining to the Ca.R.E. program evaluation study that stakeholders find applicable.

Table 5.1

Types of Questions That Users of the Caregiver Resilience Education Program Evaluation Data May Ask

Stakeholder group	Research question
Caregivers of children with disabilities	**Formative** • Does the program allow sharing of individual viewpoints? • Am I satisfied with the mode of delivery? • Is the program cost-effective and accessible? • What needs to be added to or removed from the program? **Summative** • How did this program benefit me? • How did this program benefit my child? • Did the program help my confidence levels? • Do I feel more engaged in my child's therapy sessions?
Multidisciplinary rehabilitation professionals (occupational, physical, and speech therapists, special educator, and community-based rehabilitation workers)	**Formative** • Was program participation good throughout the modules/weeks? • Was the program easy to understand/accessible? • Did participants face problems or give feedback/criticism during the program about the implementation? • What is the optimal time/venue to conduct the program? • When should the follow-up be scheduled? • Can this program be improved upon? • Should the mode of delivery of the program change? **Summative** • Did this program raise the caregivers' awareness about the importance of their involvement? • Did this program raise caregiver's awareness of resources available to help them?

Stakeholder group	Research question
	• Did this program help create a community of parents going through the same thing, as a support group? • Was the amount of caregiver stress reduced after taking part in the program? • Did the caregivers' self-efficacy improve? • Would participants recommend this program to other caregivers?
Social worker	**Formative** • How was program participation over the course of 5 weeks? • How was the online response to social media and blog posts? • Did the quality of therapy sessions improve during the program? **Summative** • How many caregivers were recruited for the program? • How many social media posts/blogs were designed/published online? • How many caregivers did participants refer to the program? • Did caregiver session attendance improve during the course?
Administrative board of Handimachal Therapy Center	**Formative** • How much does this program cost the clinic? • Is the caregivers' participation satisfactory? • How does the program implementation affect other clinic functions? • Will the evaluation research benefit the clinic? **Summative** • How can we determine the staff/participants' satisfaction with the program and record their recommended changes? • How can we ensure sustainability of the program? • Will the community well receive the program?
Future funding agencies, policymakers	**Summative** • Is the program effective? • Can this program be disseminated globally? • Is the program globally relevant? • Is the program marketable/can it create income? • Does the program influence change in treatment standards of care?

Research Design

In its earliest iteration, the research design for the Ca.R.E. program evaluation research is a nonexperimental mixed methods design consisting of pre and post data from one participant group. Formative program evaluation will be gathered using qualitative methods of data collection. For example, the stakeholders will provide necessary data via focus group discussions. The discussions will be transcribed by a co-investigator and submitted for analysis. Summative program evaluation will include quantitative methods. For example, the participants will be asked to complete a survey regarding their overall satisfaction, engagement, participation, and self-efficacy after participating in the program. Later on, when the author receives adequate funding, a randomized control trial will be planned to assess the effectiveness of the Ca.R.E. program. This will require the author to check the engagement and self-efficacy of caregivers who attend the Ca.R.E. program, and those who do not.

Methods

Prior to implementing the pilot program and conducting evaluation research, the author will submit the proposed project for Institutional Review Board approval. The application will include the outline of the program content, modules, resources, and informed consent forms (example at Appendix D) with translated and back-translated versions. The author will also include measures to ensure confidentiality and ethical research by ensuring all co-investigators undergo the basic level human subject research ethics training. The participant's demographic data will be encoded to ensure privacy. Codenames will conceal the participant's and stakeholders' identities, or

Numbers, and the data will only be stored on an encrypted hard drive with the author.

Formative Data Collection

Formative data collection will occur using a focus group discussion with caregivers via a recorded secure Zoom video conference call. A co-investigator will be assigned to coordinate the meeting timings and send out the meeting link and necessary resources. The researcher must ensure that the participants do not cause a threat to internal validity and that the method can be generalized to other settings. The participants will be ensured of the confidentiality of data through the signing of informed consent (Appendix D). Data will be collected from the focus group discussion using the open-ended questions asked by the facilitator/researcher. Additionally, another focus group discussion can take place with other stakeholders involved in the program's planning, implementation, and refining to collect qualitative information on how the program can be streamlined and improved upon.

Methods for Formative Data Management and Analysis

A co-investigator will be assigned to take informed consent from the participants, record the session using the secure version of Zoom, and review and edit the transcribed data. The researcher will assign a peer mentor to re-check the recordings and transcribed data before submitting it for re-check and data analysis. The participants' names and revealing information will be coded based on pre-determined terminology. Themes will be generated using NVivo (released in March 2020) software to report the results.

Summative Data Collection

Summative data collection will take place via questionnaires. The author will distribute forms for the program participants (i.e., caregivers of children with disabilities) to fill out. The dependent variables are caregiver engagement and caregiver self-efficacy. This data will be collected using questionnaires for each variable. This data will be collected before the program and after the program. The independent variable is the program itself. The quantitative data will be collected using a survey rating their satisfaction with the program on a Likert scale.

Additionally, a survey will be administered to other stakeholders, such as the multidisciplinary rehabilitation team, social worker, and administrators, to study their perception of the program's impact on caregiver self-efficacy and engagement. Clinical data, such as the number of sessions the caregivers attended with their children and the caregiver-therapist meetings they attended, can be used to quantify the Ca.R.E. program's impact. Qualitative data can be collected using open-ended questions at the end of each survey. This may add value to the quantitative data.

Methods for Summative Data Management and Analysis

The researcher will design a data collection Excel sheet for the co-investigators to enter data from the questionnaires and surveys on. Another peer will cross-check these. The data will then be analyzed using IBM SPSS software (version 27). A descriptive and correlational analysis will be done. The qualitative data will be transcribed and categorized into themes using the NVivo software. The data will be encrypted on a hard drive to ensure security and confidentiality and the participants demographics will be

coded.

Anticipated Strengths and Limitations of Program Evaluation Research

One of the main strengths of the Ca.R.E. program evaluation research is the mentorship available to the author through her mentors at Boston University's doctoral program, who are experienced in research. The next is the circle of advisors of Handimachal Therapy Center who are experienced in program implementation and evaluation in community-based settings in rural India. Furthermore, the author will have access to funding for the evaluation research, including data collection, analysis, and dissemination of the findings. Lastly, the author will have the help of co-investigators in the form of the multidisciplinary rehabilitation team of the Handimachal Therapy Center.

The possible limitations to the author's research design include a fault in participant attendance due to unforeseen circumstances such as poor weather, travel issues, or a sudden illness. There may be time constraints at the time of data collection, requiring the author to increase visits to the site to complete the process. Finally, not all participants may agree to participate in the research study due to sociocultural and familial barriers. These limitations will be addressed beforehand by offering multiple options for focus group discussion timings to ensure maximum participation, arranging daycare services for the caregivers' children, and thoroughly explaining confidentiality and informed consent before program implementation.

Dissemination of the Findings of Program Evaluation Research

The results of this program evaluation research will first be disseminated to the stakeholders involved in the planning and implementation of the program for further

reflection and refinement of the Ca.R.E. program. Once this is done, the results will be written into a manuscript that can be published in a reputable peer-reviewed journal as a research study article. The program evaluation and implementation process can also be made into a short audio-visual format that can be shared via social media. The researcher will also compile the results of the program evaluation research into a presentation/infographic to present at caregiver support or occupational therapy conferences, or to occupational therapy association board members. The program can be modified into a digital format, which will be proposed as a continuing education program for occupational therapists. As the primary aim of the program is to empower caregivers, the results can be disseminated at various caregiver groups/associations, to create a ripple effect of change.

CHAPTER SIX – Funding Plan

Summary

The Caregiver Resilience Education (Ca.R.E.) program is a group-based education program aiming to improve caregiver engagement and self-efficacy in caregivers of children with disabilities. The Ca.R.E. program utilizes a combination of approaches, such as coaching, therapist modeling, evidence-based information sessions, and caregiver support groups. The pilot program of the Ca.R.E. program will be conducted at the site of inspiration for the author, Handimachal Therapy Center, in Kullu, India. The author will lead and facilitate the program with the assistance of the administration and support staff employed at Handimachal Therapy Center. The guest speakers will be the multidisciplinary rehabilitation team, including the physical therapist, speech therapist, and special educator. The board of directors will be approached for permission to conduct the education program at the primary therapy center. The participants, caregivers whose children are enrolled at Handimachal, will receive the entire module content and resources in a folder, as well as a journal, refreshments, and daycare services for the children at each session. The Ca.R.E. program will take 5 weeks to complete. The author hopes that the group education program will improve confidence in caregivers in implementing the strategies they learned at school and home. The increase in generalization may lead to an increase in caregiver advocacy initiatives and an improvement in children's therapy progress (Gee & Petersen 2016).

Available Local Resources

Several community resources will be incorporated into the Ca.R.E. program to support the local community. First, the author has first-hand experience living in and working with the local community as the occupational therapist and executive head of Handimachal Therapy Center for the past 3.5 years. This provides the author with in-depth understanding and experience of the children and their caregivers, ensuring their needs are met in the Ca.R.E. program. Second, the Handimachal Therapy Center Board of Directors is willing to provide the primary therapy center as a venue for the duration of the program, free of cost, based on the author's previous affiliation with the nonprofit organization running. Next, the administration, support staff, and social worker at Handimachal Therapy Center are from the local community, and this adds value to the implementation and planning of the program. The multidisciplinary rehabilitation professional team has over 2 years of experience working with and living in the local community. Their combined expertise in local social and cultural norms will prove valuable as guest speakers. Finally, the Ca.R.E. program will be conducted on Saturdays so as not to disturb the children's therapy sessions and promote maximum participation.

The author created a network of people from different walks of life to support Handimachal within their capacities and circle of influence, called "Friends of Handimachal." During her time as the therapy center's executive head, the author also made meaningful connections with local businesses, who have become allies of the therapy center and provide their products at discounted prices. For example, a local design and printing business helped the organization by printing posters, banners, and

stickers for fundraising campaigns at a discounted price. The author will approach the same business through the auspices of the Handimachal Therapy Center to order printed informational resources for the participants of the Ca.R.E. program. Handimachal Therapy Center also is affiliated with a local bakery to provide refreshments at a discounted price. Established local businesses and organizations supporting the community may be approached to sponsor other as-needed supplies for the Ca.R.E. program. The author's friend has a web designing and marketing business, through which he regularly invests time and money toward nonprofit organizations like Handimachal. He may be approached to assist the author in marketing the Ca.R.E. program pilot version and future online dissemination to reach a global population.

Needed Resources: Budget

The personnel will constitute the most significant budget expense of the Ca.R.E. program. Costs for the pilot Ca.R.E. program can be found in Table 6.1. The budget primarily reflects the author's compensation as she is the occupational therapy practitioner responsible for leading and facilitating the Ca.R.E. program. The cost was calculated using the author's hourly rate, and the time to conduct each of the five sessions was identified as 3 hours per module. An additional 20 hours' compensation for the author includes the preparation and meeting time needed before the program implementation. This adds to a total of 35 hours for the program author. The expense for the guest speakers was calculated similarly, factoring in 6 hours for the three modules they will be a part of and an additional 4 hours to prepare for the single session at which they will be asked to speak. A 1-hour meeting before the program to discuss the content

and plan is also included in their fee structure. This adds up to 11 hours per guest speaker. The support staff, administrative staff, and social worker cost was calculated similarly, including their hourly rate and the 4 hours they spent before the program and in discussion meetings to prepare for its implementation. This is 8 hours for the administrator; 4 hours before and 4 hours after the program. The social worker’s time is 18 hours, as they must attend all the sessions. The support staff’s time is 16 hours, including the workshop sessions and one 1-hour meeting before the program is facilitated.

Equipment such as the audio-visual system and seating arrangements used for the program will be borrowed from existing supplies at Handimachal Therapy Center. Handimachal Therapy Center’s overhead costs will provide stationery supplies like pens and pencils. However, the journal, printed material, and folder for the program resources must be purchased from a local business affiliated with Handimachal. These were calculated at one journal, one set of printed resources, and one folder per participant, assuming will be 15 participants in the pilot program. The author will provide refreshments for the participants who sign up beforehand. Handimachal Therapy Center will provide refreshments for walk-in participants. The refreshments and water bottles must also be ordered and purchased locally. This will come to one hundred and fifty refreshments and half-liter water bottles for the pilot program, assuming each participant will bring their child to the program.

Table 6.1

Operating Budget for Implementing the Pilot Program of the Caregiver Resilience Education Program

Expense item	Pilot program cost	Quarterly implementation cost (1 year)
	Indian rupees (U.S. dollars)	
Personnel		
Author/occupational therapy practitioner	28,700 (350.00)	86,100 (1,050.00)
Guest speakers		
Physical therapist	6,765 (82.50)	20,295 (247.50)
Speech therapist	7,502 (91.50)	22,506 (274.50)
Special educator	5,005 (610.00)	15,015 (183.00)
Support and administration		
Administrator	3,200 (39.00)	9,600 (117.00)
Support staff (4)	14,720 (179.50)	44,160 (538.50)
Social worker	5,580 (68.00)	6,740 (204.00)
Equipment		
Audio-visual equipment	0	0
Laptop	0	0
Room rent	0	0
Supplies		
Journals	2,250 (27.50)	6,750 (82.50)
Folders	1,500 (18.00)	4,500 (54.00)
Pens and pencils	0	0
Printed materials	3,000 (36.50)	9,000 (109.50)
Communication		
Phone calls and WhatsApp messages	0	0
Marketing materials	0	0
Travel to India for pilot program		
Air tickets to Kullu, India	200,000 (2,440.00)	
Accommodations	73,800 (900.00)	
Transportation	12,000 (150.00)	
Food	12,000 (150.00	
American Occupational Therapy Association Conference, 2024		
Registration	22,550 (275.00)	
Accommodation	65,600 (800.00)	
Travel	24,600 (300.00)	
Food	28,700 (350.00)	
Transportation	16,400 (200.00)	
Total	**533,872 ($7,067.50)**	**224,666 ($2,860.50)**

Communication expenses, including telephone calls, WhatsApp messages, internet, and fliers will be provided by Handimachal overhead costs. Similarly, the room rental fee will also be covered by Handimachal Therapy Center. The author will have the lecture slides and material on her laptop. The author also intends to pilot the Ca.R.E. program in person, requiring her to travel to India. The travel budget includes a cab, air tickets, and accommodation. The author is also applying to present the Ca.R.E. program at the 2024 annual American Occupational Therapy Association conference in Orlando, Florida. The Conference budget includes registration, travel, accommodation, and food.

Potential Funding Sources

Funding for the supplies, equipment, and communication for the Ca.R.E. program will come from the Handimachal Society's budget. Handimachal Society is the nonprofit organization in charge of running the Therapy Center. The mission of the Handimachal Society is to treat, educate, and empower children with disabilities in the Kullu Valley of India. The author will seek out other potential funding sources for the personnel's budget. The potential alternative sources are listed in Table 6.2.

Conclusion

The Ca.R.E. program, including the pilot program intervention, will cost about 6,500 USD to operate for 1 year. While the program will not generate revenue, it supports the Handimachal Society and Therapy Center's vision and mission to serve children with disabilities and their families in the local community. The author will try to attain funding through the Handimachal Society's budget and, if unsuccessful, approach the other potential sources of funding for the personnel and explore the options as required.

Table 6.2

List of Potential Funding Sources for the Caregiver Resilience Education (Ca.R.E.) Program

Funding source	**Description**
Government grants	Ministry of Social Justice and Empowerment. The Persons with Disabilities Act of 2016 includes a provision to apply for funding for a research project proposal that will benefit people with disabilities and the organizations that provide services to them. The amount awarded varies every year.
Corporate social responsibility (CSR)	The author can apply for small grants from corporate business organizations under their CSR requirements. The CSR requires large business organizations to donate some of their profits to nonprofit organizations supporting various causes. The author will create a proposal for the Ca.R.E. program and send it to organizations supporting children with disabilities and their families. Examples of companies offering CSR grants are the TATA Institute, Google, Microsoft, and Mahindra Motors. The amount awarded ranges from 2,00,000 to 15,00,000 Indian rupees.
Small grants	The author plans to approach other nonprofit associations affiliated with the Handimachal Society and present the proposal to them for funding. The Kullu Valley in India has other nonprofit organizations working for the betterment of their communities and support each other, like Himalayan Friends' Trust, Samphia Foundation, and Faizl Socks. These organizations can be approached for support. The amount would depend on each organization's donations and budgets.
Crowdsourcing	The author will appeal to local businessmen and stakeholders who have invested time and money in the Handimachal Therapy Center through the "Friends of Handimachal" group. Finally, the author can approach the public through social media and crowdfunding to raise money to facilitate the Ca.R.E. program.

CHAPTER SEVEN – Dissemination Plan

Introduction

The Caregiver Resilience Education (Ca.R.E.) program is for caregivers of children with disabilities. The pilot program of Ca.R.E. will be implemented at Handimachal Therapy Center in Kullu, India, where the author has worked for the past 3.5 years. The administration, support staff, social worker, and multidisciplinary rehabilitation professional team employed at Handimachal Therapy Center will assist with the program implementation. The caregivers enrolled at Handimachal for their children's therapies will be recruited as program participants. They will be given printed resources and materials required for the program. The caregivers will also be provided with refreshments and daycare services for their children so they can attend the sessions comfortably. The author envisions caregivers becoming more empowered and advocating for their children's rights in a discriminating and unjust society.

Dissemination Goals

Figure 7.1 lists the dissemination goals for the Ca.R.E. program indicating favorable evaluation results.

Target Audiences and Key Messaging

The author considers several audiences for the dissemination of the Ca.R.E. program results. Of them, the author gives priority to three. The primary audience would be the Board of Directors of Handimachal Therapy Center and the Friends of Handimachal group. Their passionate focus on caring for children with disabilities within their community helps them provide financial and networking support. The secondary

audience will be the district of Kullu’s Disability Welfare Officer and the District Commissioner; both officials are critical for government endorsement and funding. The tertiary audience will be occupational therapists across India and the United States. The author is a part of the AOTA and the All-India Occupational Therapy Association (AIOTA), which meet annually for their conferences. The key messages for all three audiences will be delivered as stated next.

Figure 7.1

Dissemination Goals for the Caregiver Resilience Education Program

Long-term goals

The dissemination plan will:

1. Provide an opportunity for caregiver advocacy at the district, state, and national levels. This can be determined by the number of caregiver-mediated meetings conducted with the government officials at various levels.
2. Assist in reducing expenditure for rural, community-based rehabilitation clinics.

Short-term goals

The dissemination plan will:

1. Assist in improving caregiver self-efficacy and engagement.
2. Produce at least two articles and one conference presentation within a year.
3. Increase the number of participants in future program iterations.

Primary Audience Message

The results of the Ca.R.E. program evaluation demonstrate the program’s instrumental role in improving the well-being of children with disabilities and their

caregivers in the community it serves. The findings are significant as they support the vision and mission of Handimachal Therapy Center by utilizing approaches based on evidence-based practice. The Ca.R.E. program will help reduce expenditure for Handimachal Therapy Center by improving caregiver engagement and self-efficacy. When caregivers are more engaged in their children's therapies, they do not require as many therapy sessions per week, allowing the therapists at Handimachal Therapy Center to manage the high child-to-therapist ratio. To expand the reach and to keep the Ca.R.E. program accessible and affordable across similar settings within the Kullu district, further funding is required to keep the Ca.R.E. program support and networking to continue its work toward empowering caregivers of children with disabilities.

Secondary Audience Message

The Kullu district has a dearth of qualified health care and rehabilitation professionals. This leads to a high child-to-therapist ratio. Handimachal is one of two pediatric multidisciplinary rehabilitation centers in the entire district. There is a need for government collaboration to help increase awareness and disability advocacy efforts. The results of the Ca.R.E. program intervention at Handimachal Therapy Center will help demonstrate the organization's instrumental role in improving the well-being of children with disabilities and their caregivers in the community it serves. The program utilizes evidence-based approaches for the growth and progress of all rehabilitation units serving children with disabilities. The Ca.R.E. program has the potential to be a workshop offered as continuing education and service quality improvement sessions at various rehabilitation units across the district. Future referrals to the Ca.R.E. program are

anticipated to collaborate with government initiatives and improve the health and well-being of children with disabilities and their caregivers.

Tertiary Audience Message

The Ca.R.E. program can improve caregiver self-efficacy and engagement using evidence-based approaches. The findings of the Ca.R.E. program provide insight into its effectiveness in reducing the burden on occupational therapists working in clinical settings with limited human and material resources.

Messengers

Two different messengers will be required to communicate the key messaging to the primary, secondary, and tertiary audiences to improve the effectiveness of the delivery. For the primary audience, the author, who is an occupational therapist leading the Ca.R.E. program, will be responsible for communicating the key messaging as she had a good working relationship with the Board of Directors of Handimachal Therapy Center and was instrumental in forming the Friends of Handimachal group. The author will be able to provide necessary detail regarding the program and answer any questions that may arise, given the author's significant role in the Ca.R.E. program's planning and implementation.

The messenger to the secondary audience will be the Administrator of the Handimachal Therapy Center. The administrator already actively communicates with the districts' government officials as the Handimachal representative and has agreed to undertake the role of the messenger. Given the administrator's understanding of the role of the various rehabilitation disciplines and the importance of caregiver engagement and

self-efficacy, she would be able to relay the critical message confidently. The administrator will likely be deemed a more credible source of information by government officials as she is from the community Handimachal Therapy Center serves.

The author will approach the tertiary audience. As aforementioned, the author is an occupational therapist and a member of the AIOTA and the AOTA. The author will be able to provide essential details regarding the designing, planning, and implementing of the Ca.R.E. program at the conferences and related events held by these associations.

Dissemination Activities

The primary audience will gather at a local conference hall upon an invitation given by the author. They will initially be informed via WhatsApp messaging and phone calls to inform them of an in-person meeting at the venue. The PowerPoint presentation briefing will last 1 hour, followed by half an hour for questions about the Ca.R.E. program and evaluation research. A soft copy of the brief will be emailed to the primary audience before the in-person meeting. A printed version of the brief is then provided at the meeting for further reference. The author will also provide hard copies of brochures about the Ca.R.E. program to the audience so that they can be distributed at various places, such as places of work, local clinics, and hospitals. The brochure will include information about the Ca.R.E. program, the program's benefits, and participants' testimonials.

The secondary audience, the District Commissioner and Disability Welfare Officer will be approached in person in their offices. Initially, the Administrator will set up an appointment to meet them via phone calls to their secretaries. Then, once the

meeting is scheduled, the administrator will use a laptop with a PowerPoint presentation to present the Ca.R.E. program, its benefits, and participant testimonials to them. The entire presentation, including time for questions and answers, must be completed in 30 to 40 minutes, depending on the official's availability. The author will email a soft copy and give the printed presentation and brochures about the Ca.R.E. program for further reference and future referrals.

The tertiary audience, occupational therapists across India and the United States, will be approached by the author in person at their association's annual conferences in 2024. First, the author will submit proposals to the AIOTA and AOTA in response to their call for papers. If selected, the author will travel to the conference venue and present a poster of the findings of the Ca.R.E. program. The conference delegates who view the poster presentation will receive a soft copy of the Ca.R.E. program fact sheet (Appendix F) by scanning a QR code on the poster. Alternatively, or in addition, the author can write a report or article about the Ca.R.E. program and its evaluation results in the *OT Practice* by AOTA and publish a manuscript in the *American Journal of Occupational Therapy*, the *Open Journal of Occupational Therapy*, or other peer-reviewed journals.

Dissemination Budget

The dissemination budget for the Ca.R.E. program is in Table 7.1. Most expenses are to pay for the author's travel to the conferences and the time spent preparing for the presentations. The remaining costs are tied to accommodation, living, and the provision of printed brochures and information sheets.

Table 7.1

Dissemination Budget for the Caregiver Resilience Education Program

Expense item	Cost in Indian rupees (U.S. dollars)
American Occupational Therapy Association conference	
Registration	22,550 (275.00)
Accommodation	65,600 (800.00)
Travel	24,600 (300.00)
Food	28,700 (350.00)
Transportation	16,400 (200.00)
All-India Occupational Therapy Association conference	
Registration	2,000 (24.50)
Accommodation	12,300 (150.00)
Travel	164,000 (2,000.00)
Food	5,000 (61.00)
Transportation	5,000 (61.00)
Primary and tertiary audience meetings	
Conference hall rent	3,000 (36.50)
Refreshments	10,000 (122.00)
Printed materials	10,000 (122.00)
Travel	5,000 (61.00)
Total	**374,150 ($4,563.00)**

Evaluation

Evaluation of the Ca.R.E. program dissemination efforts will be measured in multiple ways. For the primary audience, success in dissemination efforts will be realized through increased participant referrals to the Ca.R.E. program. Funding will be secured for at least two more cohorts of the Ca.R.E. program for the forthcoming year. For the secondary audience, one outcome will be a working partnership between the government

and the Handimachal Therapy Center to bring the Ca.R.E. program to more areas in the district. Another successful outcome will be securing program funding through government schemes. For the tertiary audience, dissemination efforts will produce at least two articles in peer-reviewed journals. The program evaluation research findings can increase referrals for the Ca.R.E. program in similar low-resource settings outside India.

Conclusion

The program evaluation findings of the Ca.R.E. program will be disseminated to the leadership of the Handimachal Therapy Center and the Friends of Handimachal group via an in-person meeting and briefing. This briefing aims to report on the pilot of the Ca.R.E. program's effectiveness and pitch for funding for the forthcoming year. They will also be provided with written information and a printed brochure. Key messaging will be disseminated to the district's Commissioner and Disability Welfare Officer by the Administrator of Handimachal Therapy Center via an in-person meeting to promote government collaboration and funding for the Ca.R.E. program. The author intends for the findings of the Ca.R.E. program to be disseminated to occupational therapists attending the AOTA and AIOTA conferences. The total budget for all three dissemination ventures will amount to $4,563. The overall goal of sharing the Ca.R.E. program results is to ensure the program's long-term sustainability. This improves caregiver engagement and self-efficacy for all caregivers attending Handimachal Therapy Center and similar low-resource clinical settings in India, the United States, and other countries. The aim is to keep the Ca.R.E. program affordable and accessible, in alignment with occupational justice.

CHAPTER EIGHT – Conclusion

Limited caregiver engagement leads to low self-efficacy (Angelin et al., 2021). Low self-efficacy, in turn, leads to caregiver stress and anxiety. Ultimately, increased caregiver stress and anxiety levels can lead to poor outcomes in their children's therapy progress (Vadivelan et al., 2020). This situation is made worse by insufficient evidence-based solutions to address the problem. The Caregiver Resilience Education (Ca.R.E). program is designed to fulfill a need created by the lack of culturally relevant, cost-effective, evidence-based group education programs for caregivers of children with disabilities, particularly those in low-income areas with limited access to therapy services. The goal of the Ca.R.E. program is to improve caregiver engagement and self-efficacy in an affordable and accessible manner.

Based on a literature review, numerous factors act as facilitators or barriers to caregiver engagement and self-efficacy that can be grouped into three categories. *Personal caregiver factors*, such as a lack of awareness of the right to be involved in the therapy decision-making process, limited knowledge about their child's diagnosis and intervention, and lack of familial support (Angelin et al., 2021; Tully et al., 2017; Vadivelan et al., 2020), are more pervasive than the other two categories. The environmental and contextual factors, like the low availability of human resources, lack of accessible transportation, and lack of infrastructure (Pitt et al., 2013), are important to consider as potential limitations in community-based clinical settings. Finally, the third category is underrepresented in the literature: therapist and health care system factors such as cultural humility and a lack of collaboration between caregivers and occupational

therapy practitioners (D'Arrigo et al., 2020b; Haine-Schlagel et al., 2020; Willoughby et al., 2019). These factors laid a cornerstone for understanding the problem and the need to develop the Ca.R.E. program, designed to serve caregivers in low-income and low-resource community-based clinical settings.

The Ca.R.E. program is designed based on theories and frameworks such as the self-determination theory (Deci & Ryan, 2000), social cognitive theory (Bandura, 1986), adult learning theory (Knowles, 1984), Hoover-Dempsey and Sandler model of caregiver involvement (Hoover-Dempsey et al., 2005), and Epstein's framework of the six types of involvement (Epstein et al., 2018). Each theory acts as a building block to support the foundation of the Ca.R.E. program's focus on improving caregiver engagement and self-efficacy. These foundational theories help provide caregivers with the tools to improve their peer support and child outcomes.

The Ca.R.E. program incorporates strategies from the literature that have proven effective in improving caregiver self-efficacy and engagement. This includes implementing the Ca.R.E. program in a group format (Collis et al., 2020) and using appropriate and accessible technology as a mode of communication (Tully et al., 2017). Other specific strategies include approaches such as coaching, caregiver support groups, peer discussions, involvement styles, collaborative goal-setting, and therapist-facilitated information sessions (An et al., 2017; Angelin et al., 2021; Dunn et al., 2012; Gobrial & Raghavan, 2018; Mahuro & Hungi, 2016; Pitt et al., 2013; Walker et al., 2010).

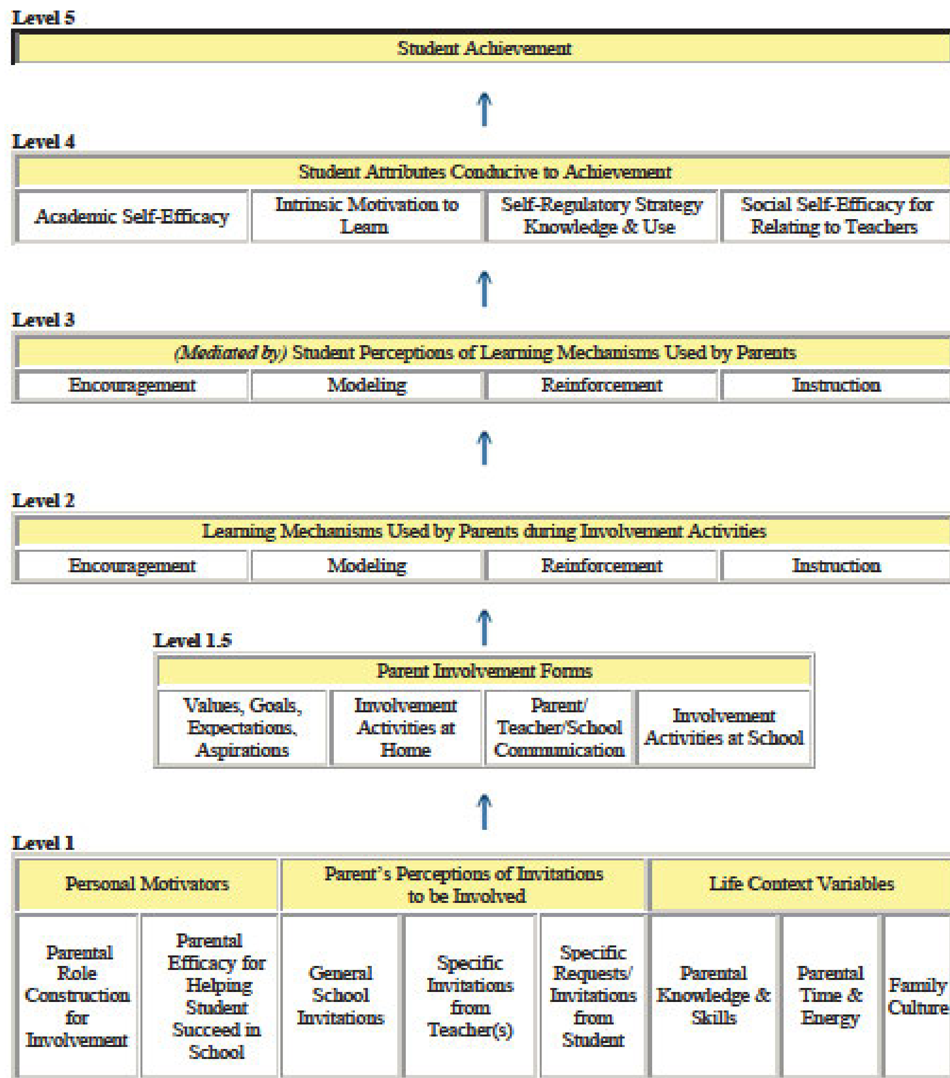
The Ca.R.E. program incorporates theory and evidence to resolve the problem of limited affordable, efficacious, occupational therapy-driven caregiver education programs

for community-based settings. At no-cost for participants, the Ca.R.E. program will be delivered for 2 hours every week over five consecutive weeks. All five of its modules are group-based, with interactive activities such as group discussions, guest speaker panel discussions, and role-playing. One module will include a demonstration of one-on-one caregiver coaching. The Ca.R.E. program will be piloted at a nonprofit organization's community-based pediatric rehabilitation clinic in rural India. Participants will be provided with necessary handouts of resources, as well as daycare services to help alleviate the stress of childcare. All modules will be facilitated by an occupational therapy practitioner and supported by a multidisciplinary rehabilitation team and support staff.

The Ca.R.E. program's evaluation will utilize formative and summative data collected before and after program implementation. The author intends to disseminate the Ca.R.E. program's evaluation research findings to stakeholders who can help influence positive change. The author mindfully designed the Ca.R.E. program to overcome barriers created by occupational injustice. With the successful implementation of the Ca.R.E. pilot program in rural India, the author intends to reach more community-based settings across the globe and help them overcome similar barriers. Occupational therapy practitioners in community-based rehabilitation settings can potentially realize their role and influence as effective health educators. The author also envisions the Ca.R.E. program as a steppingstone to empower caregivers who can advocate for the rights of their children and themselves in a transformative way.

APPENDIX A – Hoover-Dempsey Sandler Model of Parent Involvement

Used with permission of the authors (Hoover-Dempsey et al., 2005)



Overview of the Hoover-Dempsey & Sandler model of the parental involvement process

The model is a representation of decades of research on family involvement. Structured in five levels, the model addresses **three essential questions:**

1. Why do (and don't) families become involved?
2. What do families do when they are involved?
3. How does family involvement make a positive difference in student outcomes?

This overview describes the model beginning with parents' motivations for involvement in their children's education (Level 1).

Level 1

Personal Motivators		Parent's Perceptions of Invitations to be Involved			Life Context Variables		
Parental Role Construction for Involvement	Parental Efficacy for Helping Student Succeed in School	General School Invitations	Specific Invitations from Teacher(s)	Specific Requests/ Invitations from Student	Parental Knowledge & Skills	Parental Time & Energy	Family Culture

Level 1 of the model suggests that **three major factors influence** the variety and frequency of family involvement. These three factors are parents':

1. Personal motivators.
2. Perceptions of invitations to be involved.
3. Life context variables.

These factors at Level 1 interact to shape the forms and frequency of family involvement.

Personal Motivators

Central to the model is the idea that **parents' motivations for involvement are a function of the social systems** to which they belong. For instance, parents' role construction and sense of efficacy are influenced by their:

- Own family and academic experiences during their childhood.
- Current family systems.
- Recent experiences in the school systems that their children attend.

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The **two personal motivators** identified in the model are **parental role construction** for involvement and **parents' sense of self-efficacy** for helping their children succeed in school.

1. **Role construction** is parents' beliefs about what they are supposed to do in relation to their children's schooling. In essence, it is their job description from their own viewpoint.

2. **Self-efficacy** for helping their children succeed in school refers to parents' beliefs about whether or not their involvement is likely to have a positive influence on their children's education. Just as student self-efficacy influences students' academically related behaviors, parents' sense of self-efficacy shapes what parents do.

Parents' perceptions of invitations to be involved

Contextual motivators of involvement take three forms:

1. **General invitations from the school.** Does the school feel welcoming? Do all school staff members (including front office staff, custodians, etc.) greet parents warmly?

2. **Specific teacher invitations,** such as teacher requests for supporting learning at home or attending a parent-teacher conference.

3. **Specific invitations from the child.** Invitations from the child can be explicit—"I need help," "I just don't understand this," "I hate school!" They can also be implied. The child might be struggling with homework or procrastinating to get a school project done.

Life context variables

- **Parents' understanding of their own skills and knowledge** influences their thinking about the kinds of involvement activities they take on. When students' or teachers' requests for involvement fit parents' beliefs about their skills and abilities, they are more likely to act; however, if parents believe their skills or knowledge are inadequate, they may be reluctant to take action.

- **Parents' perceptions of the time and energy** they have available for involvement influence their decisions about involvement. Parents may be constrained by long work hours, varied family obligations and the reality that opportunities to become involved in many educationally-related activities are scheduled for the school's convenience.

- **Family culture may play a significant role** in parents' ideas about the ways they can and should be involved in supporting their child's learning. For example, even when schools are inviting, families whose cultures have traditionally suggested that parents should play a limited role in students' formal schooling may stay "on the side lines." Conversely, families whose cultures expect regular and direct family engagement may offer considerably more active engagement than their students' schools expect.

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Level 1.5

Parent Involvement Forms			
Values, Goals, Expectations, Aspirations	Involvement Activities at Home	Parent/ Teacher/School Communication	Involvement Activities at School

Level 1.5 of the model defines several forms of involvement:

- One form of involvement incorporates parents' clear communication with their children about their **personal and family values, goals, expectations and aspirations** for student learning. The communication of these goals and expectations, in turn, shape students' beliefs and behaviors related to learning (see Level 4).
- The model also acknowledges that families support student learning through **involvement activities at home.** These often include such activities as talking about the school day, expressing interest in the student's learning, and monitoring and reviewing student work.
- Effective **family-school communication** influences students' academic progress. The value of effective communication is generally strongest when the communication is consistently characterized by mutual respect, careful listening, and school responsiveness to parents' questions, ideas, suggestions and concerns.
- Finally, the model includes **participation in school-based activities.** Educators sometimes assume that parents who are not at school are not involved. The breadth of involvement forms described in Levels 1.5 and 2 of the model are important reminders that involvement at school is not necessarily a good indicator of parents' actual breadth and level of involvement.

Level 2

Learning Mechanisms Used by Parents during Involvement Activities			
Encouragement	Modeling	Reinforcement	Instruction

Level 2 of the model argues that parents influence the student attributes necessary for school success (outlined in Level 4) via **four specific kinds of activities.** These "active ingredients" are: **encouragement, modeling, reinforcement and instruction.**

Level 3

(Mediated by) Student Perceptions of Learning Mechanisms Used by Parents			
Encouragement	Modeling	Reinforcement	Instruction

Level 3 asserts that these mechanisms remain inert unless students perceive their parents' actions. In this way, **student perceptions of their parents' use of the four mechanisms** is an essential channel whereby parents' beliefs and behaviors are translated into attributes that lead to academic success.

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For example, when parents encourage their child to persist in academic work, and the child perceives this encouragement, parents contribute to the development of student academic self-efficacy or confidence in their child's ability to learn.

In another example, when parents attend meetings and events at school or ask their child about the school day, and the child is engaged in these activities, parents are modeling the importance of education.

Level 4

Student Attributes Conducive to Achievement			
Academic Self-Efficacy	Intrinsic Motivation to Learn	Self-Regulatory Strategy Knowledge & Use	Social Self-Efficacy for Relating to Teachers

This level of the model views students as the authors of their academic success. It describes a set of **four student beliefs and behaviors** associated with academic achievement:

1. One belief important to achievement is **academic self-efficacy.** Put simply, efficacy is the belief that "I can." When students believe that they are capable of learning, they are more likely to persist in the face of new and sometimes challenging academic work. If they do not hold this belief then they are less likely to persist.
2. Another important student attribute is **intrinsic motivation to learn.** Highly effective learners have a genuine interest in mastering the content and this curiosity sustains their engagement in learning both in and out of school.
3. A third attribute is **self-regulatory skills.** This means that students behave in ways that support their learning, including managing time well, setting goals and monitoring their progress.
4. The fourth attribute at this level of the model underscores the **social dimensions of school success.** Successful students know how to ask for help when they are confused and how to work cooperatively with others in the classroom. We know that these attributes are important to academic success.

Level 5

Student Achievement

Our ultimate goal is **student achievement.** The Hoover-Dempsey & Sandler model asserts that parent involvement, as described at each level of the process, influences and to some degree predicts student outcomes.

See also: Hoover-Dempsey, K.V., Walker, J.M.T., Sandler, H.M., Whetsel, D., Green, C.L., Wilkins, A.S., & Closson, K.E. (2005). Why do parents become involved? Research findings and implications. *Elementary School Journal, 106*(2), 105-130.

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APPENDIX B – Epstein's Model of Parent Involvement

Used with permission of the authors (Epstein et al., 2018)

SUMMARY TYPE 1–PARENTING

Information and activities that assist families with responsibilities for

- Housing, health, nutrition, clothing, safety
- Understanding child and adolescent development
- Home conditions that support children as students at all grade levels

And assist schools in

- Understanding family backgrounds, cultures, and goals for their children

CHALLENGES

- Provide information to all families who want it and need it, not just to the few who attend workshops or meetings at the school building.
- Enable families to share information with schools about their backgrounds, cultures, children's talents, goals, and needs.

REDEFINITIONS

"Workshops" are not only meetings on topics held at the school building but also the content of the meetings to be viewed, heard, or read at convenient times and varied locations by those who could not attend.

RESULTS FOR STUDENTS

- Balanced time spent on chores, homework, and other activities
- Regular attendance
- Awareness of family supervision and importance of school

RESULTS FOR PARENTS

- Self-confidence about parenting as children proceed through school
- Knowledge of child and adolescent development

RESULTS FOR TEACHERS AND ADMINISTRATORS

- Understanding families' goals and concerns for children
- Respect for families' strengths and efforts

For presentations, see the *Handbook* CD or visit resources.corwin.com/PartnershipsHandbook for usable slides on the types, challenges, redefinitions, and results for Type 1.

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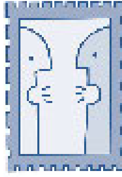

SUMMARY
TYPE 2–COMMUNICATING

SCHOOL-TO-HOME COMMUNICATIONS

- Memos, report cards, conferences, newsletters, phone calls, e-mails, text alerts, websites
- Information on school programs, state tests, report cards, and children's progress
- Information about choosing or changing schools, courses, programs, or activities

HOME-TO-SCHOOL COMMUNICATIONS

- Two-way channels of communication for questions, suggestions, and interactions

CHALLENGES

- Make all memos and other print and electronic communications clear and understandable for ALL families, including communicating in languages that parents understand.
- Obtain ideas from families to improve the design and content of communications such as newsletters, report cards, conference schedules, and options for two-way connections for parents' questions and suggestions.

REDEFINITIONS

Communications about school programs and student progress go not only from school to home but also from home to school and within the community.

RESULTS FOR STUDENTS

- Awareness of own progress in subjects and skills
- Knowledge of actions needed to maintain or improve grades
- Awareness of own role as courier and communicator in partnerships

RESULTS FOR PARENTS

- Understanding of school programs and policies
- Support for child's progress and responses to solve problems
- Ease of interactions and communications with school and teachers
- High rating of school quality

RESULTS FOR TEACHERS AND ADMINISTRATORS

- Ability to communicate clearly
- Use of parents' networks to communicate with all families

For presentations, see the *Handbook* CD or visit resources.corwin.com/PartnershipsHandbook for usable slides on the types, challenges, redefinitions, and results for Type 2.

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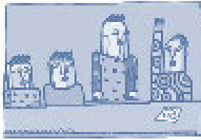

SUMMARY
TYPE 3–VOLUNTEERING

INVOLVEMENT AT AND FOR THE SCHOOL

- IN schools or classrooms: Assist administrators, teachers, and students as aides, tutors, coaches, lecturers, chaperones, boosters, and mentors, and assist in other ways.
- FOR schools or classrooms: Assist school programs and student activities from any location at any time.
- AS AUDIENCES: Attend assemblies, performances, sports events, recognition and award ceremonies, celebrations, and other student activities.

CHALLENGES

- Recruit widely, provide training, and create flexible schedules for volunteers so that all families know that their time and talents are welcomed and valued.

REDEFINITIONS

- "Volunteer" not only means someone who comes to school during the school day but also anyone who supports school goals and children's learning and development in any way, at any place, and at any time.

RESULTS FOR STUDENTS

- Skills that are tutored or taught by volunteers
- Skills in communicating with adults

RESULTS FOR PARENTS

- Understanding of the teacher's job
- Self-confidence about ability to work in school and with children
- Enrollment in programs to improve own education

RESULTS FOR TEACHERS AND ADMINISTRATORS

- Readiness to involve all families in new ways, not only as volunteers
- More individual attention to students because of help from volunteers

For presentations, see the *Handbook* CD or visit resources.corwin.com/PartnershipsHandbook for usable slides on the types, challenges, redefinitions, and results for Type 3.

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SUMMARY
TYPE 4–LEARNING AT HOME

INVOLVEMENT IN ACADEMIC ACTIVITIES

- Ways to help at home with homework
- Required skills to pass each subject
- Curriculum-related decisions by and for the student
- Development of student's other skills and talents

CHALLENGES

- Design and implement interactive homework on a regular schedule that guides students to demonstrate skills and discuss ideas with a parent or family partner.
- Involve parents with their children in important curriculum-related decisions in a timely way.

REDEFINITIONS

- "Homework" not only means work that students do alone but also interactive activities that students share and discuss with others at home and in the community to link schoolwork to real-life experiences.
- "Help" at home means how families encourage, listen, praise, guide, monitor, and discuss schoolwork with their children, not whether or how they "teach" school subjects.

RESULTS FOR STUDENTS

- Skills, abilities, and test scores linked to classwork
- Homework completion
- View of parent as more similar to teacher and home as similar to school
- Self-confidence in ability as learner and positive attitude about school

RESULTS FOR PARENTS

- Discussions with child about school, classwork, homework, and future plans
- Understanding of curriculum, what child is learning, and how to help each year
- Appreciation of teacher's work and skills

RESULTS FOR TEACHERS AND ADMINISTRATORS

- Respect for family time
- Satisfaction with family involvement and support
- Recognition that single-parent, dual-income, and low-income families and families of all racial and ethnic backgrounds can motivate their children and reinforce student learning

For presentations, see the *Handbook* CD or visit resources.corwin.com/PartnershipsHandbook for usable slides on the types, challenges, redefinitions, and results for Type 4.

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SUMMARY
TYPE 5–DECISION MAKING

PARENT PARTICIPATION AND SHARED LEADERSHIP ON

- School Council or School Improvement Team
- Action Team for Partnerships (ATP)
- PTA or PTO
- Title I advisory and other committees
- Independent advisory and advocacy groups

CHALLENGES

- Include parent leaders from all racial, ethnic, socioeconomic, and other groups on advisory councils, teams, and committees.
- Offer training for parent leaders to develop leadership skills and to represent other parents.
- Include student representatives in high schools along with parents on committees.

REDEFINITIONS

- "Decision making" in schools includes a process of partnership—for example, sharing views, solving problems, and taking action toward shared goals for excellent education and student success—not a power struggle of conflicting ideas.
- "Parent leader" means a representative who shares information with and obtains ideas from other families, not just a parent who attends school meetings.

RESULTS FOR STUDENTS

- Awareness that families' views are represented in school decisions
- Specific benefits linked to policies enacted by parent organizations and committees

RESULTS FOR PARENTS

- Awareness of and input to policies that affect children's education
- Development of participation and leadership skills in responsibilities for activities and in representation of other parents

RESULTS FOR TEACHERS AND ADMINISTRATORS

- Awareness of families' perspectives in policies and school decisions
- Recognition of equality of family representatives on school committees

For presentations, see the *Handbook* CD or visit resources.corwin.com/PartnershipsHandbook for usable slides on the types, challenges, redefinitions, and results for Type 5.

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SUMMARY TYPE 6–COLLABORATING WITH THE COMMUNITY

COMMUNITY CONTRIBUTES TO SCHOOLS, STUDENTS, AND FAMILIES

Business partners, cultural organizations, health services, recreation centers, senior citizens, faith-based programs, governmental agencies, and other groups

SCHOOLS, STUDENTS, AND FAMILIES CONTRIBUTE TO COMMUNITY

Service learning, philanthropy, and special projects to share talents and solve local problems

CHALLENGES

- Prevent or solve problems among partners of turf, goals, responsibilities, and funds.
- Inform all families and students about community programs and services, and ensure equal opportunities for participation and for services.

REDEFINITIONS

- Community includes not only families with children in the schools but also others who are interested in and affected by the quality of students' education.
- Communities are rated not only on economic qualities but also on the strengths and talents of people and organizations who may support students, families, and schools.

RESULTS FOR STUDENTS

- Knowledge, skills, and talents from enriched curricular and extracurricular experiences and explorations of careers
- Self-confidence and feeling valued by and belonging to the community

RESULTS FOR PARENTS

- Knowledge and use of local resources to increase skills and obtain needed family services
- Participation with others to strengthen the community and build a sense of community

RESULTS FOR TEACHERS AND ADMINISTRATORS

- Knowledge and use of community resources to enrich the curriculum, instruction, and students' experiences
- Knowledge of referral processes for families and children with needs for special services

For presentations, see the *Handbook* CD or visit resources.corwin.com/PartnershipsHandbook for usable slides on the types, challenges, redefinitions, and results for Type 6.

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APPENDIX C – Example CA.R.E. Program Modules

The Ca.R.E. Program

The Caregiver Resilience Education Program

Photograph of an art piece done by the children at Handimachal Therapy Center during a group therapy session with their caregivers (owned by Handimachal Therapy Center, used with permission).

Written and Designed by

Grace E. Myppidi

BOT, OTD Candidate, Boston University

Photograph of a child receiving community-based rehabilitation home visits from the Handimachal Therapy team, while the caregiver actively observes the session (owned by the author, used with permission).

Welcome

Greetings and welcome to the Caregiver Resilience Education (Ca.R.E.) Program, written and designed for caregivers of children with disabilities. The program's author understands the importance of caring for our loved ones and providing them with the support and assistance they need. As a caregiver, you play a vital role in ensuring the well-being of your children. This program will equip you with the knowledge and skills to provide the best care possible. The goal is to empower you and help you feel confident in your abilities as a caregiver. The author believes that you can make a significant difference in your children's lives with the right tools and resources. Thank you for joining us on this journey of learning and growth.

Contents

This document consists of an outline of the first 3 modules of the Ca.R.E. program. The author hopes this document will help provide a peek into the thoughtfulness and evidence-based approaches used to develop the program.

The modules of the Ca.R.E. program are titled as follows:

1. Caregiver Engagement and Self-Efficacy
2. Collaborative Goal Setting
3. Caregiver Coaching
4. Caregiver Involvement Styles
5. Caregiver Support Groups

Photograph of a child receiving community-based rehabilitation home visits from the community-based rehabilitation worker (Owned by Handimachal Therapy Center, used with permission).

Photograph of a caregiver demonstrating an exercise to their child, while the physiotherapist assists the child on a home visit near Handimachal Therapy Center (owned by the Handimachal Therapy Center, used with permission).

Module One: Caregiver Engagement and Self-Efficacy

Materials Required by the Instructor:

- A laptop loaded with PowerPoint or presentation software like Prezi or Canva
- Slides for Module 1 lesson content
- Materials for learning activities
- Adequate audio/visual systems

Materials Provided to the Participants:

- Journal
- Pen/Pencil
- The Ca.R.E. program folder
- Module 1 resource materials

Module 1 Session Breakdown

The entire session will last two hours, and will be conducted as follows.

Welcome and Program Introduction (10 minutes)

The author will warmly welcome the participants to the Ca.R.E. program, and thank them for sparing their valuable time. The author will introduce herself and the support team. Then, the author will give an overview of the course materials provided. Finally, the author will thank the Handimachal Therapy Center staff and administration for facilitating the pilot program and its venue.

Participant Introductions and Ice Breaker (20 minutes)

The author will ask the participants to go around the room introducing themselves.

PowerPoint Presentation (30 minutes)

The author will prepare and present a PowerPoint presentation spanning about 30 minutes. The presentation will cover the primary topic of caregiver engagement and self-efficacy, including definitions, role play scenarios, and how to develop these skills.

Question and Answer Time (15 minutes)

The participants will be given time to ask the author questions based on the module lesson content.

Refreshments Break (15 minutes)

The participants will be given time to enjoy the refreshments provided and socialize.

Break-Out Discussion Groups (20 minutes)

The author will divide the participants into smaller groups of 3, depending on the number of attendees. The author will then provide them with 3-4 guiding questions to discuss and share their insights with the group.

Reflection and Wind-Down (10 minutes)

The author will ask the participants to share their insights with the larger group, and remind them to reflect upon what they learned till the next session.

For more information about the Ca.R.E. program, please contact Grace Muppidi
gmuppidi@bu.edu

Photograph of a child receiving community-based rehabilitation home visits from the author, and the community-based rehabilitation worker, while the caregiver passively observes the session (owned by the author, used with permission).

Module Two: Collaborative Goal Setting

Materials Required by the Instructor:

- A laptop loaded with PowerPoint or presentation software like Prezi or Canva
- Slides for Module 2 lesson content
- Materials for learning activities
- Adequate audio/visual systems
- Multidisciplinary team seated as a panel of guest speakers

Materials Provided to the Participants:

- Journal
- Pen/Pencil
- The Ca.R.E. program folder
- Module 2 resource material

Module 2 Session Breakdown

The entire session will last two hours, and will be conducted as follows.

Welcome and Ice Breaker (10 minutes)

The author will warmly welcome the participants to the second week of the Ca.R.E. program, and welcome any new participants. The author will re-introduce herself and the support team. Then, the author will ask the participants to introduce themselves and concisely share their journey that led them to Handimachal Therapy Center.

Review of Module 1 (20 minutes)

The author will ask the participants to go around the room and share what they learned in Module one. They will also be asked to share, if willing, excerpts from their journals and reflections.

PowerPoint Presentation (30 minutes)

The author will prepare and present a PowerPoint presentation. The presentation will cover the topic of collaborative goal setting, and include insights and active involvement from the team of multidisciplinary rehabilitation professionals employed at Handimachal Therapy Center.

Question and Answer Time (15 minutes)

The participants will be given time to ask the author questions based on the module lesson content.

Refreshments Break (15 minutes)

The participants will be given time to enjoy the refreshments provided and socialize.

Panel Discussion (20 minutes)

Prior to the module 2 session, the author will provide case scenarios to the multidisciplinary rehabilitation team to discuss and prepare goals for each. These case scenarios will be presented, and the caregivers will be given opportunities to practice contributing to the collaborative goal setting as equal partners.

Reflection and Wind-Down (10 minutes)

The author will ask the participants to share their experiences with the group, and remind them to reflect upon what they learned, and find ways to practically apply them, till the next session.

For more information about the Ca.R.E. program, please contact Grace Muppidi
gmuppidi@bu.edu

Photograph of the author demonstrating a seating position to the caregivers of the child on one of the community-based rehabilitation home visits by Handimachal Therapy Center (owned by the author, used with permission).

Module Three: Caregiver Coaching

Materials Required by the Instructor:

- A laptop loaded with PowerPoint or presentation software like Prezi or Canva
- Slides for Module 3 lesson content
- Materials for learning activities
- Adequate audio/visual systems

Materials Provided to the Participants:

- Module 3 resource material

Module 3 Session Breakdown

The entire session will last two hours, and will be conducted as follows.

Welcome and Ice Breaker (10 minutes)

The author will warmly welcome the participants to the third consecutive week of the Ca.R.E. program and welcome any new participants. Then, the author will ask the participants to introduce themselves and share an experience where someone had taught them a skill. The author will also ask them to share what they liked about the way they were taught this skill, and what they did not like about the teaching method.

Review of Module 2 (20 minutes)

The author will ask the participants to go around the room and share what they learned in Module two. They will also be asked to share, if willing, excerpts from their journals and reflections.

PowerPoint Presentation (20 minutes)

The author will prepare and present a PowerPoint presentation. The presentation will cover the topic of caregiver coaching. This module will contain definitions, benefits of caregiver coiaching, and the steps to develop a successful coaching relationship between therapists and caregivers.

Question and Answer Time (15 minutes)

The participants will be given time to ask the author questions based on the module lesson content.

Refreshments Break (15 minutes)

The participants will be given time to enjoy the refreshments provided and socialize.

Demonstration and Discussion (20 minutes)

The author, accompanied by the community-based rehabilitation workers of Handimachal Therapy Center, will plan and demonstrate an occupational therapy session. In this role play scenario, the author, the occupational therapy practitioner, will demonstrate a caregiver coaching session, and open the floor for discussion.

Reflection and Wind-Down (10 minutes)

The author will ask the participants to share their experiences with the group, and remind them to reflect upon what they learned, and find ways to practically apply them, till the next session.

For more information about the Ca.R.E. program, please contact Grace Muppidi
gmuppidi@bu.edu

APPENDIX D – Informed Consent Form

Informed Photograph Consent and Release Form

Clients Name: Handimachal Therapy Center

I consent to the photographs taken of children, their caregivers, and the multidisciplinary rehabilitation team during therapy sessions at Handimachal Therapy Center.

I consent to the aforementioned photographs being used in the doctoral thesis titled: The Caregiver Resilience Education (Ca.R.E.) Program, by Grace Muppidi, a doctoral candidate at Boston University.

I understand that I will not be compensated by consenting to the use of these photographs.

Furthermore, I acknowledge that these photographs belong to Handimachal Therapy Center, and informed consent for these photographs has been collected from each caregiver and therapist involved.

I authorize using these photographs to disseminate educational and academic document purposes of the Ca.R.E. program: Fact Sheet/ Executive Summary/ Ca.RE.program modules/ and marketing and social media posts related to the Ca.R.E. program.

By signing this form, I confirm my understanding of this consent. If I wish to withdraw my consent in the future, I may do so via a written request submitted to Grace Muppidi or by completing a new form.

Client Signature: DIVYA RANI
ADMINISTRATOR
The Henimlchal Society
Auth. Signatory

Date: 30-06-2023

APPENDIX E– Executive Summary

Introduction

No matter where facilitated, pediatric occupational therapists face high caseloads, excessive administrative tasks, lack of time, and constant interruptions to service provision (Goffredo et al., 2022). A lack of knowledge and awareness regarding the importance of caregiver engagement and self-efficacy also contributes to a larger problem with providing pediatric occupational therapy services. Further, rural and low-economic communities need more occupational therapy practitioners to manage the growing service demand due to increased awareness and knowledge about the profession.

Hiring occupational therapy practitioners to meet the need is not always possible in rural community-based clinical settings with low budgets. For example, Handimachal Therapy Center in Kullu, India, is a nonprofit organization that works toward the well-being and multidisciplinary rehabilitation of children with disabilities in the local community of Kullu, where the author previously worked. The occupational therapists on staff at the Center must treat almost 50 children with various disabilities weekly. The author’s work in rural India is the inspiration for this project. The combination of high caseload and the subsequent lack of ability to provide one-to-one intervention lay a foundation for inviting caregivers’ engagement, education, and motivation to participate in their children’s occupational therapy services at the clinic and at home. Without further support from India’s government and health care system, the author aims to develop an evidence-based, affordable, and accessible solution to improve caregiver engagement and self-efficacy.

A detailed review of the evidence-based literature by the author revealed factors contributing to the problem of low caregiver engagement and self-efficacy. Further research was conducted by the author on existing caregiver education approaches to help create an evidence-based caregiver education program that could be piloted at the site of inspiration, Handimachal Therapy Center. Research revealed that approaches like caregiver coaching, group-based education, and therapist modeling were associated with positive outcomes (Angelin et al., 2021; Bryne et al., 2019; Collis et al., 2020; Pitt et al., 2013). The author utilized adult learning, social cognitive, and self-determination theories to build a theoretical foundation for the education program. After reviewing the theories and literature found pertinent to the development of such a program, the author developed five complete module contents, a program evaluation, funding, and dissemination plan. The author's affordable and accessible caregiver group- and evidence-based education program aiming to improve caregiver engagement and self-efficacy is called the Caregiver Resilience Education (Ca.R.E.) program.

Project Overview

The creation of the Ca.R.E. program began with identifying three research questions that addressed: (a) lack of caregiver engagement and self-efficacy contributes to the deterioration of children with disabilities' well-being, (b) sociocultural, personal, and therapist factors that influence caregiver engagement, and (c) caregivers' limited access to occupational therapy/rehabilitation services. A review of factors contributing to the problem revealed three categories, personal, environmental, and contextual, and practitioners themselves. Personal factors of the caregiver contribute to the problem, such

as lack of knowledge and awareness, low levels of confidence, help-seeking behavior, cultural expectations, as well as lack of familial support (Edwards et al., 2003; Lin et al., 2018; Tully et al., 2017; Vadivelan et al., 2020). Environmental and contextual factors include lack of access to public and private transportation options, rough terrain/geography, social stigma, discrimination, scheduling conflicts, and unfavorable workplace environments (Edwards et al., 2003; Stargel et al., 2020; Vadivelan et al., 2020). The practitioners can compound these issues due to a lack of cultural sensitivity and limited caregiver-therapist collaboration (Brassart et al., 2017; Edwards et al., 2003).

Next, to help guide the development of the Ca.R.E. program, a review of relevant theories was conducted to address the identified problem. The following frameworks and models significantly guide the Ca.R.E. program and form its theoretical foundation: self-determination theory (Deci & Ryan, 2000), social cognitive theory (Bandura, 1986), adult learning theory (Knowles, 1984), the Hoover-Dempsey and Sandler model (Hoover-Dempsey et al., 2005), and Epstein's framework (Epstein et al., 2018). Caregiver engagement is an internal state influenced by internal and contextual factors. Self-determination theory explores that people's motivation requires consideration of innate psychological needs, which provide a foundation for engagement components: affective, behavioral, and cognitive (D'Arrigio et al., 2017). Social cognitive theory (Bandura, 1986) plays a role in adopting, initiating, and maintaining health behaviors (Luszczynska & Schwarzer, 2005). The author applied the principles of adult learning theory, such as active participation, group interaction, goal-oriented learning, and relevant practical approaches (Knowles, 1984), to the Ca.R.E. program. The Hoover-Dempsey and Sandler

model depicts five levels, beginning with parents' motivational beliefs, perception of invitations, and contextual factors, leading to student achievement at Level 5 (Walker et al., 2010). These levels describe the parental involvement process and were included in the Ca.R.E. program content. Epstein's framework discusses parental/caregiver involvement within the three contexts of school, family, and community, encompassing a child's development and learning (Mahuro & Hungi, 2016).

The author also reviewed existing approaches to improve caregiver engagement and self-efficacy. The review revealed evidence supporting group-based education programs, collaborative goal-setting, caregiver coaching, therapist modeling, and caregiver support groups. Technology, such as audiovisual information resources as a primary mode of content delivery to ensure accessibility and to overcome barriers such as scheduling conflicts and transportation difficulties were also incorporated (Tully et al., 2017). The author also included conditions to reevaluate the outcomes after the program concludes and again 1 or 2 years after the program implementation to assess its long-term benefits (Wilkes-Gillan et al., 2017).

The Ca.R.E. program consists of five modules to be conducted over five consecutive weeks, lasting 2 hours each weekend. This 10-hour program will be piloted at the primary clinic of Handimachal Therapy Center in Kullu, India. The author, an occupational therapy practitioner, is the program's primary instructor. The multidisciplinary rehabilitation professional team, support staff, administrative staff, and a social worker of Handimachal Therapy Center are the key personnel assisting the author with the Ca.R.E. program implementation. The professional team will collaborate

with the author for session lectures and group discussion facilitation. The support staff will assist the author with setting up, providing daycare services to the children, and in-session assistance. The administrative staff will ensure the smooth running of the Ca.R.E. program by providing resources and coordinating with the entire team. The social worker will assist with program marketing, social media, and caregiver recruitment. Each in-person session includes an icebreaker, an information session based on an evidence-based topic, a practical demonstration and coaching, and a group discussion. The Ca.R.E. program is further supported by providing a journal, printed resources and module content, and refreshments for each session.

Key Findings

Several essential findings became apparent during the development of the Ca.R.E. program. First, there is a need for affordable, accessible, and evidence-based education programs for caregivers of children with disabilities in low-income, rural communities. Secondly, evidence-based approaches have been identified based on literature reviews to ensure the effectiveness of the Ca.R.E. program, such as group-based education, collaborative goal-setting, therapist modeling, coaching, information resources delivered using technology, group discussions, and caregiver support groups. Finally, the theoretical basis of caregiver involvement, self-efficacy, and motivation was incorporated into the Ca.R.E. program to provide a descriptive, appropriate, and holistic intervention for caregivers of children with disabilities that can effectively deliver in a rural community-based rehabilitation clinic setting.

Recommendations

The key findings mentioned previously can serve as guidelines for occupational therapy practitioners developing or intending to develop caregiver education programs. Program developers can investigate expanding the audience to any setting, not just rural and low-income settings, as caregiver engagement and self-efficacy influence children's positive outcomes. When developing and delivering program content, practitioners must also consider the cultural and socioeconomic context. The key findings of the Ca.R.E. program may be presented as a continuing education program for other occupational therapy practitioners who wish to develop evidence-based education programs for caregivers.

General Conclusions

The Ca.R.E. program is a group-based education program for caregivers of children with disabilities, meant to be piloted in rural India. It attempts to fill the gaps in caregiver education while maintaining accessibility and affordability. The author envisioned this program as a pathway to developing caregiver advocacy and empowerment to fight occupational injustice. Handimachal Therapy Center's vision and mission are to rehabilitate, empower and train children with disabilities to improve their well-being and build an accepting and safe society within their community. The Ca.R.E. program pilot is ready to be launched. Once successfully implemented, the author intends to conduct the program evaluation research and disseminate the findings to a global community of caregiver advocates and practitioners.

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APPENDIX F – Fact Sheet

The Caregiver Resilience Education (Ca.R.E.) Program

Grace E. Muppidi, BOT

OTD Candidate

The problem the **Caregiver Resilience Education (Ca.R.E.) program** addresses is based on the author's clinical work with caregivers of children with disabilities in a community-based rehabilitation setting called Handimachal Therapy Center in rural India. The author observed that only a small percentage of caregivers engaged in their children's therapy sessions and carried over activities or plans at home. This, coupled with a high patient-to-therapist ratio at the center, led to delayed progress and ineffective therapy sessions.

Pictured above is the author treating a child on a home visit under the community-based rehabilitation program, with the caregivers present. The photograph is owned by the Handimachal Therapy Center and used with permission.

Factors contributing to the problem:

Personal Caregiver Factors

Help-seeking attitudes | Cultural expectations | Lack of knowledge and awareness | Limited familial support | Reduced confidence

Environment and Contextual Factors

Lack of accessibility and resources | Social stigma | Discrimination | Scheduling conflicts

Therapist and Healthcare Factors

Lack of cultural sensitivity | Inadequate caregiver–therapist collaboration

Theoretical Foundation:

The Ca.R.E. program is guided by the self-determination theory (Deci & Ryan, 2000), social cognitive theory (Bandura, 1986), adult learning theory (Knowles, 1984), the Hoover-Dempsey and Sandler model of the parent/caregiver involvement process (Hoover-Dempsey et al., 2005), and Epstein's framework for six types of involvement (Epstein et al., 2018).

Summary of the Ca.R.E. program:

The Ca.R.E. program was carefully curated using evidence-based practices and approaches from current literature. The pilot Ca.R.E. program will be implemented at the Handimachal Therapy Center and includes five 2-hour modules to be conducted in person for five consecutive weeks. The five modules begin with discussing the importance of caregiver engagement and self-efficacy. The program modules utilize approaches such as coaching, group discussions, therapist modeling, and role play to actively engage participants and support the adult learning process. The program culminates in the formation of sustainable caregiver support groups.

Pictured above is a group caregiver-education class at the Handimachal Therapy Center. The photograph is owned by the Handimachal Therapy Center and used with permission.

Module 1: An Introduction to Engagement and Self-Efficacy
Module 2: Collaborative Goal-Setting
Module 3: Caregiver Coaching
Module 4: Caregiver Involvement Styles
Module 5: Caregiver Support Groups

Impact on Occupational Therapy Practice:

The Ca.R.E. program was designed with the vision to create an affordable and accessible education program for caregivers of children with disabilities living in low-resource communities. Keeping the Ca.R.E. program cost-effective, accessible, culturally relevant, and evidence-based is of paramount importance to the author because she believes it has the potential to serve communities beyond rural India.

Pictured above is a group art therapy project done by the caregivers and their children at the Handimachal Therapy Center. The picture is owned by the Handimachal Therapy Center and used with permission.

It is hoped that occupational therapy practitioners using and teaching the Ca.R.E. program will see improvement in caregivers' self-efficacy and engagement at the clinic, at home, and in other social settings. The author also foresees improvement in children's therapy outcomes. This improvement can lead to caregiver advocacy for their children's rights and occupational justice. As an added benefit, the more engaged and self-efficacious caregivers are, the less burden is placed on occupational therapy practitioners working in rural, community-based settings.

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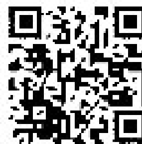

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