CEREBRAL PALSY: EXPLORING AND INFORMING THROUGH THE ICF LENS

Exploring and expanding stakeholders' perspectives on the management of Cerebral Palsy, using the International Classification of Functioning, Disability and Health (ICF) and Knowledge Translation framework

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LAY ABSTARCT

Exploring and expanding stakeholders’ perspectives on the management of Cerebral Palsy, using the International Classification of Functioning, Disability and Health (ICF) and Knowledge Translation framework

Cerebral Palsy (CP) is the most common cause of physical disability in children. Parents and professionals from multiple disciplines work together to provide developmental support for children with CP. This thesis explored parents’ views about management of CP in India and Canada; assessed the scope of the scientific literature from India addressing CP; and developed and evaluated educational videos to inform parents and professionals about the use of the International Classification of Functioning, Disability and Health (ICF) in the management of CP. Parents’ views towards their children in both countries are influenced by the availability of resources, professional attitudes, and cultural beliefs. Research in India focuses on ‘fixing’ the child’s impairments. The videos developed to encourage parents and doctors to focus on increasing activity and participation in children, were judged to be useful in creating awareness about the use of the ICF in the management of CP.

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ABSTRACT

Introduction: Cerebral Palsy (CP) is the most common cause of disability in children. Healthcare providers aim to facilitate optimal function and participation by working with children and their families. The success of this endeavor depends on shared understanding, collaboration, and contextual factors that affect resource availability. The aim of this thesis was to understand parents' perspectives in Indian and North American cultures towards management of CP using an ICF lens, to evaluate the extent to which this lens is evident in literature conducted in an Indian context and to evaluate a Knowledge Translation (KT) resource to inform parents and healthcare professionals (HCP).

Methods: In the five thesis papers: study 1 explored parents' perspectives towards the management of their children with CP (qualitative design); study 2 described the contextual factors shaping parents' perspective in India (reflective design); study 3 and 4, described the research trends in the management of CP in India (scoping review); and study 5 describes the development and evaluation of a KT resource created to inform parents about incorporating the ICFconcepts into management of CP.

Results: The qualitative study identified that Indian parents focus more on Body Structure and Function (BSF) challenges and have more resource limitations, as compared to the Canadian context. The scoping review identified that research also focuses on BSF, with less research addressing activity and participation, or its environmental determinants. KT resources showing the application of the ICF concepts into CP management received widespread uptake and were perceived as helpful by parents and HCP.

Discussion and Conclusion: ICF was useful for understanding and informing parents and HCP about management of CP. Despite the importance of environmental considerations and contextual factors, these were insufficiently addressed in the literature and in stakeholder perspectives. To optimize CP management across contexts, further research and KT is needed.

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"Coming together is a beginning, keeping together is progress, working together is a success."
- Henry Ford

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TABLE OF CONTENTS

Chapter 1. INTRODUCTION TO THESIS

Chapter 2. PERSPECTIVES ON REHABILITATION FOR CHILDREN WITH CEREBRAL PALSY: EXPLORING A CROSS-CULTURAL VIEW OF PARENTS FROM INDIA AND CANADA USING THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF) ………………………………P. 20

LIST OF FIGURES

The figures are identified below with the first digit representing the chapter, followed by a period, and the second digit indicating the figure or table number in the chapter.

FIGURES:

LIST OF TABLES AND APPENDICES

The tables and appendices are identified below with the first digit representing the chapter, followed by a period, and the second digit indicating the table/appendix number in the chapter.

TABLES:

Appendices

ABBREVIATIONS AND SYMBOLS

CP – Cerebral Palsy
ICF – International Classification of Functioning, Disability and Health
QoL – Quality of Life
HCP – Healthcare Professionals
WHO – World Health Organization
KT – Knowledge Translation
KTA – Knowledge to Action cycle
P-ICF – Parents ICF
BSF – Body Structure and Function

CONTRIBUTIONS

This thesis follows a sandwich style. It consists of five separate manuscripts, each one is presented in the format of the target journal for publication.

I, Pranay Jindal, am the first author for all of the manuscripts herein. All aspects of the study including study design, ethical clearance, data collection and analysis, manuscript preparation, and submission are primarily my own work.

The co-authors on four manuscripts include my supervisor, Dr. Joy C. MacDermid, committee members, Drs. Peter Rosenbaum, Briano DiRezze, and Amitesh Narayan (Local principal investigator in India). All committee members helped to refine the objectives, provided assistance in data analysis and interpretation, provided content knowledge, editorial assistance, gave feedback on the manuscripts, and approved the final version of all the papers. Dr. Amitesh also helped in getting ethical clearance and recruiting participants from India.

For the second manuscript, I am the sole author as it is a reflective paper. The target journal and publication status is noted for every paper in context.

Chapter 1

BACKGROUND TO CEREBRAL PALSY

Cerebral Palsy (CP) refers to a group of permanent disorders of the development of movement and posture causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disorders of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems (Rosenbaum et al., 2007). Despite a variety of impairments to various aspects of the person's body, successful medical, educational and social interventions at various time points can enable children with CP and their families live meaningful lives (Shevell, Miller, Scherer, Yager, & Fehlings, 2011).

Despite advances in neonatal care, CP is the most common cause of lifelong physical disability in children in the 21st century (Oskoui & Shevell, 2009; Pakula, Van Naarden Braun, & Yeargin-Allsopp, 2009; Romantseva & Msall, 2006; Rosenbaum, 2003). In Western countries, the prevalence of CP ranges from 1.5 to 3 per 1000 live births (Arneson et al., 2009; Cans, 2000; Pakula et al., 2009; Paneth, Hong, & Korzeniewski, 2006). Worldwide prevalence of CP has been reported to be 2.11 per 1000 live births (Oskoui, Coutinho, Dykeman, Jetta, & Pringsheim, 2013). Being a lifelong disorder, CP has an impact on the individual, family and society in terms of financial, physical and psychological costs (Honeycutt et al., 2003; Kruse et al., 2009; Wang et al., 2008).

MANAGEMENT OF HEALTH NEEDS OF CHILDREN WITH CEREBRAL PALSY

In conditions like CP, available treatments only address the signs and symptoms and are unable to cure the actual pathology underlying the disorder (Rosenbaum & Gorter, 2012). For a long time, treatment of CP has been based upon a biomedical model of health. Traditional biomedical approaches for treating CP have focussed on changing the impairments of CP with the assumptions that resolving the impairments will lead to a better functioning and possibly "normal" child (Rosenbaum & Gorter, 2012).

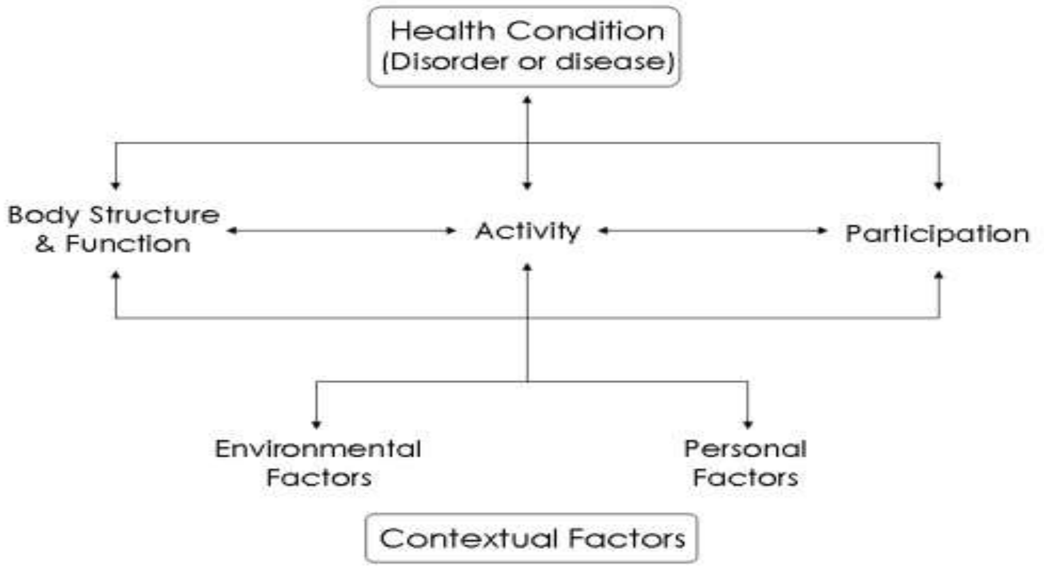
Recent studies suggest that many impairment-level approaches do not have conclusive evidence or impact when used in clinical practice, and interventions at the impairment level alone do not lead to increased function and engagement in life activities (Anttila, Autti-Ramo, Suoranta, Makela, & Malmivaara, 2008; Brown & Burns, 2001; Cauraugh, Naik, Hsu, Coombes, & Holt, 2010; Kulak-Bejda, Kulak, Bejda, Krajewska-Kulak, & Kulak, 2016; Narayanan, 2012; Novak et al., 2013; Novak et al., 2016; Park & Kim, 2014; Wiart, Darrah, & Kembhavi, 2008; Wright, Rosenbaum, Goldsmith, Law, & Fehlings, 2008). Studies also show that therapies aimed to promote functional activities have incremental or equal functional benefits over conventional therapies that focus on fixing impairments (Chen, Pope, Tyler, & Warren, 2014; Huang, Fetters, Hale, & McBride, 2009; Ketelaar, Vermeer, Hart, van Petegemvan Beek, & Helders, 2001; Kruijsen-Terpstra et al., 2016; Law et al., 2011).

Since the goal of therapy is to increase a child's function and participation in various age appropriate activities, healthcare professionals need a comprehensive understanding of all the areas influencing a child's development, activity, and participation. Multidimensional interventions in different areas and time points of a child's life are required to make a change in the child's and family's Quality of Life (QoL).

THE ICF FRAMEWORK AND ITS ROLE IN THE MANAGEMENT OF CEREBRAL PALSY

The World Health Organization (WHO)'s International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2002) (Figure 1) provides a framework to understand and describe the factors that healthcare professionals and other stakeholders should consider while managing a health condition. The ICF views health in five interconnected domains: body structure and function, activity, participation, environmental and personal factors (the latter two are called contextual factors).

Figure 1: the ICF framework



The ICF provides the following definitions for the domains mentioned above (World Health Organisation, 2002).

1. Body structures are defined as "anatomical parts of the body such as organs, limbs, and their components." P-10
2. Body function is defined as "physiological functions of body system" (including psychological functions). P-10
3. Activity is defined as "an execution of a task or an activity by an individual," and activity limitation is defined as "difficulties an individual may have in executing activities." P-10

4. Participation is defined as "an involvement in life situation," and participation restriction is defined as "problems an individual may experience in involvement in life situations." P-10
5. Environmental factors are external factors and are defined as "the physical, social and attitudinal environment in which people and live and conduct their lives." P-10. Examples of environmental factors include social attitudes, architectural, legal and social characteristics.
6. Personal factors are internal factors like age, gender, coping styles, social background, education, profession, past and current experience, overall behaviour patterns and other factors that influence how an individual experiences disability. Personal factors are considered as a background of an individual's life and living that are not a part of a health condition, but can impact the functioning positively or negatively (Grotkamp, Cibis, Nuchtern, Von Mittelstaedt, & Seger, 2012). Personal factors are not classified in their entirety under the ICF framework due to their cultural and social variability.

The biopsychosocial nature of the ICF framework helps to expand on possible options while planning interventions for children with CP. The interconnected and dynamic nature of the ICF framework gives an opportunity to intervene at any or all the domains of health, and changes in any one domain may influence the other domains (Rosenbaum & Gorter, 2012; Rosenbaum & Stewart, 2004; Rosenbaum & Rosenblooom, 2012).

Having clinicians and other stakeholders incorporate the ICF concepts into the rehabilitation of children with CP broadens the scope of services that can be provided to children with CP (Rosenbaum & Gorter, 2012; Rosenbaum & Stewart, 2004). The use of the ICF in clinical practice and research is increasing (Escorpizo & Bemis-Dougherty, 2015), but more efforts are needed to engage, educate and empower parents of children with CP and other stakeholders to use ICF in decision-making and treatment planning for CP. In this thesis, I use the ICF framework to 1) explore parents' perspective of their children with CP, 2) explore the scope and nature of research regarding CP management in India, and 3) inform parents and other stakeholders about the management in CP.

THE INFLUENCE OF THE ENVIRONMENT AND THE ROLE OF PARENTS

Though the ultimate goal of all the therapies and management strategies is, or ought to be, to increase participation of children with CP, participation is a complex construct and is strongly influenced by environmental factors. Studies in Western and resource-rich countries illustrate that in children and youth with CP, environmental factors like socio-cultural attitudes, physical and transport barriers, negative (or poor) social and peer attitudes, and limited resources could negatively impact on participation in leisure (Boucher, Dumas, Maltais, & Richards, 2010; Thomas, Majnemer, Law, & Lach, 2008), school (Anaby et al., 2014; Pratt, Baker, & Gaebler-Spira, 2008), home (Anaby et al., 2014; Law et al., 2013), and interpersonal relationships (Wiegerink, Roebroeck, Bender, Stam, & Cohen-Kettenis, 2011). Qualitative studies reporting parents' and children's views also highlight that attitudinal and physical barriers hinder the participation of children and adolescents with CP in different areas of life (Kramer, Olsen, Mermelstein, Balcells, & Liljenquist, 2012; Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006; Lindsay, 2016; Mei et al., 2015; Piškur, Beurskens, Jongmans, Ketelaar, & Smeets, 2015; Shimmell, Gorter, Jackson, Wright, & Galuppi, 2013). Social support, geographical location (Anaby et al., 2013) and positive parental attitudes (Verschuren, Wiart, Hermans, & Ketelaar, 2012) positively influence children's development.

Incorporating the concepts of the ICF in the past decade in Western countries, the focus of management in CP has shifted towards increasing participation in children with CP, as opposed to fixing the child's impairment (Law & Darrah, 2014; Rosenbaum, 2015). India is still a resource-limited country, with high maternal and infant mortality rates (Paul et al., 2011). Disability rates in India are rising rapidly, but the government's focus currently is to decrease mortality rates, and rehabilitation of neurological disorders is not a priority in government policies (Paul et al., 2011).

On a societal level in India the healthcare system (fee-for-service model compared to insurance or publicly-funded as in some resource-rich countries), literacy rates, and the reach and use of the Internet for searching health information online differ from the way these factors influence people's lives in resource-rich countries (Backman et al., 2008; Borg, Lindstrom, & Larsson, 2011; Parnes et al., 2009; Prakash, Patel, Hariohm, & Palisano, 2016; World Bank, 2015a; World Bank, 2015b). Infrastructural barriers, cultural and religious beliefs, and social stigma hinder participation of children with CP in India (Dhar, 2009; Janardhana, Muralidhar, Naidu, & Raghevendra, 2015; Kumar & Gupta, 2012; Nimbalkar, Raithatha, Shah, & Panchal, 2014; Parnes et al., 2009; Reddy et al., 2011; Sekaran et al., 2010; Sharma & Sinha, 2014). Parents' educational status and attitudinal barriers also pose a significant challenge for rehabilitation of neurological disabilities in India (Vajravelu & Solomon, 2013). Even healthcare professionals in India learn in a traditional curriculum, and there is less focus on research, curriculum design, and resource development (Solanki & Kashyap, 2014; Supe & Burdick, 2006).

These socio-cultural, financial, architectural and literacy factors all influence the conceptualization, incorporation and implementation of participation-based approaches in the management of CP in India and other resource-limited countries. To work towards incorporating participation-based approaches for CP in India, it is important to understand the focus of current research about CP in India, and what factors are facilitating it. Using the ICF framework, in this thesis, I explore the scope and nature of the research about CP in India.

Parents are an essential part of the child's environment. Parents serve an integral part in the rehabilitation of their children with CP (Murphy et al., 2011), and are often looking for more information to support the development of their child (McHugh, Bailey, Shilling, & Morris, 2013; Palisano et al., 2010; Piskur et al., 2012; Siebes, Ketelaar, Gorter, Alsem, & Jongmans, 2012). Parents involve in the major decision-making processes with the health care team, are responsible to implement the exercise program at home, and also to advocate for their child. To make informed decisions, to understand the rationale of exercise programs, and to advocate effectively for their child, parents need to have proper information about their child's health and rehabilitation. To involve parents actively in the management of their child with CP, it is important to understand parents' perspectives towards their child's management and the factors shaping these perspectives.

THE ROLE OF QUALITATIVE RESEARCH IN UNDERSTANDING PARENTS's PERSPECTIVES ON REHABILITATION IN CEREBRAL PALSY

Parents' perspectives influence their attitudes and behavior towards their child's health condition, its management and the treatment outcomes (Danseco, 1997). Qualitative studies allow researchers to explore and understand the issues like experiences, attitudes, perspectives, and behavior (Huston & Rowan, 1998), which cannot be captured effectively in the same detail through quantitative studies. Qualitative research is a form of social inquiry that aims to provide an in-depth understanding of the social world by exploring people's circumstances, experiences, perspectives and stories (Atkinson, Coffey, & Delamont, 2001; Snape & Spencer, 2003). Qualitative research is rooted in the field of social sciences and is based on an ontological principle concerning the nature of reality, with the notion that realities are relative, context-bound, experientially based, constructed through social interaction, and subject to redefinition realities that are (Charmaz, 2014; Hunt, 2009). One of the main strengths of qualitative research is that it seeks to explore and understand the phenomenon from the perspective of the participant regarding the way that they experience, interpret, and attach meaning to it (Atieno, 2009).

Multiple approaches to qualitative inquiry exist. The interpretive description is a qualitative approach that originated in nursing but is being used with increased frequency across disciplines within health science (Olson, Young, & Schultz, 2016; Thorne, Kirkham, & MacDonald-Emes, 1997). Developed by Thorne and colleagues to generate clinically relevant knowledge for allied health disciplines, interpretive description is an inductive and constructivist way of qualitative inquiry and falls within an interpretive paradigm (Hunt, 2009; Thorne et al., 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004). Epistemologically (concerning ways to gain knowledge), the interpretive description approach believes in understanding multiple views of people in a particular social situation. It allows researchers to identify themes and patterns, and to explore variations between individuals (Thorne et al., 2004). It allows the researcher and participant to co-create knowledge and recognizes the clinical knowledge of the researcher as an advantage (Hunt, 2009). The interpretive description approach is designed to address applied clinical research questions and complex, experiential healthcare issues in a way that not only reports or depicts but includes clinical interpretation of experiences.

Studies in Western countries exploring parents' perspectives on children's functioning (Mei et al., 2015; Schiariti et al., 2014) and therapy (Peplow & Carpenter, 2013; Verschuren et al., 2014;

Wiart, Ray, Darrah, & Magill-Evans, 2010) illustrate that it is important to collaborate with parents for increased satisfaction with their child's rehabilitation. Resource-limited countries, like India, have financial, literacy, architectural, and social barriers. Parents' perspectives towards their children with CP might differ from Western, resource-rich countries. In this thesis, I used the interpretive description approach to explore parents' perspective on management of children with CP in India and Canada, and the factors shaping these perspectives.

THE NEED FOR KNOWLEDGE TRANSLATION TO MOVE RESEARCH INTO PRACTICE

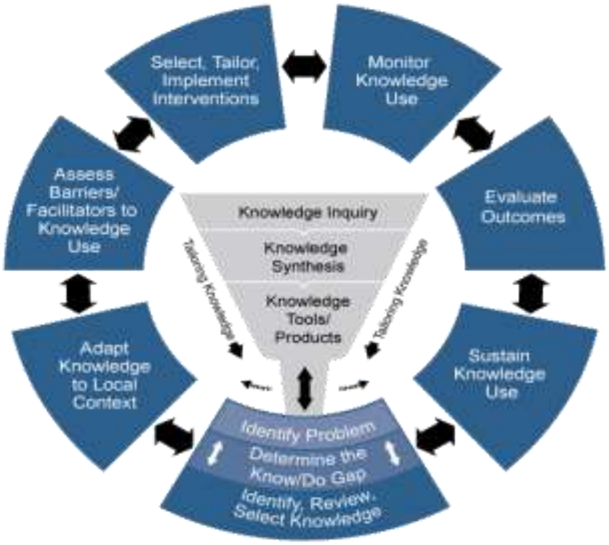
Knowledge Translation (KT) is a dynamic and iterative process that involves synthesis and dissemination of knowledge to consumers in an accessible and easily understandable method (Canadian Institutes of Health Research, 2013). It focuses primarily on activities that aim to close the gap between research, clinical decisions and practice (Graham et al., 2006). Knowledge translation activities help in creating awareness, increasing knowledge, and facilitating the uptake and implementation of research evidence by stakeholders, by simplifying and summarising the research findings in a non-technical format that is easy to access and interesting (Cross, Rosenbaum, Grahovac, Kay, & Gorter, 2015; Iles & Davidson, 2006; Jeong, Law, DeMatteo, Stratford, & Kim, 2016; MacDermid & Graham, 2009; McColl, Smith, White, & Field, 1998; Rivard, Camden, Pollock, & Missiuna, 2015; Salbach, Jaglal, Korner-Bitensky, Rappolt, & Davis, 2007; Salbach, Veinot, Jaglal, Bayley, & Rolfe, 2011). Knowledge that is readily available and understandable can help consumers by improving their understanding of the health condition and its management, thus strengthening the healthcare system (Straus, Tetroe, & Graham, 2011).

Suboptimal uptake and utilization of research evidence into clinical practice is a frequently reported finding (Brekke, Ell, & Palinkas, 2007; Glasgow & Emmons, 2007; McGlynn et al., 2003; Rynes, Bartunek, & Daft, 2001). Complexity of medical knowledge (Cranney & Walley, 1996; Lyons, Brown, Tseng, Casey, & McDonald, 2011; Nilsson Kajermo, Nordström, Krusebrant, & Björvell, 1998), lack of time (Cranney, Warren, Barton, Gardner, & Walley, 2001; Ely et al., 2002; Grimmer-Somers, Lekkas, Nyland, Young, & Kumar, 2007; Humphris, Littlejohns, Victor, O'Halloran, & Peacock, 2000; Iles & Davidson, 2006; Jette et al., 2003; Nilsson Kajermo et al., 1998; Retsas, 2000), lack of skills needed to understand and apply the research findings among professionals (Cranney & Walley, 1996; Grimmer-Somers et al., 2007; Iles & Davidson, 2006; Lyons et al., 2011; Nilsson Kajermo et al., 1998; Upton, 1999), and inaccessibility of research articles (Grimmer-Somers et al., 2007; Iles & Davidson, 2006; Lyons et al., 2011; Nilsson Kajermo et al., 1998; Retsas, 2000) are commonly cited reasons for the existing research-to-practise gap. Resource-limited countries lack financial and infrastructural resources and have less health literacy compared to resource-rich countries. To encourage stakeholders in resource-limited countries to use recent evidence in the management of children with CP, there is an essential need to create and disseminate knowledge resources in simple and interesting formats. Even in resource-rich countries, a recent study in Canada suggests that

Health Care Professionals (HCPs) prioritize impairment-based treatment approaches over environment- and participation-based approaches (Anaby et al., 2016; Saleh et al., 2008), and KT interventions are needed to bridge this gap (Anaby et al., 2016).

In this thesis, I used the Knowledge to Action (KTA) cycle (Graham et al., 2006) (Figure. 2) to develop ICF framework-based video education modules to inform parents and other stakeholders about the treatment of CP. The KTA cycle was proposed by Graham et al. (Graham et al., 2006) as a conceptual framework to create and disseminate KT resources to various stakeholders. The KTA cycle is divided into an inner a) knowledge funnel, and an outer b) action cycle. The knowledge funnel describes the processes by which knowledge is refined and customized to the target end user. The knowledge funnel transitions into the action cycle by a knowledge tool. A knowledge tool presents the knowledge in a user-friendly format and meets stakeholders' information needs and also influences what stakeholders do with the knowledge. The action cycle describes the processes involved in the application of tailored knowledge to achieve health benefits.

Figure 2: Knowledge to Action Cycle



THE STATEMENT OF RESEARCH PROBLEM:

Various studies have assessed parents' perspectives towards the management of their children with CP in Western and resource-rich countries. Fee-for-service healthcare systems, limited financial support, inaccessible infrastructure and cultural beliefs might lead parents' perspectives in low-resource countries to differ from those of parents in resource-rich countries. Disability rates in low-resource countries are rising, and there are limited data exploring parents' perspectives in low-resourced countries (Maulik & Darmstadt, 2007). To engage parents and families successfully in the management of their children with CP, it is important to explore their perspectives and knowledge needs, and to provide them with simple evidence-based educational tools to inform them about the management of CP.

Parents' perspectives are shaped by the society they live in. It is expected that parents' perspectives and the treatment strategies used by HCP are influenced by each other. There is a need to explore the current research trends regarding CP research in India, to understand whether HCPs provide evidence-based care for CP management or not. To increase the QoL of children and families with CP, it is important for HCPs to provide the best evidence-based care for the management of CP.

OBJECTIVES OF THESIS WORK

The overall aim of this thesis is to explore parents' perspectives and information needs about their children with CP in a low-resource and resource-rich country; understand the research focus on CP and develop and evaluate a knowledge resource to educate and inform stakeholders about using the ICF framework in managing health children of with CP. The specific objectives were:

1. To explore parents' perspectives, knowledge needs, and the factors shaping those perspectives regarding the management of their young children with CP in a resource-rich and a resource-limited country;
2. To explore the scope and nature of research in CP management in India using the ICF framework, and to analyze current trends in CP research in India; and
3. To develop and evaluate a KT intervention using the ICF framework to inform parents and stakeholders about the evidence-based management of CP

COMPOSITION OF DISSERTATION

The thesis is comprised of five chapters (Chapter 2-6). It includes Chapter 2, a qualitative interview study with parents of young children with CP in India and Canada, and Chapter 3, a reflective piece based on the author's experience and knowledge of working in India, highlighting the potential challenges in informing parents of children with CP in India. The next two studies are a scoping review protocol (Chapter 4) and a scoping review (Chapter 5) to explore the nature and scope of research on CP in India. The final study (Chapter 6) outlines the process of development and evaluation of a KT intervention tool that aims to inform parents and stakeholders about the management of CP using the ICF framework.

These five chapters will help to advance the knowledge about the management of CP in low-resource countries. The findings will help to shape and guide the future research work in the field of childhood disabilities in low-resource countries.

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Chapter 2

Perspectives on rehabilitation for children with Cerebral Palsy: exploring a cross-cultural view of parents from India and Canada using the International Classification of Functioning, Disability and Health (ICF)

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Abstract

Purpose: To explore parents' perspectives on rehabilitation of their child with Cerebral Palsy (CP), and their information needs. **Methods**: Semi-structured interviews were conducted with parents of children with CP aged 2-10 years from India (n=11) and Canada (n=7). Data were transcribed and analyzed through an interpretive description approach using the framework of the WHO's International Classification of Functioning, Disability and Health (ICF). **Results**: *Body Structure and Function (BSF):* Indian parents were more focussed on fixing BSF challenges, and the goal of independent walking, than Canadian parents. *Activity and Participation:* All Canadian children were actively involved in school and fun activities in the community. Due to lack of accessible services, Indian children had less school and community participation. *Environmental factors:* accessible communities, occupational therapy services, and greater use of assistive devices enabled Canadian children. Indian parents experienced barriers like social and cultural beliefs, lack of access to services and inaccessible communities. *Information needs*: both groups needed information to make their child more functional. **Conclusion**: Canadian parents experience a more enabling environment and express a more social view of their child's health, suggesting both education on the ICF principles and services are needed to better enable and empower Indian parents. There remains a need for healthcare professionals and services in both countries to be more family-centered.

Keywords: Perspectives, Parents, caregiving, Cerebral Palsy, International Classification of Functioning, Disability and Health (ICF), information needs

Introduction

Parents of children with Cerebral Palsy (CP) are involved in the decision-making process with the healthcare team and are responsible for their children's continuous care [1–3]. Parents' perspectives about their child's health condition influence their attitudes and behavior towards the child's healthcare, its management and the treatment outcomes [4–6]. Studies in Western countries exploring parents' perspectives on child's functioning [7,8] and therapy [9–11] reveal the importance of collaboration with parents for increased satisfaction with their child's rehabilitation.

Parents' perspectives and society are shaped and influenced by each other. India is a lower-middle income economy and a resource-limited country [12], where the healthcare system predominantly works on a fee-for-service model, and there is a lack of public or government support to cover the healthcare expenses. Since India has the greatest burden of maternal and infant death in the world [13], governments currently focus on prevention and cure of infectious diseases, malnutrition, decreasing infant mortality rates and ensuring safe pregnancy; rehabilitation is not yet a priority [13]. In contrast, Canada is a high-income country [14] and has a strong public health funding and social support system. Since socio-economic factors, literacy levels, religious and cultural beliefs shape parents' perspectives about their child's disability and rehabilitation [15–17], parents might have different perspectives towards their children with CP in different countries, and may have different expectations from rehabilitation services.

Exploring and contrasting parents' perspectives on rehabilitation of their children with CP from resource-rich and resource-limited countries may provide insights into the factors shaping those perspectives, and reveal specific areas where knowledge or attitudinal barriers could influence the child's rehabilitation. Knowledge of parents' perspectives about their child with CP and the factors shaping these perspectives will enable healthcare service providers (HCPs) and policymakers to provide better healthcare services by incorporating parents' perspectives to change the healthcare systems and policies.

Qualitative methods can best answer research questions that aim to examine parents' perspectives, especially as ontological principles (at the root of qualitative research) aim to examine realities that are relative, context bound, and constructed through interaction [18–21]. Qualitative research is rooted in the field of social sciences and is based on an ontological principle that the realities are relative, context bound, experientially based, constructed through social interaction, and subject to redefinition [22,23]. One of the main strengths of qualitative research is that it seeks to explore and understand the phenomenon from the perspective of the participant regarding the way that they experience, interpret, and attach meaning to it [24].

Commonly, a diagnosis of CP occurs around the age of 2 years of age [26], and the age range of 2-10 years encompass pre-school and school-aged children. Children at this age are physically, cognitively, and socially active, and parents are dynamically engaged in facilitating their child's development. Therefore, focussing on parents' perspective of children aged 2-10 years will help to know their views on a wide range of their children's activities and participation in diverse social environments.

The International Classification of Functioning, Disability and Health (ICF) [27] views an individual's health in interconnected domains, namely: 1) body structure and function, 2) activity and participation, and 3) contextual factors (environmental and personal factors) (see supplementary material for definitions of these concepts). The ICF provides a platform and framework to understand all the factors that should be considered while managing CP. The ICF framework will serve as a guidepost to explore parents' perspectives on rehabilitation of their children with CP and will help to develop clinically important knowledge. Rehabilitation in CP often involves professionals from social, medical and educational domains, and the biopsychosocial view of the ICF will help to explore parents' perspective on all the aspects influencing rehabilitation of their child with CP. The interconnectedness of the ICF domains may help to identify the relationships and interdependence of various factors shaping parents' perspectives.

Previous studies that have explored parents' perspectives on functioning [7,8], therapy [9–11], and quality of life [28,29] among children with CP originate in resource-rich western countries. On the other hand, there is a lack of public health research in India [30,31]. Specifically, there is a lack of qualitative studies exploring parents' perspectives on rehabilitation in CP [32]. Studying parents' perspectives on rehabilitation of CP from a resource-rich and resource-limited country might suggest whether positive or negative perspectives dominate and the potential reasons for them. Exploring parents' perspectives on rehabilitation on CP from two different level economies might also suggest possible solutions to the challenges experienced by parents in both countries. Thus, the purpose of this study is to explore: a) perspectives of parents with different socio-economic and cultural backgrounds on rehabilitation of their children with CP, and b) parents' information needs regarding rehabilitation of their children with CP.

Methods

Interpretive Description: We used an Interpretive Description (ID) approach to explore parents' perspectives on rehabilitation in CP. Developed by Thorne and colleagues to generate clinically relevant knowledge for allied health disciplines, ID is an inductive and constructivist method of qualitative inquiry and falls within an interpretive paradigm [25,33,34]. Ontologically, the ID approach believes that there are multiple realities that are context-bound, experientially based, and constructed through social interaction [34]. Epistemologically, the ID approach believes in understanding multiple views of people in a particular social situation. It allows researchers to identify themes and patterns, and to explore variations between individuals [33]. The ID approach allows the researcher and participant to co-create knowledge and recognizes the clinical knowledge of the researcher as an advantage [34]. In this study, an ID approach helped to explore parents' subjective perspectives on rehabilitation in CP within a biopsychosocial framework. The combination of the biopsychosocial view of the ICF and the opportunity to co-construct knowledge using an ID approach will help to generate clinically useful information.

Sample

A purposeful criterion sampling was used for this study. Parents were eligible to participate if they had a child with CP aged 2-10 years and could communicate in English. Since parents' perspectives and needs vary according to child's abilities and limitations in gross motor functioning [35,36], we included children with various levels of gross motor functioning. Using the five-level Gross Motor Functional Classification System Levels (GMFCS) [37,38] to identify children across the functional spectrum of CP, we included children from GMFCS level I-V in this study.

We selected parents from India (resource-limited country) and Canada (resource-rich country). India and Canada differ with respect to the level of education, health literacy, available healthcare and support services, healthcare systems and funding, socio-economic status, cultural values and beliefs, use of technology in rehabilitation, and the use of the Internet for information seeking [39–44].

Data collection procedure

Manipal University and McMaster University research ethics boards both approved the study. Using recruitment posters and social media, we recruited eighteen parents of children with CP (11 in India and 7 in Canada). In India, parents were recruited from the Neuro-Sensory Developmental Unit of Paediatric Physiotherapy department at a teaching hospital in Mangalore, India. In Canada, parents from various provinces volunteered to participate in the study. Data collection was done during Dec. 2014- June 2015.

After obtaining written consent, semi-structured interviews were conducted with the parents based on an interview guide (see supplementary material). Interviews were conducted either face-to-face or over the telephone or Skype by the first author. Sampling and analysis continued until data saturation, which is achieved when no new information is obtained from the interviews [45]. Interviews were audio recorded. Only one parent per family, either mother or father, was interviewed. An iterative approach to data collection and analysis was followed. For Indian children, the GMFCS levels were obtained from clinical records. For Canadian children, parents were asked about the most recent assessment of child's GMFCS level. Parents' level of education was assessed by asking the highest level of qualification achieved by the participant during the interview.

Data analysis

A thematic analysis approach, as suggested by Braun et al. [46], was used to analyze the interviews. This approach allows flexibility that is more aligned with the interpretive paradigm [47]. Interpretive or constructive paradigms aim to understand human experience and rely on participant views of the situation being studied [48]. Interviews were transcribed verbatim by a transcriptionist. To become familiarized with the data, audio recordings were listened to, and the transcripts were read a couple of times before analysis. First four researchers (×, ×, × ,×) coded one transcript individually to decide on a coding strategy. Later, all the transcripts were coded by the first author using Quirkos version 1.3.2. In congruence with Thorne's suggestions [25,34], line-by-line coding was avoided, and codes were assigned to the text based on the broad domains of the ICF framework. An inductive approach was used to generate initial codes from the manifest content. By asking questions such as "What is going on here?" and "What are we learning about parents' perspectives?" we moved from the manifest to the latent content. Two criteria have been suggested to ensure trustworthiness in qualitative studies [49]. To ensure methodological rigor in the methods, we explained the process and the approach that guided the sampling, data collection, and analysis [50]. To maintain trustworthiness, we maintained a reflexive field journal and grounded the findings in the data [51]. Body structure and function, activity and participation, and environmental factors served as the main themes, and under the main themes, the results were organized under the following sub-themes:

Body Structure and Function (BSF)	**Activity and Participation (A&P)**	**Environmental factors**
1. What BSF problems do parents talk about? 2. What do parents do about the BSF problems? 3. What do parents count as an improvement?	1. What is the child participating in? What are the challenges? 2. What do parents do to promote A&P? 3. What do parents count as positive A & P?	What are the positive or negative environmental factors parents' face that affect their child's rehabilitation/disability?

Results

Parents in both groups were well-educated, at least one parent per couple had a high school and/or a college or university degree. Most Canadian parents were working, and all Indian mothers stayed at home. None of the parents in Canada had emigrated from India. In India, all parents were living in Mangalore. In Canada, parents were from different provinces (Ontario {Hamilton}, Alberta {Calgary}, and Newfoundland).

Details of the participants are provided in Table 1.

Table 1: Participant details

Country	GMFCS level	Age range (years)	Gender
India N = 11	3 children in level III	2 - 9.5	M = 8
	5 children in level IV		
	3 children in level V		F = 3
Canada N = 7	1 child in level I	4 - 10	M = 5
	2 children in level II		F = 2
	2 children in level III		
	2 children in level V		

A. Body structure and function domain

a) What BSF problems do parents talk about? Both groups of parents talked about problems in muscle tone, speech, vision, oro-motor issues, mobility, balance, behaviour, hearing, and developmental delay. A mother reported: "*When I came here, his hands were twisted, his toes were up and he was very tight, there was no flexibility at all, his hamstrings were very tight, he had a bad squint, his drooling was too much,…*" (P. no. 7, 5 years, GMFCS IV, male, India). Another mother said: *"He has very low muscle tone, so his tummy kind of sags, everything sags, especially his arms, his legs, he does not have muscle in that"* (P. no. 18, 9 years, GMFCS I, male, Canada).

b) **What do parents do about the BSF problems?** Both groups of parents were interested in learning therapeutic exercises that were prescribed for their child, to do at home; and many had equipment for exercises at home. Both groups used orthotics like Ankle Foot Orthoses (AFOs) to enhance their child's functioning. Beyond AFO, a few Indian parents used non-abductable stitched pants to avoid "W" sitting and bunny hopping and to prevent future complications like contractures and deformities. A mother said: "*Her joints, everything was very loose…there was no tightness in her muscles, muscles were very weak, so to tighten that. So that she could keep her leg properly. Otherwise, she used to keep her legs on the floor, very widely open."* (P. no 2, 3.5 years, GMFCS III, female, India). All Indian parents were taking their children for regular physiotherapy and speech-language therapy services. A few Indian parents were giving Ayurvedic medicines, massage, multivitamin tablets, and syrups to enhance their child's strength and function. Indian parents strongly believed in physiotherapy to improve the child's function. A mother said: *"I know exercise is the only way to make my son walk. I do not believe in medicines, as I have seen other people who have taken medicine, have undergone surgeries and have not improved at all"* (P. no 7, 5 years, GMFCS IV, male, India). All Indian parents were doing home exercises for approximately one to three hours daily to improve the strength and length of muscles, posture and function in their children. Exercises included stretching, positioning, strengthening, and traditional treatments like a steam bath and oil massage. One mother said: "*Give a warm steam bath and then start the head down exercise. Head down exercise is, since the brain has some problem and message passing is difficult, so do 3 to 4 times these exercise. I put his head upside down for 2 minutes and then 5minutes right up."* (P. no 4, 6 years, GMFCS V, male, India).

Canadian parents were taking their children for physiotherapy, occupational therapy, and speech-language therapy services. Beyond therapy, Canadian parents kept their child actively involved in activities like horseback riding, dance, music, and swimming to improve function. A mother said: "*She gets physiotherapy and occupational therapy. She is doing horseback riding and swimming privately. So, those things she does to build muscle."* (P. no 14, 4 years, GMFCS III, female, Canada). Canadian parents also involved their children in functional forms of exercises. One mother reported: "*We practice balance exercises,… practice walking on the ground, with steps we practice getting up and down, jumping, squeezing, we do a lot of fine motor where he squeezes, prints and types.*" (P. no 18, 9 years, GMFCS I, male, Canada).

c) What counts as an improvement in BSF? Both groups of parents counted increased stamina and increase in child's level of understanding as improvements. A mother said: "*I noticed a difference in his understanding. He certainly understands what we never thought he did. And we just know this from his responses and reactions when people are talking around him."* (P. no 13, 10 years, GMFCS V, male, Canada). Indian parents counted increase in body flexibility, an increase in muscle strength, balance, clarity and fluency in speech, and normalisation of muscle tone as an improvement. One father stated: "*Some improvements are there. Maybe little weight he can take on his hands… Initially, he didn't have neck control, now his neck control is fine. It's difficult to explain… his hands were always fisted; now he can at least open his fingers. Earlier he used to sleep in one position now he moves.*" (P. no 11, 6 years, GMFCS IV, male, India).

B. Activity and participation

a) **What is the child participating in**? **What are the challenges?**

Both groups of parents emphasised the importance of activity and participation in their child's development.

i. **At home and in the community:** Beyond going for therapy, most Indian children stayed at home with family, listening to music, watching television, doing exercises, and playing with toys. A father said: "*On weekends.... I take her to sightseeing and shopping because she is at home every day. I take her and my wife, and we just go to shopping malls. Just for her to have fresh air.*" (P. no 3, 7 years, GMFCS V, female, India).

Canadian parents actively engaged their children in various outdoor activities. A mother said: *Beyond therapy, I keep him involved in social events and music therapy. He does music therapy in a group, and he loves being around other children and socialize. I think it is important to keep him involved in social activities beyond school and hospital."* (P. no 13, 10 years, GMFCS V, male, Canada). Another mother said: "*Outside of school she does ballet, she does yoga, and now she will be going to do horseback riding probably, and she likes to swim. At the end of May, she will do rock wall climbing.*" (P. no 12, 7.5 years, GMFCS II, female, Canada).

At home, many Indian children were either crawling or being carried by parents or were just sitting on a chair. Most Canadian children used assistive devices for enhancing home mobility. A mother said: "*He has an adapted tricycle and walker at home to move around from room to room. He plays soccer in his walker. We have a fire-fly scooter which he uses for mobility in the house.*" (P. no 15, 5 years, GMFCS III, male, Canada).

ii. **In the school:** All Canadian parents were sending their child to school, compared to few Indian children going to school. Indian parents did not send their children to school as they have to get the child to the hospital for various therapy sessions, or the child was not able to sit and/or walk. Many Indian parents were waiting for the child to walk or sit independently and to become semi-independent in activities of daily living to be admitted to a school. One father reported: "*He is not able to walk, so I thought we will wait up to 5 or 6 months. He is sitting properly now, but sometimes he slides. So, someone has to be there in school to watch him."* (P. no 6, 3.5 years, GMFCS IV, male, India). Indian children going to school relied heavily on family support and cooperation from school teachers. One father said: "*My mother drops him with an auto rickshaw… Morning, we are leaving him, lunch time, again my mother goes there. And again, at 3.30, she will go and pick him…he has to go to the second floor and all.*

Teachers are carrying him and taking (to second floor)." (P. no 10, 7 years, GMFCS IV, male, India). All Canadian children were attending school and had an educational assistant provided by the school to help the teacher manage the child. Canadian parents reported that their schools a had the adaptive equipment to support the child's needs. A father said: "*He attends a specialized school… it is equipped with all sorts of different equipment and a swimming pool. There are two students to one teacher.*" (P. no 17, 4 years, GMFCS V, male, Canada). Canadian children were physically active at the school. One mother said: "*He has an activity chair at school; a mobile stander… He uses that at recess for moving and playing. He has an adapted tricycle, a toileting system and a walker in the school. He has a floor sitter as well. It has a pummel, a strap, as he cannot sit long enough without support."* (P. no 15, 5 years, GMFCS III, male, Canada). Indian children had fewer supports to facilitate engagement and were not physically active at school; however, they were socially included in play activities although often in less active roles. A father said: "*In the physical training period, the teacher will take him to ground, but he cannot involve in all activities because he cannot stand. But they will take him to the ground, and he will also enjoy. They are not leaving him alone."* (P. no 10, 7 years, GMFCS IV, male, India).

b) **What do parents do to promote activity and participation**?

Both groups of parents were seeking physiotherapy and speech-language therapy services; Canadian parents were seeking occupational therapy services to enhance child's function and involvement. Difficulty in standing and walking independently was identified as an important activity limitation by both groups of parents. Both used orthoses to mitigate this limitation. Indian parents used orthosis like Standing Walking and Sitting Hip Orthosis (SWASH), Walker and AFOs to help the child stand and walk. Canadian children used AFOs and walkers to facilitate walking but more often used wheelchairs to enhance home mobility and community participation.

Both groups of parents were assisting their children in daily activities in various capacities; however, only Canadian parents used adaptive devices to enable the child to be independent in activities like toileting, showering, and feeding. Indian parents seemed unaware and reluctant to use assistive technology to enable any function other than walking. Indian parents did not identify the need and importance of making the child independent in activities of daily living. A father said: "*…In the morning we do everything. We had to bathe her, brush her teeth everything. Have to put clothes, powder, lotion, pampers, SWASH, everything."* (P. no 3, 7 years, GMFCS V, female, India).

c) **What counts as an improvement in activity and participation?**

Progress in mobility, understanding, stamina, communication, and independence were counted as improvements by both groups of parents. A mother stated: "*Now he can talk, lift head, grab, hold, open fingers, his toes are now flat. His body was never straight, now at least he stands* *straight with SWASH, AFO and shoes, and he walks with a walker now holding the wall."* (P. no 7, 5 years, GMFCS IV, male, India).

C. Environmental factors:

Both groups of parents had an optimistic and supportive attitude towards their child. The factors influencing the child's rehabilitation were: a) the attitude of the family and society, b) social beliefs, c) parent attitudes, and d) policy and system issues.

a) **Family and society attitude**:

Canadian parents found family, friends and society helpful and supportive; and they emphasised the emotional and informative value of a peer group. A mother said: "*I think the biggest thing is the emotional support… Maybe when he is upset, and I don't know what is wrong… The doctors can talk about the diagnosis and prognosis and other technical stuff; I think it is more about the emotional and the practical part of daily living."* (P. no 13, 10 years, GMFCS V, male, Canada). A few Indian parents found the extended family helpful in their child's development; however, some parents also reported about the negative attitudes and beliefs of the extended family and society as barriers to their child's development. A mother said: "*Being in a joint family, with grandmother, grandfather, my sister, is a very big advantage. She is able to communicate more.*" (P. no 2, 3.5 years, GMFCS III, female, India).

Indian parents emphasised how society's attitude influenced their choices for their child's rehabilitation. One father said: "*Wheelchair is the last option. In US and Canada, they don't have that stigma in the society. Here it is different. There are relatives and all these people in the society, at least, you will want him to walk to some extent."* (P. no 11, 6 years, GMFCS IV, male, India).

b) **Social attitudes and values about disability:**

Both groups of parents emphasised the importance of walking. Indian parents placed a strong emphasis on the social and personal beliefs about walking. They also expressed a strong negativity towards accepting wheelchair for their children. A mother explained: "*Exercise is going on; she should walk… If we give her the facility, that without walking she can reach everywhere, then it will become her habit."* (P. no 8, 9.5 years, GMFCS III, female, India). Another mother said: "*I don't want a wheelchair. I just can't imagine my son in a wheelchair. At least, I want them to walk. If they are given wheelchair, whole life, they will be in wheelchair only."* (P. no 4, 6 years, GMFCS V, male, India). Traditional beliefs about disability are still prevalent in India. A mother said: "*In my family, many people said, you did something wrong, the baby was cursed, and all."* (P. no 7, 5 years, GMFCS IV, male, India).

c) **Parent attitudes and advocacy:**

Both groups of parents had a positive attitude towards their children and tried to expose them to various possible activities. A mother said: "*Regardless of your child's abilities or inabilities you have to give them a chance to be exposed to, just like you would to any other child. And I think* *that's very crucial, no matter they can do it or not, but exposure is a very integral part of a child's development.*" (P. no 12, 7.5 years, GMFCS II, female, Canada). Canadian parents strongly advocated for their child's needs and to make the child more independent. A mother said: "*Walkers are not built for grass; they are built for the mall. Wheels are not meant for outside at all. I plan on contacting some companies. I already did, and I haven't heard from them, so I am going to push a little harder.*" (P. no 15, 5 years, GMFCS III, male, Canada).

For more information, Canadian parents asked lots of questions to the HCPs; and the HCPs and therapists primarily directed indian parents. Indian parents advocated more for therapy to make the child walk and often took a more passive role in dealing with health professionals. A mother said: "*Doctor is helping him out anyways, and I have full faith on him that when time comes he will give us the next step.*" (P. no 7, 5 years, GMFCS IV, male, India). Both groups of parents worried about their child's future and wanted to make their child as independent as possible before their death.

d) System and policy issues:

1) **Availability and quality of healthcare and support services:**

Indian parents expressed concerns about the availability of healthcare services and the struggles for getting a specialist referral. A mother said: "*During the delivery, there was a problem... later, one of my husband's colleagues' friend, who was a doctor, told us, actually your baby is having a problem, and this requires a pediatric neurologist. In NIMHANS* (National Institute of Mental Health and Neurosciences)*, if you have any influence you will get the appointment very fast. He got us the appointment.*" (P. no 2, 3.5 years, GMFCS III, female, India).

Most Indian parents appeared to be waiting with an expectation that their child would recover one day and would then be able to start a normal life. Indian parents raised concerns about the availability, quality of care and education in the schools for children with CP. A father explained the reason for not sending his child to school as: "*Ya, but at least, he should get to a level where he should be able to sit. Not walk, but at least, if he gets to a sitting position, then we can put him in a school. Unfortunately, here we don't have that kind of special schools which you might have in other places like Canada. Normal schools cannot make such changes.*" (P. no 11, 6 years, GMFCS IV, male, India).

Canadian parents also expressed concerns over 1) the decrease in the frequency of therapy services due to funding cuts, 2) the quality and time of therapy children receive in the school due to increased load of children with special needs and the insufficient supply of professionals, 3) the amount of paperwork needed to avail services, and 4) unfriendly attitudes of service providers. A father said: "*When he reached three and a half, he had the Ministry of Health services therapy stopped, and was transferred to the Ministry of Education. It was hard to get information through the health services about therapies available. For example, in the children's hospital, they have a very nice therapy pool, and we had asked... who gets to use the therapy pool?...they said, we don't know. That was frustrating. There is a lot of paperwork for the social services and the services he is receiving. For funding, the therapists and the aids, you kind of* *have to plead your case to them to get that..... It feels like you are going up in front of a court and try arguing your case in front of a panel and explaining why...You have to in some cases learn about it yourself and go and kind of demand it from them… We are native English speakers and we find the process to be a challenge and we can only imagine that for a family for whom English is a second language or if they have less confidence in dealing with bureaucracies over the agencies we suspect a lot of people are going without some of the services that we are receiving."* (P. no 17, 4 years, GMFCS V, male, Canada).

2) **Healthcare and service provider's attitude:**

Both groups of parents expressed concerns about the HCPs attitudes and healthcare services. Indian parents expressed concerns about HCPs not taking sufficient preventative precautions during pregnancy, not telling parents the child's diagnosis, and the struggle in receiving the child's diagnosis, and information about the child's health and future. A mother said: "*My delivery happened in the hospital. The doctor didn't take it seriously. My legs were very watery, and she didn't care for it."* (P. no 9, 2 years, GMFCS III, male, India).

A few Canadian parents expressed concerns about the time and effort spent to advocate for their child to be seen by a specialist and for the services they receive. A mother said: "*My daughter had a doctor who said I was an anxious mom, and I was making it up. I asked for a second opinion and the second opinion came around. It was actually not a physical thing, but she was missing all her milestones, and she got an MRI from the ophthalmologist and the ophthalmologist sent it to the developmental pediatrician… to go to an ophthalmologist and taking an MRI was not fun..."* (P. no 14, 4 years, GMFCS III, female, Canada). Canadian parents requested that HCPs should be more knowledgeable about the supports and resources available for their child's rehabilitation and should be able to help parents navigate the system. They also requested that HCPs should give them time to discuss their child's health and alternative rehabilitation options, and should provide parents with more useful knowledge. A mother said: "*From a family doctor, I would like some more information rather than suggesting 3 or 4 big text books that I could read about CP. I would rather have some definitive answers like each case is different. I would rather have some blunt information than hoping for maybe this will work or maybe that will work."* (P. no 14, 4 years, GMFCS III, female, Canada).

Canadian parents expressed concerns about the way service providers treat their children. A mother said: "*The people in special needs swimming program don't push him hard enough. They are afraid to push him. I need someone who is like, you are like everybody else, get in there and swim. That is what I need because that will shape his life.*" (P. no 15, 5 years, GMFCS III, male, Canada).

3) **System and policies that are not user-friendly:** Canadian parents referred to non-user-friendly policies, an enormous amount of paperwork, and the struggles in navigating the system. A mother said: "*FSCD (Family Support for Children with Disabilities) are set up to provide financial support, and they are continuously making it really difficult to access that stuff. I am*

going through his shoes like crazy, because he is growing through the toes. My clothing allowance is only $200 a year, but if it is not specifically from companies that make clothing for people with AFOs or shoes specifically made for AFOs, I do not get reimbursed. I have seen 2 pairs of shoes that are made from 2 different companies for AFOs, and they are $175. Well, there is my clothing budget for the whole year that he is going to wear out the toes in 4 months." (P. no 16, 6 years, GMFCS II, male, Canada).

D) Parents' information needs:

Both groups of parents requested a) information on how to make their child more functional and independent; b) help in understanding CP and the terms related to it; c) new treatments in the field; and d) information on what to expect in future about their child's development. Indian parents relied mainly on the HCP, and very few searched online for information. Canadian parents relied on peer-support groups, HCPs, and the Internet as sources of information.

Indian parents wanted to know if and when the child would be able to walk and do other things like typically developing children; and what could parents do to facilitate walking. Canadian parents requested a) simple, connected, comprehensive, centralised, and frequently updated information and resources about healthcare services and supports available to children; b) help from the HCPs to connect to other families of children with the similar diagnosis, and c) continuation of therapy as long as the child needs it. A father said: "*I wish there was a more centralized place like a website or printing material which your doctor could hand to you and say, ok we diagnosed your child with this condition or that condition, here is a list of all of the government agencies, all of the programs that you can get at some places."* (P. no 17, 4 years, GMFCS V, male, Canada).

Discussion:

This study described the perspectives of parents in a resource-limited and a resource-rich country and found that ICF was a useful lens to identify areas of common concerns and where differences in context affected the child's disability and engagement in rehabilitation or life roles. Previous studies have focused mainly on mothers' perspectives. One of the strengths in this study was the inclusion of fathers' perspective, which enriches our results. While both groups of parents talked about similar problems, they perceived and dealt with the issues differently. Children in both countries were receiving physiotherapy and speech therapy services, but Canadian parents also sought occupational therapy services. Indian parents seemed more concerned about the BSF problems and were doing vigorous physiotherapy at home with their children compared to the extent of focus on therapy by Canadian parents. Canadian parents actively involved their child in many age-appropriate school and fun activities, in contrast to Indian parents. Environmental factors significantly influenced parents' efforts in rehabilitating their child and their access to school and health services.

Physiotherapists tend to use therapeutic exercises to restore maximum movement and functional ability [52], while occupational therapists tend to have a greater focus on modifying the environment or the task to help a client succeed [53]. Occupational therapy is a relatively new field in India with only fourteen colleges [54], compared to more than two hundred physiotherapy schools [55]. In contrast, Canada has an equal number of universities (13 each) offering physiotherapy and occupational therapy courses. Less exposure of occupational therapy services in India might have made parents less aware about any modifications they could make to their environment to help their child get involved in age-appropriate activities. Additionally, due to the inaccessible infrastructure of Indian society [56], it is possible that parents were focused on fixing the BSF issues, and did not consult or follow up with occupational therapists. To some extent, the focus exhibited by parents on changing body structure and function versus changing the environment reflects the perspectives of the health care providers that they are exposed to, particularly in India where parents took a more passive role. Medical curriculum in India is largely traditional and less research based [57]. Incorporating the ICF into medical training and clinical practice to inform healthcare professionals that both changing the impairment and changing the environment can have positive impacts on child's health and participation may indirectly affect Indian parents.

Negative attitudes and socio-cultural beliefs towards the disabled child and the family exist in society [58–62]. In this study, Indian parents referred to the society's negative attitudes towards disability; and Canadian parents more often found society and peer groups helpful in giving emotional support. Social and peer support are important in empowering parents by providing them a feeling of connectedness and belonging [63]. Peer groups help parents to share and learn from each other's' experiences [63,64], and online, social media-led parent-to-parent networks have been regarded as a valuable learning tool to gather information and cope with emotional challenges of raising children with special healthcare needs [64,65]. The study also suggests that lack of trust, perceived lack of benefit, lack of time, and high levels of stress [63] are barriers in forming a peer support group. Other factors like negative societal attitudes, lack of awareness and resources, and cultural values could serve as barriers in forming peer support groups among Indian parents. Further research is needed in this area to explore the potential reasons.

Participation is influenced by the environment [66]; in India, non-accessible infrastructure, limited transport and social services, along with social stigma may have forced parents to keep the child inside the home to a greater extent than in Canada. The fact that Indian parents were focused on walking might be related to cultural values, or it might be the practical consequence of living a society where the infrastructure in less accessible. Parents may realize that major infrastructure changes are unlikely, particularly in the short-term, and think that better physical abilities are essential to their child's function. In general, parents in India have less knowledge and awareness about CP, and medicines are commonly used for the treatment of CP [60,67,68]. Less knowledge about CP and its rehabilitation may have caused parents to believe that CP can be treated and fixed, and led them to focus more on BSF issues. To increase parents' knowledge and to lessen the social stigma regarding CP, India needs awareness and education programs for society, healthcare providers and parents about CP and its rehabilitation. Counseling might also help parents to understand CP and its rehabilitation, and might provide strategies to cope successfully with the child and the society.

In this study, both groups of parents reported their struggles with HCPs and the medical system in receiving their child's diagnosis. India has fewer HCPs specialized in managing children with disability [59], and HCPs lack time, necessary knowledge, skills and resources to identify and refer a child with special needs early [69]. Consistent with other Canadian studies, this study also reported the bureaucratic nature of HCPs and dissatisfaction with healthcare and support services due to funding cuts [7,70–73]. Family-centered services help to increase parents' satisfaction [74,75]; however, the effectiveness of family-centered care depends on the individual characteristics of the child, family, and HCP [74]. Lack of clear understanding of the principles of family-centered care [76], beliefs of HCPs and parents [77], struggles in shifting the decision-making power [78], parents' educational status and cultural beliefs [79], and lack of clear parental expectations [80] might have posed challenges in successfully implementing a complex philosophy into clinical practice.

Similar to other studies [81–85], in this study parents requested more generic information on CP and help to understand the medical terms related to it. Specifically, parents asked for information on therapeutic options, new treatments, child's prognosis, and how to make their child more functional. This quest for information from parents suggests that parents are willing to learn more about their child's health condition so they can better assist in child's rehabilitation. Canadian parents advocated for more services for their child and asked more questions compared to Indian parents. Despite being educated and having access to the internet, Indian parents relied on HCPs for information. This could reflect cultural differences in the roles of patient/ healthcare provider regarding power or shared decision-making. The socio-cultural belief that a HCP knows better about the child compared to parents [3] may explain why Indian parents took less active advocacy roles than their Canadian counterparts. Lack of a clear understanding of the rehabilitation process or fear of offending the HCP might make Indian parents take a more passive role. Lack of time and resources with Indian healthcare professionals to educate and inform parents may also add to the non-advocacy culture among Indian parents. A clear understanding of the principles of family-centered care, increased self-efficacy and education among parents, specialized education and skilled training for HCPs, willingness to collaborate, time, policy, organizational and human support are all needed to create an attitude change in the area of child healthcare delivery in both countries.

Both groups of parents favored the use of assistive technology to improve their child's mobility and participation; however, Indian parents seemed unaware of any assistive technology for enhancing their child's function other than walking. Despite the evidence that using a wheelchair does not hinder a child's development [86], and the positive effects of powered mobility on children [86,87] and their caregivers [88], Indian parents were reluctant to use a wheelchair for their children. Since environmental barriers influence the use of assistive technology [89], lack of occupational therapy services, inaccessible Indian society, the social stigma around using a wheelchair, and the high cost of buying a powered wheelchair may have stopped parents from using a wheelchair for their children. Indian parents chose an AFO and SWASH, compared to a wheelchair, as they were seen as facilitating their child to walk, being less costly, and being associated with less stigma as they are hidden underneath the clothes.

In the absence of universal health coverage [90], and in the face of financial and transport constraints [91] and architectural barriers [56], it is possible that parents in India focus on fixing their child, as it seems more doable compared to changing the society. Indian parents were spending many hours doing things they viewed as the right things for their child and shared many of the same concerns for their child to have a good present and future quality of life. Thus, the burden on the family may be even greater in the Indian context.

Similar to previous studies [92,93], both groups of parents placed a strong emphasis on the value of walking. Indian parents followed a watch and wait approach and were waiting for the child to walk so that the child could start schooling and other daily activities. In this study, compared to the Canadian children, most Indian children were not attending school and were passively participating in sports and extra-curricular activities. Ambulatory level, ability to speak [94] and being toilet trained [59] are generally used as admission criteria by Indian schools. Indian schools lack the infrastructure and human support to accommodate the needs of children with disability. Studies also report a lack of training among teachers, lack of necessary equipment, negative attitudes of teachers towards inclusive education, and the challenges teachers face to teach children with special needs [69,95–97]. These findings indicate the critical role of the environment in determining disability and the importance of seeing disability as a social problem. Policy reforms are needed in India to develop infrastructural and human support to educate children with a disability. Figures 1 and 2 illustrate the factors which influence parents' efforts in rehabilitating their child in India and Canada.

Future research is needed to explore HCPs' and policy makers' perspectives regarding rehabilitation of children with CP to understand the challenges they face in developing and implementing rehabilitation services for children with CP.

Limitations: In India, we interviewed only English-speaking parents and only in Mangalore. Generally, English-speaking parents in India are more educated/informed, have higher incomes, and are more capable of accessing information and services compared to non-English speaking Indian parents. This may be a bias in our sample, and thus our findings may not reflect Indian parents from lower socioeconomic groups. The socioeconomic class might also affect access to services and educational levels in Canada, but the social systems in Canada are more extensive than India. In our sample, Indian children had more severe CP as per GMFCS level, compared to Canadian children. In India, more focus is given to children with more severe CP (more limitations), and children with less severe CP (better functioning) are only seen as needed. We used recruitment posters and social media for enrolling parents into the study. This method of enrollment is susceptible to soliciting a higher response rate from educated and motivated parents. The findings of this study might not be fully reflective of the perspectives of hard-to-reach and less educated parents. To enroll a greater variety of participants, future studies should include more rigorous approaches like house-to-house survey, contacting government hospitals (generally, financially disadvantaged and less educated people tend to access government/public healthcare services in India, while those who are better educated and financially strong seek healthcare services from private healthcare providers), and partnering with other healthcare providers and hospitals.

Conclusion: In contrast to Canadian parents, Indian parents were more concerned about remediating their child's impairments and fixing their child. Positive attitudes, support services, accessible social environments allowed Canadian children to have greater participation in school, recreation, and social activities than Indian children. Children and families in both countries would benefit from user-friendly policies, access to services and HCPs skills in providing family-centered care. In India, there are additional needs for a better understanding of the social dimensions of health, more accessibility for disabled people, function-focused rehabilitation and financial help to assist parents in their child's rehabilitation.

Figure 1: Factors influencing rehabilitation of Indian children with CP

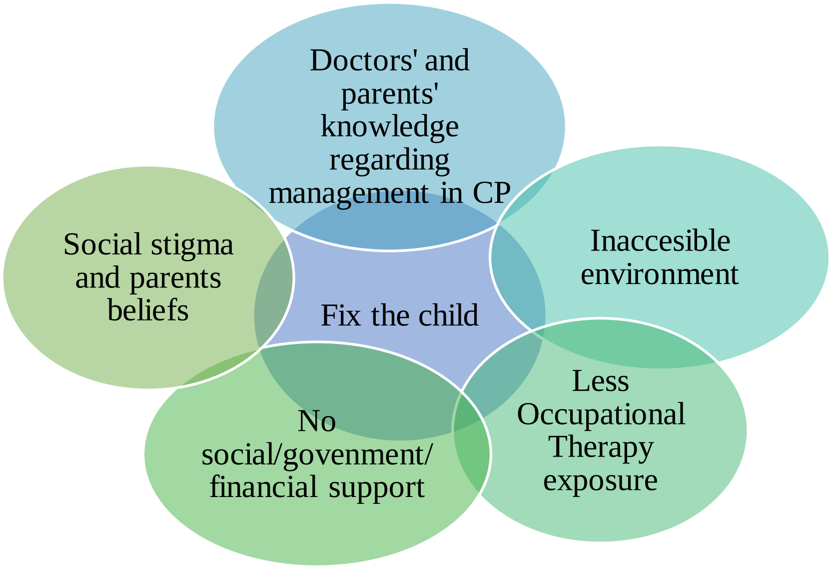
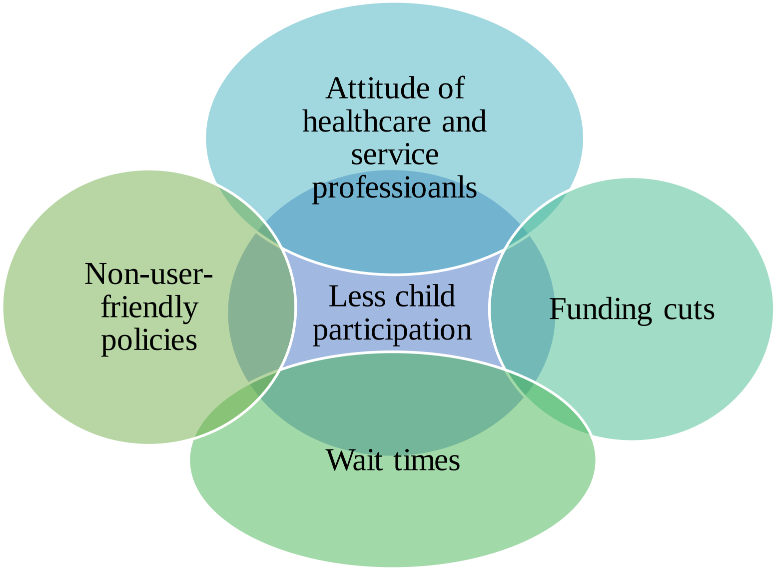


Figure 2: Factors influencing rehabilitation of Canadian children with CP



Clinical and policy implications for rehabilitation: A) to help parents in rehabilitating their children with CP, in India, there is a need to 1) incorporate ICF education into medical curricula and clinical practice; 2) increase the availability of skilled healthcare professionals and centres; 3) make infrastructural and policy reforms to make the society more accessible for the disabled children.

B) Education, counselling and awareness about CP might help both groups of parents, society, and HCPs to change their beliefs and attitudes regarding CP and its rehabilitation.

C) both countries would benefit from user-friendly and transparent policies. This will help parents to become more aware of them and use them in the rehabilitation process.

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Chapter 3

Title: Expanding parents' awareness of childhood disability: An experience with parents of children with Cerebral Palsy in India.

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Title: Expanding parents’ awareness of childhood disability: An experience with parents of children with Cerebral Palsy in India.

Abstract:

Purpose: Patient education is an essential part of clinical practice. Information about a child’s health condition helps parents make evidence-informed decisions about treatment goals and therapies. In this commentary, I discuss 1) the challenges faced by healthcare professionals in informing parents about Cerebral Palsy (CP), and formulating and implementing evidence-based treatment goals in India, 2) the potential reasons for these challenges, and 3) plausible solutions. **Methods:** This commentary is based on my recent experience of both my studies and previous clinical experience working with children with CP in India. Discussions with colleagues from India and Canada working with children with CP have further shaped these reflections. **Results:** the challenges and their potential reasons are discussed in three sections: 1) illiteracy and poverty, 2) mind-set, 3) health education and healthcare system. Inaccessible society, lack of funding, and loose healthcare regulations make it difficult for a healthcare provider to discuss treatment goals for CP with parents. **Conclusion:** Reforms in medical education and practice to incorporate the use of the ICF framework, measures to enhance literacy, use of knowledge translation strategies to make evidence-based knowledge accessible, and increase accessibility might make parents more receptive to education and information about CP.

Keywords: Health Education, patient engagement, India, Parents of children with disability, medical education, Cerebral Palsy, childhood disability

Introduction: Informing patients about their health status is an integral part of clinical practice, and healthcare providers (HCP) are frequently engaged in patient education. In childhood disability, family education becomes critical, as parents have many questions about their child’s current health status and future life. By becoming knowledgeable about the child’s health condition, parents can make better-informed decisions about their child’s healthcare. To HCP, such education is a means to discuss with the parents the various treatment choices, and to come to a common understanding and set treatment goals for their child.

This reflection stems from my experiences of conducting a qualitative study in India with parents of children with Cerebral Palsy (CP) [1](under review) and following up with the development of educational videos to inform parents about rehabilitation in CP [2]. During interviews, a few parents expressed their desire to discuss with me what can they do to make their child more functional (with a hope that I will offer advanced foreign advice!). I quickly realized that they are not interested in understanding CP; rather, they are looking for a solution that can fix the problem. In this commentary, I discuss the factors that make it challenging to inform parents about their child’s health status and discuss treatment goals for their child with CP. It is necessary to acknowledge and address these factors while planning educational interventions for parents in the Indian context. These reflections have been derived by the excerpts from parent interviews and by my clinical experience, which has been further strengthened by discussions with colleagues from India, and Canada working with families of children with CP. All the factors are inter-related, and I will discuss these factors one by one below.

1. **Illiteracy and poverty:** In India, many parents with a child with a disability are illiterate, reside in rural areas [3], and have a low socio-economic status [4]. Literacy and health literacy levels [5] and socioeconomic status [6,7] influence the utilization of healthcare services among patients in India. Previous studies have shown less knowledge about the disability [8,9] and the available government rehabilitation measures [10,11] among parents and persons with disability from various socioeconomic classes. When a poor parent comes for a one-hour paid session of physiotherapy, the expectation is to get the most of the exercises done within that hour (with a hope that exercise will cure the child). They are not willing or able to understand therapist's perspectives about child's functional status and the therapy objectives. In rural areas, there is a lack of quality HCP [12,13] and an abundance of social stigma, cultural beliefs, and religious healers. It is difficult for a HCP to break the barriers of illiteracy, poverty, and cultural beliefs and to find an opportunity to inform parents adequately about the clinical state of their child.

2. **Mindset:** Having a child with CP in India creates a substantial social and financial burden on the family, and it is a genuine feeling from parents to get the child fixed. Of course, in CP we have not yet achieved this milestone! It is, however, hard to convince parents about this, especially in the early days after diagnosis. Interestingly, one colleague mentioned the unique problem they face. Many children with CP after prolonged physiotherapy, arrive at a plateau regarding functional gains, and there is not much that physiotherapy can offer. However, it is difficult to convince parents about this as they look for more and expect a "normal child" after therapy.

   It is common for Indian parents to move from place to place to shop for doctors and therapists in the hope of getting the child fixed. During one interview, an Indian mother of a 5-year-old boy with CP (GMFCS IV), reported: *"I could not accept the fact that I have a CP child; I went to 10 doctors to reconfirm that whether my child had a problem."* Fee for service models and less rigid healthcare laws in India help in fulfilling parents' quest for more treatment. Anecdotally, "free healthcare" is a prominent factor in selecting Canada for immigration by families having children with disability. Interestingly, while discussing with colleagues in Canada working with immigrant families, I realized that the mindset to fix the child also exists among parents who have emigrated from India to Canada or other western countries. However, parents get easily frustrated when they understand: a) what is (and is not) covered under widely advertised free healthcare, waiting times, amount of paperwork and advocacy needed to obtain outcomes and equipment; and b) it is difficult to shift from doctor to doctor to get a specialist referral in a regulated healthcare system in Canada. Many Indian parents living in Malaysia, Singapore, Iraq, Middle East, US and Canada, come to India for the treatment of CP for some months at a time to get more exercises, or to seek religious, faith-based, and other complementary treatments like homeopathy, acupuncture, and Ayurveda.

What shapes this mindset? Indian society is mainly inaccessible to people with mobility challenges, and environmental barriers hinder community re-integration for patients with neurological disability [14,15]. Social stigma also exists around using a wheelchair. During the interviews, a mother of a 6-year-old boy with CP (GMFCS V) reported: *"I do not want a wheelchair. I just can't imagine my son in a wheelchair. At least, I want them* (Mother has twins with CP) *to walk. If they are given wheelchair, whole life, they will be in wheelchair only."* It is not difficult for Indian parents to understand that their child with a wheelchair or walker will not be able to use it in the society for any functional activity. Even to increase the mobility within the home with a walker or wheelchair, parents have to make substantial infrastructural changes. Lack of occupational therapy exposure and lack of financial support to cover the cost of infrastructure changes and motorized wheelchairs also reinforce the mindset of fixing the child. So instead of wasting energy trying to change societal attitudes and fighting rigid, insensitive governmental policies and watchdog systems to make an accessible society, it seems reasonable to families to change/fix their child, reinforcing the mindset that "a walking child is a normal child".

3. **Health education and healthcare system:** In the last two decades India has seen a tremendous increase in the number of private medical colleges especially in rich cities [16–19]. In physiotherapy alone, there are 160 private and 21 government colleges [20]. Guidelines for establishing new medical colleges in India focus on infrastructure, resources, and staffing; however, curriculum design, research activities, teaching and assessment methodologies are often ignored [18]. The admission policies for private medical colleges are not transparent and are determined internally. Private medical colleges benefit substantially by admitting students on "payment seats" for which students pay a very high tuition fees [17]. The payment seats allow colleges to admit students based on their paying capacity, rather than aptitude and capabilities[19], making medical education a profitable business in India [19,21]. The business perspective has led to an unhealthy competition and flourishing corruption and has diluted the quality and standards of medical education in India [17].

   The healthcare system in India is primarily a fee-for-service model and is mainly paid out-of-pocket [22], compared to insurance-based or publicly-funded health models in many western countries. Rehabilitative services in India are broadly divided into government, non-government, and private services. Generally, people with poor socioeconomic status seek government and non-government services, and individuals with higher socioeconomic status seek private services.

The government hospitals have an immense workload, shortage of trained staff and resources [23–26]. Thus people with chronic disabilities have difficulty in receiving individual quality services. On the non-government level, most organizations rely on philanthropists [27] and corporate companies for funding and follow a charity model of disability [28,29]. Due to lack of funding, qualified and adequate numbers of human resources are a luxury to many of these NGOs, thus creating a wide gap in the patient-to-therapist ratio resulting in suboptimal therapy programs. This further leads to patient dissatisfaction and turning towards private healthcare services for quality treatment. The charity model further creates a tendency toward inefficacy and disempowerment among parents of children with disability, thus making it increasingly difficult to inform such parents about their child's health.

Many healthcare disciplines exist in India, including modern medicine, homeopathy, Ayurveda, yoga, and religious and spiritual healers. Parents are somehow confused and lured into so many forms of 'treatment' for CP. Illiterate and poor patients are particularly vulnerable and can easily get trapped in the false or exaggerated claims made by unscrupulous practitioners. Healthcare laws in India are also loosely controlled regarding what doctors can advertise and charge. The fee-for-service model brings the flexibility that patients can see any doctor they want without a referral and with short wait times (except in national institutes). The fee-for-service model also gives families an upper hand (as they are paying), in a way that they can force/direct the doctor to do what they want. To understand this better, consider these scenarios:

Scenario 1: a family (with a mindset to fix their child) comes to a physiotherapist for the treatment of their 5-year-old child with CP. The therapist assesses the child and classifies the child at GMFCS level 4. In the discussion of therapy goals, parents want their child to walk independently and to live a near normal life. The therapist realizes that it is not a feasible goal for this child and tries to inform parents about CP and what can be achieved through rehabilitation. However, parents are focused on fixing the child and do not want to discuss or accept anything beyond walking. What choice does a therapist have? If he does not comply with parents' wishes, parents will go to a different therapist, and the therapist will lose the opportunity to help the child, and will also lose income. If he complies with parents' wishes, he may not be providing the best potential outcomes and may violate professional ethics. However, in a fee-for-service system, many times, monetary factors play a strong role, and a therapist will comply with parents' wishes. With stricter laws to regulate the healthcare and rehabilitation profession, it would not be easy for parents to move to a different therapist; and parents might be more receptive to discuss their child's health and realistic treatment goals with the therapist.

Scenario 2: A qualified therapist with a broad experience and patient interest might charge 200-500 INR per session for physiotherapy treatment. There is a higher chance that over the

> course of time this therapist will be able to educate parents gradually about the aspects of rehabilitation in CP, which in future might be beneficial for the child. On the other hand, a novice therapist in a bid for competition might charge 100-200 INR per session, and parents will be lured to go to the one who charges less money. With the primary motive of earning more money and lack of expertise, an enthusiastic novice therapist may make tall claims, but it is highly unlikely that the therapist will make an effort to inform parents appropriately about the rehabilitation of CP. With time, parents may realize that the claims were false, but it is too late now, time has been 'wasted', and the money is gone.
>
> This money business has a ripple effect. Since the patient will choose a less costly therapist, a qualified therapist who is charging 100-300 INR per session has to decrease his charges unwillingly to keep up with the competition. However, to do so they may need to spend less time with their clients, thus decreases the quality of treatment. This further lessens the opportunity of effective goal-setting and family education since these activities do require time. So now neither the parent nor the therapist is focused on education about CP, and both are working towards the mission of fixing the child.

Pay for service models foster a mindset among HCP to see as many patients as possible in a day to make more money. This mindset is apparently more pronounced among HCP who have paid higher tuition fees for admission to a medical school, as they want to recover the money spent on education. Importantly, the parents' mindset is not tuned for listening/getting information, and the doctor is not interested, as rather than spending time in discussing and educating a family, he can see more patients and earn more money. The appeal of making more money sometimes takes doctors away from quality documentation of patient health status. Importantly, HCP have biomedical training, and probably fixing the child's impairment seems the most logical idea as this is what most doctors learn in most medical training about the approach to many conditions. It is also more fulfilling and satisfying because as a HCP, "I did my job". Traditional Indian medical curriculum, with the lack of evidence-based practice and research [19], may have also led HCP to believe that CP can be fixed. Rehabilitation of a child with a disability often involves the merger of medical, social and educational perspectives, and there might be imprecise boundaries or definitions about "Whose responsibility is it to change society" – doctors, social worker, parents, allied health professionals or government?

Thus, we see that a convergence of illiteracy, mindset, and structural healthcare issues serves as a barrier to patient education in India. Here are some suggestions and I think a combination of these is needed to make a change in the level of patient education:

a) **Reforms in medical education and practice:** The principles that underlie the International Classification of Functioning, Disability and Health (ICF)[30] need to be incorporated into Indian medical curriculum and training, and HCP can then use ICF-based clinical documentation [31]. A recent study reported an increased use of impairment-based outcome measures among musculoskeletal Indian physiotherapists [32]. Indian HCP should be encouraged to use evidence-based and patient-reported outcome measures, as this might help them to shift the focus towards holistic care. The ICF provides a platform and framework to understand all the factors which should be considered while managing CP. The use of the ICF will help doctors to become more aware of domains of healthcare that need to be addressed for rehabilitation in CP. The knowledge of the ICF might further increase inter-professional collaborations among HCP thus benefiting the family and the child with CP. Studies show less focus on research [19,33], and education research [34] in Indian medical schools. Medical schools should also give importance to research activities at undergraduate and post-graduate levels. Engagement in research activities will encourage medical students to explore issues outside of the traditional curriculum and might help sensitize them to ‘soft’ issues like perspectives and experiences. This in turn will enable them to think beyond fixing the patient towards a comprehensive view of rehabilitation. Such a view might also enable medical students to realize the limitations of their field (medicine) and learn aspects of other healthcare professions. The knowledge about scope and expertise of other medical fields might further help to decrease the prevalent tensions among various HCP in India and might lead to increased inter-professional collaborations thus further helping patients.

b) **Stricter laws and regulations:** Currently, no regulatory authority exists in India for physiotherapists. Formation of a regulatory body for physiotherapists and stricter laws for other regulatory bodies will be helpful in 1) making healthcare regulations stronger regarding what HCP can advertise and what they practice, 2) establishing standard fees charged by therapists and other doctors, and 3) encouraging therapists and other HCP to practice evidence-based care. Developing clinical practice standards will help parents to decide which doctor to consult and will increase the quality of patient care. It is equally important to incorporate watchdog systems to ensure proper implementation of laws and policies.

c) **Increasing public awareness:** Incorporate mass awareness campaigns about CP. Governments should make evidence-based information about health conditions available in the public domain, and greater use of knowledge translation strategies might help to increase the use of available knowledge in making informed evidence-based decisions. There is also need to develop measures to enhance literacy and health literacy among parents of children with disability and within the general public. Availability of simple and accessible information about CP might also lead to other “non-disabled” people reading it, which might help to reduce social stigma and foster a positive outlook in society and among HCP towards CP.

d) **Increasing accessibility:** there is a need to increase accessibility of the environment using principles of “universal design”. Increased accessibility might help to decrease parents’ focus on fixing their child’s impairments and might help them to see the child’s strengths. An accessible society might help children to access school and other age-appropriate fun activities, thus having a positive influence on child development, parent-child relationship and family quality of life.

In summary: The current healthcare scenario in India poses many challenges for HCP to inform parents about their child's health status and discuss treatment goals. Considerable reforms are needed in the areas of medical education and practice, awareness, literacy, and accessibility to increase the health status and quality of life of parents and children with disability in India. There is a need for a progressive vision, strong political and organizational will, and collaboration among healthcare regulatory bodies and different ministries, specifically the Ministries of Social Justice and Empowerment, Human Resource Development, and Health and Family Welfare, to initiate and implement policies successfully.

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Chapter 4

Title: The role of environmental factors for management of Cerebral Palsy in India: a scoping review protocol

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Title: The role of environmental factors for management of Cerebral Palsy in India: a scoping review protocol

Abstract

Objective: The purpose of this study is to: a) examine the nature and scope of the literature about medical and therapeutic management of Cerebral Palsy (CP) in India, and b) identify and classify the environmental factors addressed in these studies. *Methodology:* a scoping review methodology designed by Arksey and O'Malley will be used. We will search peer-reviewed, English-language studies about the treatment of children with CP in the Indian context from 2005-Jun 2016 on OVID, CINHAL, EMBASE, Global Health, PsycINFO, and Web of Science. Grey literature will be searched on hosting directories and Google. We will include all study types including either children or adolescents. *Discussion:* The findings will discuss types of studies, interventions and environmental determinants of outcomes in CP that have been addressed in the Indian context. This should define priorities for future research and inform our understanding of current perspectives.

Keywords: Cerebral Palsy, India, Environmental Factors, Scoping Review, Rehabilitation, International Classification of Functioning, Disability and Health (ICF)

Introduction

The traditional goal of medical and physiotherapy management in children with Cerebral Palsy (CP) was to normalize movement patterns, reduce neurological signs, and minimize the development of secondary impairments. Research within the last decade has shifted the focus of therapeutic management and has emphasized the importance of promoting functioning in children with CP [1, 2]. Currently, in many countries, the aim of therapy and medical treatments for children with CP is to promote a child's health, development and function by enhancing their level of activity and participation in play, social, leisure and school activities. Improved functioning, in turn, helps to integrate children into the community, and thus might further enhance the child's [3, 4] and caregivers' [5] quality of life.

The WHO's International Classification of Functioning, Disability and Health (ICF) framework emphasizes the importance of different domains that contribute to functioning [6, 7]. The ICF framework is helpful in understanding various factors that can influence therapy, development, and function in children with CP. The ICF views an individual's health as being comprised of four interconnected domains, namely: 1) body structure and function, 2) activity and participation, 3) environmental factors and 4) personal factors. The domains of body structure and function, and activity and participation together constitute functioning. Though all the domains of the ICF are interconnected, environmental factors importantly influence child's activity and participation in various areas of life [8-22]. Environmental factors are external to the person and are defined as "the physical, social and attitudinal environment in which people and live and conduct their lives"[2]. The ICF divides environmental factors into five chapters namely:

1) products and technology, 2) natural and human-made changes to the environment, 3) support and relationships, 4) attitudes, and 5) service, system and policies [6].

Most studies exploring the effects of environmental factors in CP management originate in the US, Canada, UK, Australia, and Sweden [23, 24]. Research in CP in resource-rich countries using the ICF concepts has expanded substantially and has explored aspects such as the role of environmental factors in school, community, home, and leisure participation in children, youth, and adolescents with CP. Parents' and children's perspectives, patient-reported outcomes measures, quality of life, satisfaction with services, transition to adulthood, sexual and intimate relations, parent, and child self-efficacy in CP have also been explored in resource-rich countries. Recent studies in resource-rich countries show that environmental modifications are feasible [25, 26], and effective [27-29] in improving participation in children with CP.

Children with CP participate less frequently and in less diverse activities compared to typically developing peers [13, 30-32]. The ICF defines participation as "an involvement in life situations"[6]. Participation in activities that provide a sense of accomplishment and enjoyment during childhood and youth helps to foster positive development into adulthood [33, 34], and is an important aspect of life [35]. Though all the therapies and management strategies focus on increasing participation of children with CP, participation is a complex construct and is strongly influenced by environmental factors. In children and youth with CP, environmental factors such as socio-cultural attitudes, physical and transport barriers, negative (or poor) social and peer attitudes, and limited resources negatively influence participation in leisure [17, 18], school [14, 16], home [13, 14], and sexual activities [36]. Social support [24], geographical location [24], and positive parental attitudes [37] have been found to be positive environmental factors. Results from qualitative studies also highlight the attitudinal, structural, and physical barriers hindering participation of children and adolescents with CP [8-12, 22].

Enriched environments favor motor and cognitive growth in children with CP [38]. Assistive technology like power wheelchairs are commonly used to increase the mobility and participation in children with CP. Power mobility has been found to have a positive impact on child and family functioning [15, 39-41]. Environmental factors have been found to influence the use of power mobility among children with CP [15, 42]. Place of living influences participation [43], such that different countries have different and unique environmental factors affecting participation among children with CP. In our previous study [44] (under review), and other studies with Indian families of children with CP [45-56], environmental factors like social attitudes, socio-cultural beliefs, lack of knowledge among parents, availability of skilled healthcare professionals and resources, infrastructural, transport and financial barriers have been found to impact treatment and participation among children and adolescents with CP. Personal factors like age [57, 58], Gross Motor Function Classification levels [57, 58], parental stress [59], income, and parent education level [60], and gender [30] also influence the types and levels of participation among children with CP.

India is a resource-limited country and cumulatively has the largest burden of maternal and infant morbidity in the world [61]. Despite questionable credibility of Indian census data [62], and changing definitions of disability in India [63], disability rates in India are rising [64]. The current focus of government policies in India is on early screening, prevention, and intervention of high-risk infants and mothers, prevention and cure of infectious diseases, malnutrition, decreasing infant mortality and safe pregnancy [61]. Rehabilitation of neurological disorders is often given less importance in the government policies [61]. Resource-limited and resource-rich countries differ in their levels of parent education, health literacy, available healthcare and support services, manpower, healthcare funding, healthcare systems, socio-economic status, cultural values and beliefs, use of technology in rehabilitation, and the use of the Internet for information seeking [65-70]. Thus, there might be different issues influencing diagnosis as well as medical and therapeutic management of children with CP in resource-limited countries compared with issues in resource-rich countries. Further given the fact that India is a resource limited country would suggest that studying environmental factors would be particularly salient.

To promote the development of children with CP in India, and to decrease the burden of care on families, it is important to understand the factors that influence treatment of children with CP in India. This information would be useful for healthcare providers (HCP) and policy makers to develop appropriate and efficient strategies and policies for managing the barriers experienced by children with CP and their families. This knowledge would depend on the availability of high-quality research that identifies various factors as significant mediators of the outcome, or interventions that focus on changing the environment as being effective. The extent to which the research investigates environmental interventions, mediators or outcomes will reflect both the perspective of healthcare providers and researchers in India and our ability to define the importance of environment in this context. A scoping review of the research addressing environmental factors will help researchers to identify whether systematic reviews would be possible based on the current literature base and identify research gaps for future studies. Similarly, such research can be used by government organizations to identify funding priorities. Finally, ecological comparisons to understand whether the research conducted in Indian context aligns with the perspective of research and clinical care in developed countries will be helpful in designing international collaborative research programs.

The purpose of this scoping review is to identify and describe the published literature that addresses the medical and therapeutic management of CP in India to determine the nature of the research, type of research and interventions as well as the environmental factors that are studied.

Methods

A scoping review of the literature is an appropriate methodology to explore the a) the scope (nature and extent) of published literature in the medical and therapeutic management of children with CP, and b) environmental factors that have been studied with respect to how they influence the medical and therapeutic management of children with CP. Scoping reviews follow a systematic and rigorous procedure [71] and describe the nature of the research reviewed and help to identify knowledge gaps that can be useful in setting research priorities. The studies describing medical and therapeutic management and relevant environmental factors in India will be identified and examined using the methodology described in recent papers outlining methodologic steps and standards [72-74]. We will follow the following steps: (1) identify the research questions, (2) identify the relevant studies, (3) select the studies, (4) chart data, and (5) collate, summarize and report the results.

1. Identifying the research questions

In the Indian context, this scoping review will explore a) the scope (nature and extent) of published literature in the medical and therapeutic management of children with CP, and b) environmental factors that have been studied as influencing the medical and therapeutic management of children with CP. The Indian context will be defined as studies that are published in Indian or non-Indian journals that includes subjects living in India as the majority of the sample and the research is situated within India.

2. Identifying the relevant studies

a) Search strategy

We will search multiple databases including: MEDLINE, EMBASE, Global Health, PsycINFO, CINHAL, and Web of Science to explore published literature about the medical and therapeutic management of children with CP in India. MEDLINE, EMBASE, Global Health, and PsycINFO will be searched via OVID. We will search the grey literature on various hosting directories like MedKnow, ResearchGate, DOAJ, ScopeMed, OMICS, Scholars Portal, Google and Google Scholar. The search strategy will be peer reviewed by a co-author using a Peer Review of Electronic Search Strategies (PRESS) checklist [75]. Hand searching of the reference listed will be conducted.

b) Search terms

The following MeSH/Keywords/free-text terms and their combination will be searched: Cerebral Palsy, parents, mother, father, caregiver, teachers, family, child, children, pre-schoolers, school-aged children, youth, adolescents, knowledge, education, caregiving, environment, participation, activities, school, leisure, home, community, play, attitudes, burden, perspectives, perceptions, experiences, stress, beliefs, society, resources, problem, ICF, assistive technology, power-mobility, walking-aid, India, rehabilitation, treatment, disability, childhood disability, South-Asia, healthcare provider, doctor, quality of life. Subject headings will be adapted for each database, allowing a more sensitive search of the literature, and consequently, broader results. We will supplement the literature search with the review of the reference lists of included studies.

3. Study selection

a) Inclusion criteria

We will consider only full-text published peer-reviewed studies in the English language conducted in India involving either children or adolescents. All study designs including qualitative and quantitative methods, knowledge synthesis (narrative, systematic and scoping reviews), case reports, commentaries, perspectives will be included. We will limit the search to the last ten years from 2005-June 2016. Studies published by any health care professionals in the area of medical and therapeutic management in CP, and in any setting (hospital, out-patient-department, community) will be considered. We will exclude studies regarding Ayurveda, dentistry, homeopathy, dermatology, ophthalmology, anaesthesia, developmental delay and animal models.

b) Screening

The eligibility criteria will be pilot tested on a random sample of five titles/abstracts by two co-authors to ensure reliability and consistency. Later, the studies will be screened for eligibility criteria by two independent reviewers. In the case of disagreement, a third reviewer will be consulted. The Covidence online systematic review tool [76] will be used to screen, sort and manage the studies among reviewers.

4. Charting the data

The research team will collectively determine which variables to extract from the studies. The first author will read each article independently and extract data on the following areas (Table 1). A data extraction sheet will be pilot tested on 5 studies, to determine its consistency and alignment with the purpose of the study. Following an iterative process, other variables that may appear later during the analysis process will be documented, and the charting form will be updated. We will reassess previous studies based on the updated variables.

Table 1: Sample data extraction chart

Year	Title	Study type (qualitative, quantitative, survey, review, RCT, cohort)	Population/age/ Sample size (children/adults)	Where is it indexed?	Research question?	Which ICF domain is explored, What environmental factors were addressed? How was the environmental factor measured? From what perspective was the environment considered (e.g. intervention, effect modifier, prognostic factor)	What is the intervention? Medical or therapeutic?	Outcomes reported and measures used	Author qualifications (first author) and Institute
1.									

5. Collate, summarize and report results

All authors will collectively discuss the charted data to identify trends, breadth, and gaps in the literature. Based on Arksey and O'Malley [72] recommendation, we will summarize the results both quantitatively and qualitatively. To identify the trends, scope and nature of published literature, we will use a numeric summary. To explore the environmental factors studied and their impact on the medical and therapeutic management of children with CP, and to identify gaps in the literature we will use an interpretive approach. The quantitative results will be reported using tables, and qualitative results will be reported with qualitative interpretive description. Where appropriate, we will use Venn diagrams to report the qualitative themes for better visualization and understanding. Through this process, we will be able to explore the current state of the literature in the medical and therapeutic management of CP in India, and will be able to identify what environmental factors are being studied and how they impact the development and health promotion of children with CP in India. This knowledge will enable us to identify the existing gaps in the literature.

Discussion

The proposed scoping review has the potential to impact clinical practice, research priorities, and policies. The findings of this scoping review should be helpful in identifying the characteristics of the published literature and the role of environmental factors in the medical and therapeutic management of CP in India. The results will be helpful for HCPs to understand various environmental factors that can influence the medical and therapeutic management of children with CP, and might make them knowledgeable about the factors that need to be considered while planning treatments and therapies for children with CP. The results of this study might help HCPs recognize the boundaries and limitations of their own research, including whether an interdisciplinary approach might provide a broader view of health. This realization might further help to increase multidisciplinary collaboration among different HCP, thus helping children with CP and their parents. The findings from this review might help researchers to identify existing knowledge gaps and may enable funders and researchers to identify research priorities and agendas. For policy-makers, the findings of this scoping review will be helpful to demonstrate the usefulness of existing policies and the need to modify or create new policies within research and social agencies We will disseminate the research findings broadly using peer-reviewed publications, conference presentations, and social media. For parents, we will develop a lay language summary of the results and will make it available online and in the print medium.

Declaration of interest

The authors report no declarations of interest.

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Chapter 5

Title: Research on the management of cerebral palsy in India: a scoping review

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Declaration of interest

The authors report no declarations of interest.

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Title: Research on the management of Cerebral Palsy in India: a scoping review

ABSTRACT

AIM To describe the nature of literature addressing the medical and re/habilitative management of Cerebral Palsy (CP) in India.

METHODS Using scoping review methodology, we searched MEDLINE, Global Health, PsycINFO, CINAHL, DOAJ, Web of Science, MedKnow, ResearchGate, ScopeMed, OMICS, and Google. Full-text articles of any study design in English language involving either Indian children or adolescents with CP and their medical and re/habilitative management, published in Indian or non-Indian journals from Jan 2005-June 2016 were included. The source and focus of research was extracted, and charted using the International Classification of Functioning, Disability and Health (ICF) domains.

RESULTS 144 studies were selected. Intervention (45%) and observation studies (30%) predominated. Re/habilitation interventions (57%) were more studied than medical interventions (43%). Most studies focused on Body Structure and Function; few were on quality of life, participation, or environmental factors. Only 62% of the studies were listed in PubMed and DOAJ.

INTERPRETATION There is a substantial literature addressing CP management in India. The research emphasis in India is predominantly on Body Structure and Function, and quantitative research. Less focus is given to other ICF domains. Increased use of qualitative research and broader views of health may enhance CP research in India.

WHAT THIS PAPER ADDS

- CP research in India reflects a focus on interventions to reduce impairment, and has minimally addressed environmental factors or participation outcomes
- Quantitative studies are the more common compared to qualitative studies
- A substantial number of Indian studies are published in journals not indexed in PubMed

Cerebral Palsy (CP) refers to “a group of permanent disorders of the development of movement and posture causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disorders of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems”.[1] CP is typically characterized by impairments in joint range of motion, muscle tone, reflexes, and sensory systems. In the later years, these impairments may manifest as problems in the areas of motor, sensory, communication, and cognitive functioning. Successful medical, educational and social interventions at various time points can enable children with CP and their families live meaningful lives.[2]

The primary aim of therapies and medical treatments for children with CP is to promote development and function. Enhancing activity and participation in play, social, leisure and school activities helps to integrate children into the community, thus potentially improving the child’s[3] and the caregivers’[4] Quality of life (QoL). Traditional biomedical approaches for treating CP have focussed on changing the impairments, with the assumptions that (1) resolving the impairments will lead to a better functioning “normal” child,[5, 6] and (2) more therapy is better.[7] Recently, the focus in resource-rich countries has shifted towards increasing function and participation in children, and a move towards activity and environmentally-based treatment approaches.[8]

The WHO’s International Classification of Functioning, Disability and Health (ICF) framework for health outlines several interconnected domains that contribute to a child’s development and functioning. The ICF framework domains are: 1) body structure and function (BSF), 2) activity and participation, 3) environmental factors and 4) personal factors.[9] The ICF framework helps us to understand and communicate about various factors that can influence development, therapy, and function in children with CP.

Most studies exploring the role of environmental factors in CP originate in resource-rich countries (US, Canada, UK, Australia, and Sweden[10, 11]), and have found that environmental factors influence the child’s activity and participation in various areas of life.[6, 12-25] In resource-rich countries studies using the ICF framework have examined issues like the role of environmental factors in home, school, and community, and leisure participation in children, youth, and adolescents with CP. Parents’ and children’s perspectives, QoL, satisfaction with services, transition to adulthood, sexual and intimate relations, and self-efficacy have also been explored.[6, 12-25] Given the importance of environmental factors in these studies, it is important to examine environmental factors in low resource countries and across different cultures, since substantial variation could be expected.

India is still considered a resource-limited country, although it is also changing rapidly. Currently, maternal and infant mortality are high[26], and disability is rising rapidly.[27] Rehabilitation of neurological disorders is not a high priority in government policies.[26] Healthcare systems, literacy rates, use of the internet for health information, and the use of technology in rehabilitation differ significantly between resource-rich and resource-limited countries.[28-33] All of these factor might affect the generalizability of the literature from developed countries to developing countries. Given the high prevalence of CP in India, research that supports evidence-based management in the Indian context is vital.

The purpose of this scoping review is to identify and describe the published literature that addresses the medical and re/habilitative management of CP in India, using the ICF framework. This will allow us to determine the nature and types of research and interventions, the current practices and preferences, use of evidence-based treatments, and the studied environmental factors for management of CP in India.

METHOD

A scoping review method was used to describe a) the scope (nature and extent) of published literature in the medical and re/habilitative management of children with CP, and b) the environmental factors that have been studied as mediators or interventions. Scoping reviews follow a structured and rigorous procedure to describe the extent and nature of the research in a given area.[34] This can be used to determine where the literature is mature enough for a systematic review, to ascertain what questions the field is focusing on, and to identify knowledge gaps that can be useful in setting research priorities. The studies describing medical and re/habilitative management and relevant environmental factors in India were identified and examined using the methodology described in recent papers outlining methodologic steps and standards.[35-37] We adhered to the following steps: (1) identify the research questions, (2) identify the relevant studies, (3) select the studies, (4) chart data, and (5) collate, summarize and report the results. A detailed protocol for this scoping review is under review. (further information available with the first author)

1. **IDENTIFYING THE RESEARCH QUESTIONS**
   This scoping review explored a) the nature and extent of published literature in the medical and re/habilitative management of children with CP in the Indian context, and b) environmental factors that have been studied as influencing the medical and re/habilitative management of children with CP. The Indian context was defined as studies that include subjects living in India as the majority of the sample, with the research situated within India and published in both Indian and non-Indian journals.
2. **IDENTIFYING THE RELEVANT STUDIES**

c) **SEARCH STRATEGY**
We searched databases including MEDLINE, Global Health, PsycINFO, CINAHL, DOAJ, and Web of Science to explore published literature about the medical and re/habilitative management of children with CP in India. MEDLINE, EMBASE, Global Health, and PsycINFO were searched via OVID. We also searched research hosting directories like ResearchGate, and Indian publishing houses like MedKnow, ScopeMed, and OMICS to search local literature. Grey literature was searched on Google and Google Scholar. The search strategy was peer reviewed by a co-author using a Peer Review of Electronic Search Strategies (PRESS) checklist,[38] and no modifications were suggested. Hand searching of the reference lists was conducted to identify potential studies.

d) **SEARCH TERMS**
The following MeSH/Keywords/free-text terms and their combination were searched: CP, parents, mother, father, caregiver, teachers, family, child, children, pre-schoolers, school-aged children, youth, adolescents, knowledge, education, caregiving, environment, participation, activities, school, leisure, home, community, play, attitudes, burden, perspectives, perceptions, experiences, stress, beliefs, society, resources, problem, ICF, assistive technology, power-mobility, walking-aid, India, rehabilitation, treatment, disability, childhood disability, South-Asia, healthcare provider, doctor, quality of life.
Following an iterative process, these additional search terms were added: hemiplegia, hemiplegic, hemiparesis, hemiparetic, spastic diplegia, spastic diplegic, athetoid CP, spastic CP, dyskinetic, wheelchair, spastic, developmental disability, inclusive education, spasticity, neurodevelopmental disability, disability, and children with disability.

3. **STUDY SELECTION**

c) **INCLUSION CRITERIA**
Only full-text published peer-reviewed studies in the English language, conducted in India involving either children or adolescents, were included. All study designs including qualitative and quantitative methods, knowledge synthesis (narrative, systematic and scoping reviews), case reports, and case studies were included. We did not include conference abstracts, research letters, editorials, opinions, letters to editors, annotations, and project evaluation reports. The search was limited to the last ten years from Jan 2005-June 2016. Studies published by any health care professionals in the area of medical and

re/habilitative management in CP, and in any setting (hospital, out-patient-department, community clinic) were included. We excluded studies regarding health professions unrelated to traditional rehabilitation and medical care. For example, Ayurveda, dentistry, homeopathy, dermatology, ophthalmology, and anesthesia. We also excluded other diagnoses that may be prevalent in children with CP, like developmental delay, and basic science (animal models).

d) SCREENING

To ensure reliability and consistency, the eligibility criteria were pilot tested by two researchers on the first ten titles/abstracts. Later, all the studies were screened for eligibility criteria by two independent reviewers. If it was unclear whether the specific studies met the inclusion criteria, they were not eliminated in the first stage. Next, the full texts of the selected studies were reviewed by the first author. The Covidence online systematic review tool[39] was used to screen, sort and manage the studies among reviewers.

4. CHARTING THE DATA

The data extraction sheet was developed by the team and piloted on the first five studies to determine its consistency and alignment with the purpose of the study. For the ICF domain studied, the research team decided to extract these data only for the studies that talk about people with CP and aspects of their lives. We will not report the ICF domain for studies that pertain to the condition “CP”, for example, narrative reviews, measurement and epidemiological studies. The ICF domains were reported from the child’s perspective (for example, depression among mothers was studied as child’s environmental factor, not as mothers’ BSF). ICF domains were reported from the perspective of ICF domain intervened and ICF domain studied as the outcome. The ICF domains were extracted by the lead author and verified by another co-author, with conflicts resolved by consensus.

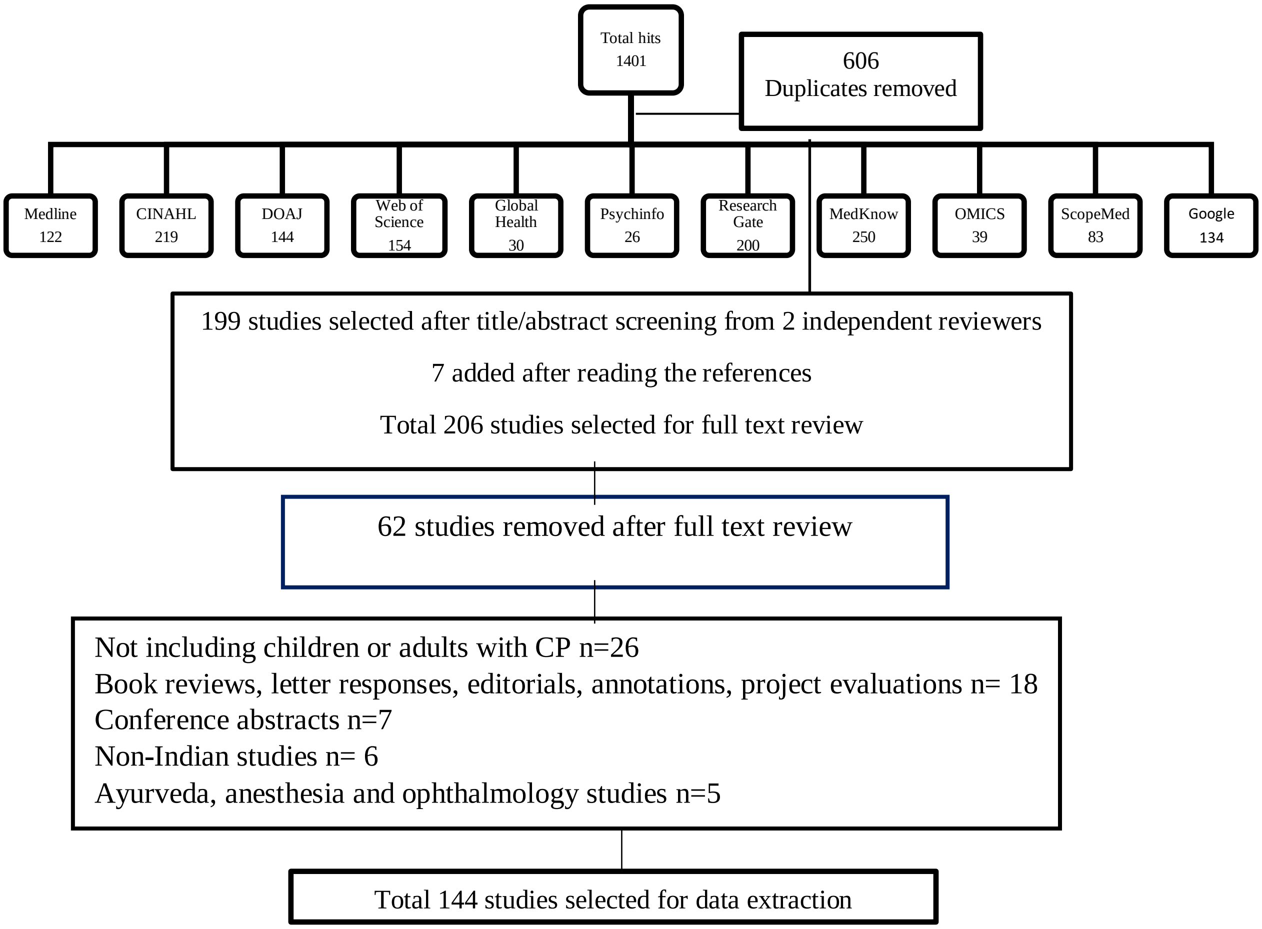
5. COLLATE, SUMMARIZE AND REPORT RESULTS

All authors collectively discussed the charted data to identify trends, breadth, and gaps in the literature. The results are summarized both quantitatively and qualitatively.

RESULTS

Using the selected inclusion and exclusion criteria at the first stage, a total of 1401 studies were identified. After removing the duplicates, title and abstract screening by two independent reviewers, and adding the relevant articles retrieved via hand search, a total 206 studies were selected for full-text review. The first author reviewed all 206 studies, of which 62 were removed as they did not fit the inclusion criteria. Thus, in total 144 studies were brought forward for data extraction. The details of study selection and their sources are outlined in Figure 1.

Figure 1: Sources and processes of study selection



199 studies selected after title/abstract screening from 2 independent reviewers

7 added after reading the references

Total 206 studies selected for full text review

62 studies removed after full text review

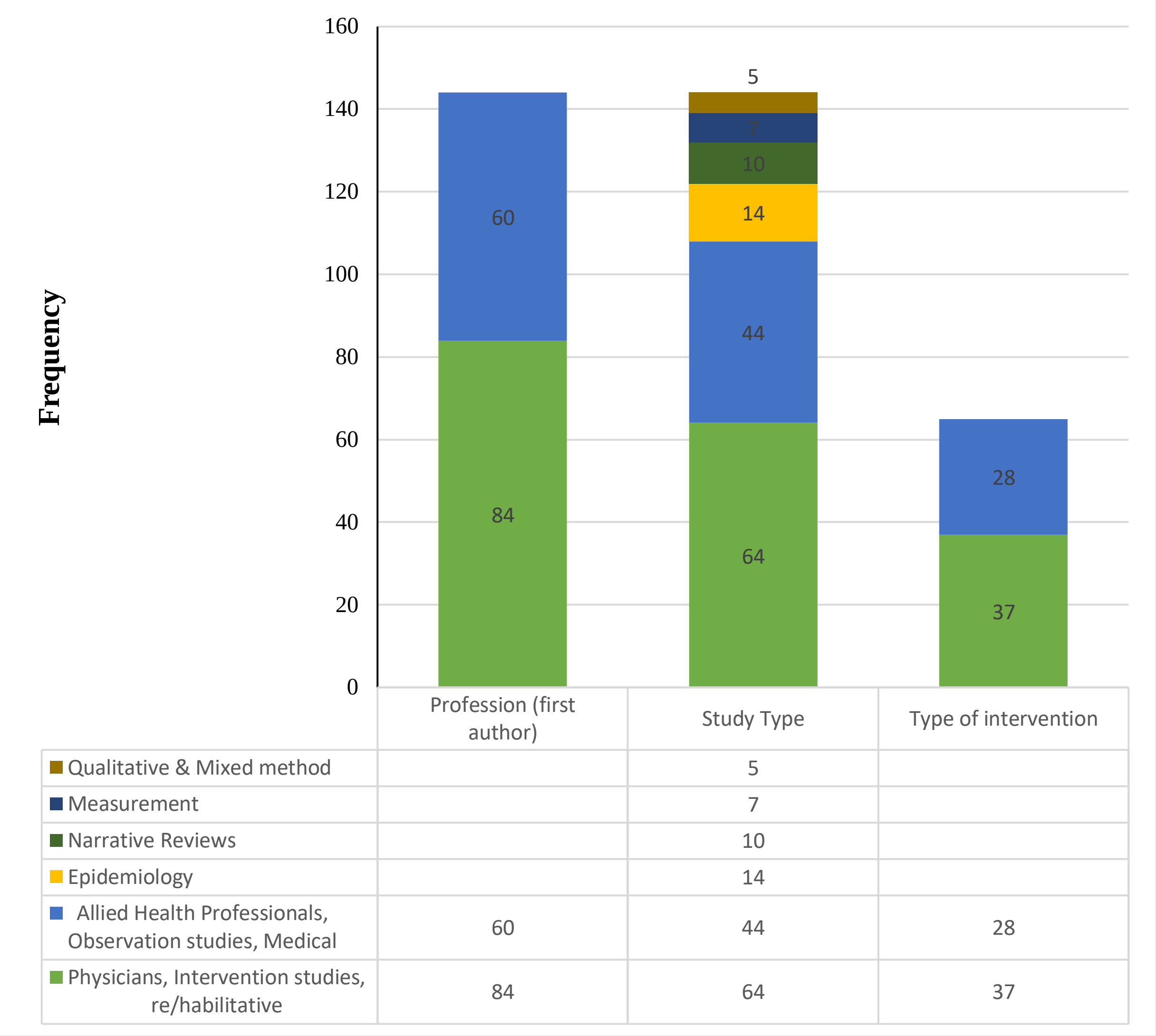
Not including children or adults with CP n=26
Book reviews, letter responses, editorials, annotations, project evaluations n= 18
Conference abstracts n=7
Non-Indian studies n= 6
Ayurveda, anesthesia and ophthalmology studies n=5

Total 144 studies selected for data extraction

We analyzed the trend of the number of publications and found an increasing trend of published literature about CP (almost a doubling) over four-year intervals: 2005 – 2008 (23 studies), 2009-2012 (42 studies) and 2013- June 2016: 79 studies.

In 58% of 144 studies, physicians were the lead author, while in 42% the primary author was an allied healthcare professional. The majority of allied healthcare professional were physiotherapists (n=53), distantly followed by speech-language pathologists (n=4), occupational therapists (n= 2) and orthotist and prosthetist (n=1). Across the studies, 45% studies were intervention studies, 30% were observation studies, 10% were epidemiological, 7% were narrative reviews, 5% were measurement studies, and 3% were qualitative in nature. Among intervention studies 39 were a pre-post comparison, 10 were randomized controlled trials, 12 were case reports, and 1 was a case series. Among observation studies, one was a cohort, and one was a chart review. Among the intervention and (one) measurement studies, 57% explored physiotherapy interventions, and 43% did medical interventions. Figure 2 outlines authors and study details.

Figure 2: Authors, study type, and types of interventions



	Profession (first author)	Study Type	Type of intervention
🟫 Qualitative & Mixed method		5	
🟦 Measurement		7	
🟩 Narrative Reviews		10	
🟨 Epidemiology		14	
🟦 Allied Health Professionals, Observation studies, Medical	60	44	28
🟩 Physicians, Intervention studies, re/habilitative	84	64	37

The epidemiological studies explored various pre-natal and natal causes of CP, associated comorbidities, types of CP, or prevalence of CP in different states across India. Narrative reviews included topics like reduction of risk factors for CP, problems associated with CP and available approaches for management of CP. Among measurement studies, four checked reliability of outcome measures in India, one checked the validity, one assessed the feasibility of an intervention, and one assessed the responsiveness of an outcome measure in Indian children with CP. All qualitative studies (4 qualitative and 1 mixed-methods) involved primary caregivers and explored psychosocial problems experienced by mothers of children with CP. One retrospective chart review examined changes in parents' expectations with a child's increasing age, and one retrospective cohort study explored the effect of lower limb surgery on mobility and energy consumption while walking in children with CP having crouch gait.

Among medical interventions, lower limb surgery and autologous stem cell therapy were the most common treatments. Surgical procedures included osteotomies, soft tissue release, and tendon transfers. In physiotherapy interventions, exercises, patient education and counselling, and orthoses were the common interventions. See Figures 3 and 4 for details of medical and re/habilitative interventions. Numbers in brackets indicate the study number as per Table 1 (Appendix 1).

Figure 3: Types of medical interventions

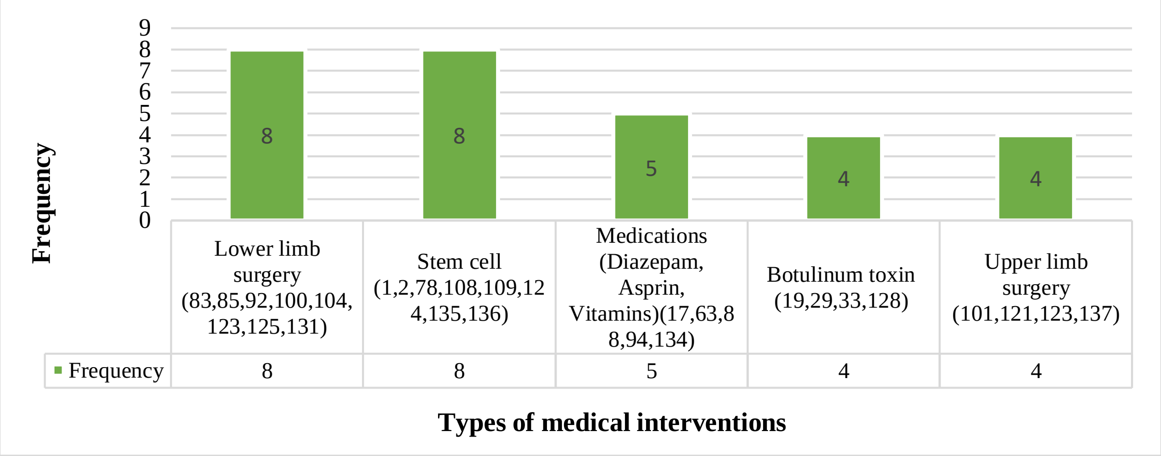
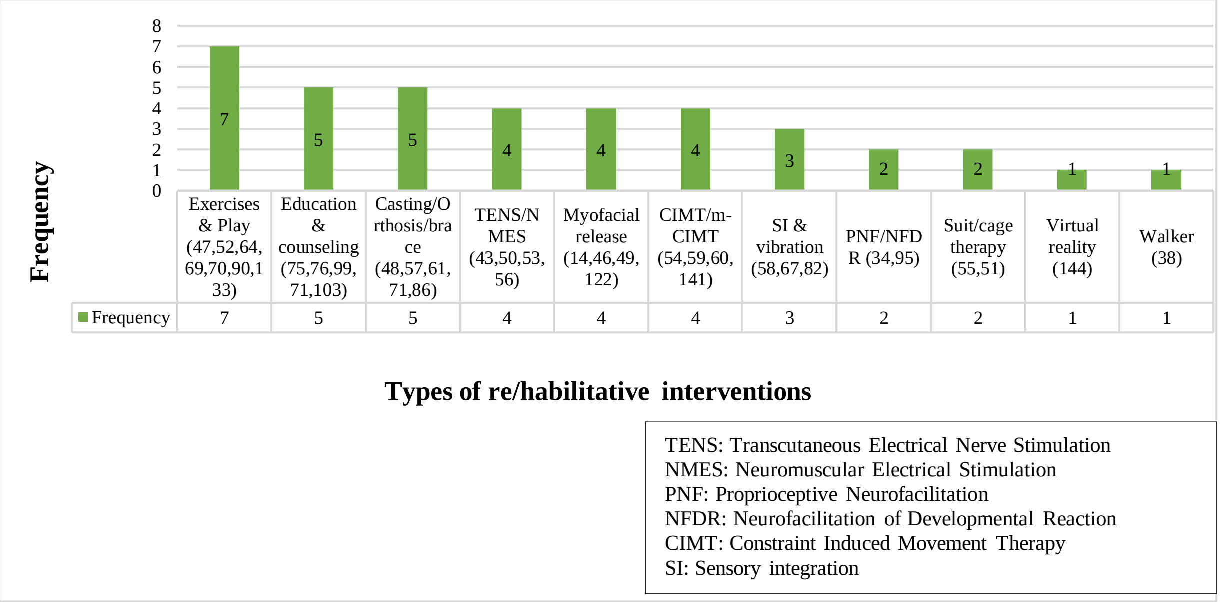


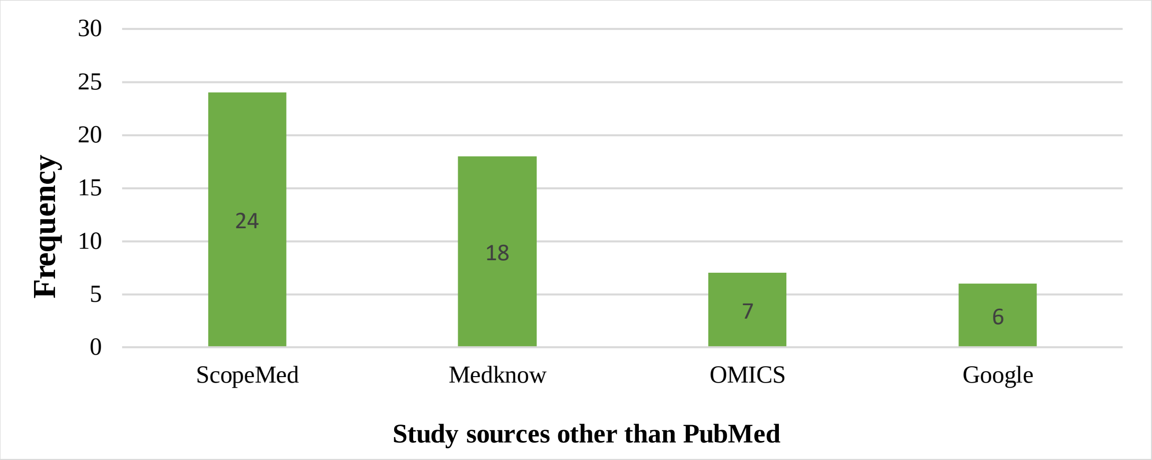
Figure 4: Types of re/habilitative interventions



State-wise comparison reveals that the majority of studies were done in 4 of India’s 29 states: Karnataka (20%), Maharashtra (15%), Delhi (13%), and Gujarat (11%). Among the studies from the national institutes, 6 were published from Swami Vivekanand National Institute of Rehabilitation Training and Research, and one each from National Institutes of Orthopedically Handicapped and Ali Yavar Jung National Institute for the Hearing Handicapped.

Looking at the sources of the studies only 89 (62%) were available on PubMed and DOAJ. The other 55 studies were not listed in any database. See Figure 5 for details of study sources.

Figure 5: Sources of the studies and their frequency



We were able to extract the ICF domain details for 113 of the 144 studies, excluding 14 epidemiological, 10 narrative reviews and 7 measurement studies. Most studies explore multiple areas, for example, the influence of Diazepam on spasticity, range of motion, walking, the burden of caring and mother's QoL. In this example, the study explored BSF (spasticity, range of motion), activity (walking), environmental factors (burden of care), and QoL (recognizing that QoL is not a formal component of the ICF). For details of the ICF domain explored for individual studies, please see Table 1 (Appendix 1). This list (Figure 6) encompasses the many ICF domains studied (observed, intervened and assessed as an effect of intervention) across the studies.

Figure 6: ICF domains explored across the studies

Body structure and function

(as an outcome = 43)
(as an intervention = 40)
(as observation = 15)

- **Observed or as an outcome:**
- Structural changes in the brain/neurophysiological findings
- Muscle strength and length
- Voluntary motor control grading
- Tone
- Posture/trunk control
- Body Mass Index
- Pain/spasms
- Energy expenditure while walking
- Bone healing/fractures/alignment
- Primitive reflexes
- Seizure frequency
- Balance
- Sleep disturbances
- **Intervened**
- Stem cells
- Botulinum toxin
- Surgery
- Muscle stretching, stimulation, vibration
- Medications

Activity

(as an outcome = 44)
(as an intervention = 17)
(as an observation = 11)

- **Observed or as an outcome:**
- Gross Motor Function using GMFM
- Feeding issues/skills
- Activities of daily living
- Walking/gait
- Function using FIM, WEE-FIM and PEDI
- Upper extremity/hand function/dexterity
- **Intervened**
- Exercises

Participation

- **Observed or as an outcome: (n=2)**
- Communication function
- Strategies to increase participation in ADL

Environmental factors

(as an observation = 24)
(as an intervention = 9)
(as an outcome = 5)

- **Observed or as an outcome:**
- Burden of care/caregiver strain
- Parents knowledge
- Mothers depression, stress, anxiety and mental health
- Psychosocial problems faced by parents (transport, attitude, resources, finances, architectural)
- Parents awareness/beliefs
- Barriers in diagnosis and treatment
- Determinants of school enrolment
- Sleep quality of mothers
- **Intervened**
- Walker
- Orthosis (upper & lower limb)
- Parent education, counselling

Personal factors

- **Observed or as an outcome: (n=6)**
- Satisfaction with program
- Satisfaction with surgery
- Child's self perception
- Compliance with walking aid
- Parents expectations
- Mother's clothing preferences for the child

Among ICF domains, most interventions, outcome measures and observed factors focus on the BSF domain. Mobility and activities of daily living were predominantly measured as activities, and exercises were the only intervention done in the activity domain. Participation received the least attention. Among environmental factors, psychosocial problems, the burden of care among caregivers, and mental health of caregivers were commonly observed factors. Orthoses, walking aids, parent education, and parent-to-parent counseling were the only interventions that addressed environmental factors (9 studies). Five studies assessed the QoL among children and their caregivers (2 studies each for child's and mother's QoL, with 1 study evaluating both).

DISCUSSION

This study describes a substantial and increasing body of literature addressing medical and rehabilitative management of CP conducted within an Indian context. Physicians and physiotherapists were the most common researchers, with a minority of studies being published by other allied healthcare professionals. Intervention and observational studies predominated, and re/habilitative interventions were more common compared to medical interventions.

The increasing number of studies by Indian researchers is analogous to a study which found an upward trend by physiotherapy researchers in India in last five years.[40] The geographic distribution of studies we found might be explained by the fact that a greater number of physiotherapy colleges (36, 28, and 22 respectively)[41] exist in Karnataka, Gujarat, and Maharashtra. Interestingly, other Indian states that have physiotherapy colleges like Uttarakhand (10), Bihar (3), Assam (2), and Tripura (1)[41] had no published studies. The lack of research in these areas may reflect lower resources to conduct research, but also suggests that even within India representation of low resource areas in research can be challenging. Bihar has high levels of poverty, tribal population, and illiteracy;[42] Uttarakhand and Northeast both have a large tribal population, and infrastructural, resource, geographical and financial challenges that contribute to high infant and maternal mortality rates.[43-45] Epidemiological and qualitative studies are needed in these geographic regions to assess the extent of CP and available resources, and to find solutions to increase mothers and child's QoL. Use of qualitative research in rehabilitation is well established and can help clinicians and researchers to explore issues relevant to children with CP and their families.[46] We found 14 epidemiological studies conducted in different states by various clinics and hospitals. With better communication and collaboration, these institutes could jointly collect and share data. The bigger pool of data would be helpful in establishing an Indian CP register, which will further help in analyzing trends and finding solutions.

On the national level, India has eight national institutes in eight states assigned to provide health services and conduct research in various areas of disability.[47] We found a total of eight studies published from various national institutes in India. Among eight national institutes, Pt. Deendayal Upadhyaya Institute for the Physically Handicapped[48] and the National Institute for Empowerment of Persons with Multiple Disabilities[49] are responsible for the rehabilitation of individuals with physical and multiple disabilities. Both institutions offer courses in physiotherapy in addition to various other courses to train professionals in skills needed for management and empowerment of people with different disabilities. However, no research studies were published by these institutes. Some variation in faculty research programs is expected since no faculty can conduct research in all areas. However, given the high prevalence of CP and the focus on disability in these institutes, attempt to facilitate this research area might be warranted. These institutes have financial and infrastructural support and serve a large number of patients, factors that could be leveraged to enhance CP research. Removing barriers such as decreasing non-essential clinical work, providing statistical and research support, and allocating time for research could help to build research capacity at national institutes.[50] Children with CP often have complications in different body parts, and the segregation of national institutes based on the type of disability is not favorable for rehabilitation and research in CP in India. A designated research and clinical Institute might support more holistic research and management of children with CP and their families. Centres like these could help in assessing, diagnosing and managing CP comprehensively, and could also assist in conducting research to find evidence-based treatments and solutions that will help the Indian community.

Among medical interventions, autologous stem cell therapy was a prominent intervention used by Indian physicians, supposedly to improve a child's function. Evidence suggests that stem cell therapy is generally well tolerated and may provide short-term improvements in motor skills (although the quality of the evidence is not strong); clearly, large and rigorous trials are needed to establish effectiveness.[51, 52] Weak to non-existent regulations and policies to safeguard patients against exploitation and harmful exposure to unproven treatments contribute to encourage a flourishing stem cell tourism in India.[53] Interestingly, all studies on stem cell were done in economically strong states of Maharashtra and Delhi, and out of eight studies, four were case studies. It is possible that the paying capacity of parents and the hope of 'recovery' help in flourishing medical tourism in financially strong metropolitan cities in India. There is a lack of knowledge translation resources;[54] however, in the absence of strict healthcare ethics and laws in India, it is important to develop lay language, disease-specific knowledge resources to help parents make informed decisions about their child's healthcare. Use of surgery, botulinum toxin, and diazepam for managing spasticity by Indian HCPs is consistent with the research evidence.[55]

Among re/habilitative interventions; exercises, orthotics, neuro-muscular electrical stimulation, myofascial release, educating and counseling parents and Constraint-Induced Movement Therapy (CIMT) were predominantly used by Indian HCPs. Other therapies like Sensory Integration (SI), Proprioceptive Neurofacilitation (PNF), and suit therapy were also used by a few HCPs. Evidence suggests that exercises can help to increase muscle strength and fitness in children with CP;[55-57] and orthotics can help in contracture management,[55] and a short-term decrease in ankle plantar flexion.[58] There is inconclusive evidence for the use of upper limb orthotics,[58] and well-designed, longitudinal research is needed to establish the long-term effects of orthotics in both upper and lower limb.[58-60] Recent systematic reviews consider CIMT as an effective intervention;[55, 61] however, future research is needed to establish the efficacy of various models and dosages.[62] The use of neuromuscular electrical stimulation, virtual reality, and parent education and counseling are consistent with the recent evidence;[55, 63-65] but future research is needed to make conclusive recommendations. There is limited to no evidence for the use of myofascial release, SI, suit therapy, and PNF techniques in children with CP, and it is suggested that these techniques should not be used.[55, 66, 67] Interestingly, few re/habilitative interventions like CIMT, patient education and counseling, virtual reality, casting or suit therapy were evaluated by HCP.

In this study, we found that most interventions, outcome measures, and observed factors focus on the BSF domain. Authors of the studies identified for this scoping review were predominantly physiotherapists; a survey of Canadian HCPs working with children with CP found that physiotherapists choose interventions focused towards BSF domains.[68] Physiotherapists tend to use therapeutic exercises to promote maximum movement and functional ability,[69] while occupational therapists tend to have a greater focus on modifying the environment or the task to help a client succeed.[70] Occupational therapy is taught at only fourteen colleges in India,[71] compared to more than two hundred physiotherapy colleges.[41] Recent studies suggest that impairment-level approaches do not have conclusive evidence to be used in clinical practice and the interventions at impairment level do not lead to increased functional independence and participation.[7, 8, 55] More integration of occupational therapists, and/or inclusion of activity-based treatment in physiotherapy training, are likely needed to help to shift the focus of HCPs to participation and environmental factors.

In this scoping review, the participation domain received the least focus. Increasing participation in children with CP has been considered a priority by a global community of professionals working with children with CP.[72, 73] Children with CP participate less frequently and in less diverse activities compared to typically developing peers.[17, 74-76] Participation in activities that provide a sense of accomplishment and enjoyment during childhood and youth helps to foster positive development into adulthood,[77, 78] and is an important aspect of life.[79] Increased use of knowledge translation resources like Pathways and Resources for Engagement and Participation (PREP),[80, 81] the ICF for parents (P-ICF) videos,[82] plain language research summary (e,.g., Changing the task or changing the environment = Changing the Child,[83]) and participation hub[84] may help to inform and possibly shift the focus of Indian HCP towards participation.

We found that most studies exploring environmental factors in India focus on mothers and caregivers and are non-experimental. Less emphasis is given to environmental factors from the child's perspective. Environmental factors profoundly influence participation in children with CP.[12-16, 25] It is noteworthy that Indian HCPs acknowledge the role of environmental factors, so future studies should focus their interventions towards modifying the environment as opposed (or in addition) to changing the child. Recent studies in resource-rich countries show that environmental modifications are feasible and effective in improving participation in children with CP,[85-89] and it is a very satisfying experience for therapists.[90]

We found five qualitative studies exploring psychosocial issues experienced by mothers of children with CP. Though parents are an integral part of child's life and play an important role in rehabilitation, it is important to consider child's perspectives,[91] as often there are divergences between child's and parents' goals, goals, priorities and preferences.[16, 91-93] Thus future qualitative studies in India should explore children's perspectives and activity preferences along with those of their parents. Exploring children's and adolescents' perspectives towards the management of CP might help HCPs in India to think differently in order to problem solve issues that are relevant to children and youth with CP. The shift in thinking and approach among HCP in India might help to empower children with CP and their families by providing services in a more holistic and family-centred way. It is equally important to explore perspectives of HCPs, service providers, policy makers and teachers towards children with CP, as this will give an insight into the challenges faced by these professionals in managing children with CP. This knowledge will further help to design tools, solutions, and knowledge translation measures to assist these professionals in better assisting children with CP.

Although we did not engage in a detailed critical appraisal of all the methodological aspects of these studies, it is clear that there are challenges. For example, many studies report Gross Motor Function Classification System (GMFCS) as an 'outcome measure', as opposed to a classification system; some studies used Functional Independence Measure (FIM) to measure QoL; and there were spelling and other grammatical errors in the published studies. This prompted questions about the academic accuracy of the studies, and the quality of the editorial and peer-review processes. Future studies could use the Problem/Population, Intervention, Comparison and Outcome (PICO) framework to analyze the use of outcome measures in Indian studies.

Interestingly, of the 144 studies, only 62% were listed in PubMed and DOAJ. PubMed and DOAJ are traditional databases and are accessible worldwide. The other 55 studies were not listed in any database and were only available from the respective websites of ScopeMed, Medknow, and OMICS. It is evident that not all Indian studies are listed in traditional databases, and it is important to include other national and regional resources to develop a comprehensive search for future research. ScopeMed and OMICS are online, open-access publishing groups based in India, and publish journals in various fields ranging from agriculture to health. Both OMICS and ScopeMed charge article processing fees to authors and are considered as predatory journals as per Beall's list.[94] A recent study found that India has the highest number of authors publishing in predatory journals and India has the largest number of predatory publishers/journals in the biomedical field.[95] MedKnow is an Asian division of Wolters Kluwer Health and publishes more than 300 medical journals. It is possible that the pressure of getting a promotion,[96, 97] and to camouflage the lack of quality, HCPs are paying predatory journals to get their work published quickly. Most reputed publishers (including MedKnow) have language editing services, and Indian HCPs are encouraged to pay and use editing services, as this will improve the quality of work, thus helping the authors and generating reliable Indian data. Universities and college librarians could help authors by educating them about predatory and scholarly journals, and various open access models of scholarly publishing.

Few potential limitations exist within this review. Studies exploring CP as a central concept were only included. Studies that included children with CP under the keywords like intellectual disability, mental retardation, children with disability, and children with special needs might have been missed. Studies done in the area of special education in the Indian context often include children with a diagnosis of visual, hearing, speech, locomotor, and mental disabilities. Children with CP often have all these problems and associated complications at various levels. Future studies should investigate various issues in special education and include children with CP, autism, and another diagnoses. To make a comprehensive search, multiple databases and research hosting directories were searched; however, research hosting directories do not have a robust system of keyword search like databases. Thus, we might have missed some studies published in research hosting directories.

CONCLUSION

There is an increasing trend of published literature regarding the medical-re/habilitative management of CP in India. Experimental and observation studies predominate over other study types. Most studies originate from Karnataka and Maharashtra, and 21% studies are published in predatory journals. Indian HCPs focus more on BSF domain; less emphasis is given to the activity, participation, and environmental domains. Most environmental factors explored focus psychosocial challenges faced by mothers and are non-experimental in nature. Future studies should use the qualitative methodology and focus on exploring children's perspectives, with interventions targeted towards modifying the environment and increasing participation. Knowledge translation strategies and knowledge brokers are needed to: a) inform Indian HCPs about the appropriate use of outcome measures and other concepts; b) inform Indian HCPs about the predatory and scholarly journals; and c) shift focus beyond BSF to participation and environmental domains.

Supporting information

Table 1 (Appendix 1)

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Chapter 6

Title: Development and evaluation of International Classification of Functioning, Disability and Health (ICF)-based education videos for parents of children with Cerebral Palsy

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Authors contribution: PJ conceptualized and designed the study. He also wrote the video scripts and coordinated with different team members to discuss and develop the videos. PJ also did data collection, analysis, and wrote the manuscript. JM, PR, BD, and AN helped in revising and spreading the videos; conceptualizing, designing, and implementing the study. All the authors helped in multiple revisions of the final manuscript and intellectually contributed towards the analysis and discussion section.

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Title: Development and evaluation of education videos for parents of children with Cerebral Palsy based on the International Classification of Functioning, Disability and Health (ICF)

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Abstract

Impairment-based treatment is the classical approach to 'rehabilitation' of children with Cerebral Palsy (CP). As emerging evidence indicates the importance of considering participation and environmental factors earlier in a child's care, it is important for parents and clinicians to see management of CP in this context. While many training resources are available for clinicians, there are limited information-based resources on CP for parents. To help parents see a broader picture of their child's rehabilitation, five videos based the WHO's International Classification of Functioning, Disability and Health (ICF) framework were developed ('Parents' ICF' [P-ICF]). Using the Knowledge to Action cycle, P-ICF videos were developed and evaluated for their ease of understanding and utility. The videos addressed the following questions: 'What is ICF?', 'What is Body structure and function?', 'What are activity and participation?', 'What are contextual factors?', and 'How do different parts of the ICF work together?'An online Google survey was created for video evaluation. The videos and the survey were uploaded on the *CanChild* website, and the research team circulated the links through their professional networks via email and social media. In 6½ months the videos received 17,950 views and were watched for 726 hours in 136 countries. In 6 months, we received 60 responses; the majority were from healthcare professionals (68%), followed by parents (25%) and individuals with CP (3%) with most views and responses from western countries. Approximately 86% of the respondents found the videos 'interesting', 84% respondents found the videos easy to understand, 66% respondents found videos helpful, and 69% respondents were confident in applying the ideas to children's rehabilitation. Overall, stakeholders perceived the videos positively and as a valuable learning tool. Future research should focus on modifying the videos for different stakeholders and testing them to create change in the management practices for CP.

Word count: 4812

Keywords: International Classification of Functioning, Disability and Health (ICF), Cerebral Palsy, Knowledge Translation, Survey, video education, awareness.

Introduction

Cerebral Palsy (CP) refers to a group of permanent disorders of the development of movement and posture causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disorders of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems (1).

Successful medical, educational and social interventions at various times during the course of CP management can enable children, and their families live meaningful lives (2). The WHO's International Classification of Functioning, Disability and Health (ICF) framework emphasizes the importance of different factors that contribute to a person's functioning (3,4). The ICF views an individual's health as being comprised of four interconnected domains, namely: 1) body structure and function, 2) activity and participation, 3) environmental factors and 4) personal factors. The biopsychosocial nature of the ICF framework allows us to expand the range of possible options while planning interventions for children with CP. Domains of the ICF framework are interconnected, which gives an opportunity to intervene at any or all the domains of health, and the changes in any one domain may well influence other domains (5-7). There is substantial evidence that a broader view of health is beneficial to children with CP and families. For example, evidence indicates that assistive technology can improve functioning in children with CP in areas of self-help, social behaviors, language (8,9), socialization (10), and development (11,12); and, has a positive impact on the family and caregivers (13,14).

In the past decade, the focus of management in CP has shifted towards increasing participation in children with CP, as opposed to fixing the child's impairment, and there is an increased push towards activity-based and environment-based treatment approaches (15). Participation in activities that provide a sense of accomplishment and enjoyment during childhood and youth helps to foster positive development into adulthood (16,17), and is an important aspect of life (18). A recent study suggests that Health Care Professionals (HCPs) prioritize impairment-based treatment approaches over the environment- and participation-based approaches, and Knowledge Translation (KT) interventions are needed to bridge this gap (19).

KT is a dynamic and iterative process involving synthesis and dissemination of knowledge to consumers in an accessible and easily understandable method (20). Knowledge that is easily accessible and understandable can help consumers to improve their knowledge about the health condition and its management, thus strengthening the healthcare system (21). To help parents of children with CP and other stakeholders see a broader picture of management in CP, and to consider children's overall development during treatment planning, five short animated videos were developed using the ICF framework ('Parents' ICF' [P-ICF]), and evaluated for their simplicity, relevance, utility, and overall acceptability.

Videos are a creative means of displaying information, and incorporate graphics, pictures, written words and music to gain attention, and inspire a response (22). Video-based education programs are effective in increasing stakeholders' knowledge, skills, and capacity, and can also influence practice patterns, coping ability, and anxiety (23-28). Video-based education allows faster and better retention of ideas and is easily understood even by less literate populations (29). Engaging stakeholders in the process of knowledge generation helps to address the consumers' knowledge needs, increases consumers' awareness of the research, increases the quality and relevance of the knowledge generated, and helps to facilitate uptake of the research by consumers (30-32). In this study, we describe the process of developing videos as knowledge tools, and report the results of their reach and evaluation with parents and other stakeholders.

Methods: The Knowledge to Action (KTA) cycle (22) (Figure 1) guided the various phases of the project. The KTA cycle is divided into (i) an inner knowledge funnel, and (ii) an outer action cycle. The knowledge funnel describes the processes by which knowledge is refined and customized to the target end user. The knowledge funnel transitions into the action cycle via a knowledge tool. A knowledge tool presents the knowledge in a user-friendly format and meets stakeholders' information needs, and can influence what stakeholders do with knowledge (33). We developed a knowledge tool in the form of five short P-ICF videos. The action cycle describes the processes involved in the application of tailored knowledge to achieve health benefits. The action cycle was used to: identify the problems in viewing and understanding the videos; explore stakeholders' knowledge needs; and to assess the simplicity and utility of the videos.

Figure 1: The Knowledge to Action (KTA) cycle

A) Development of videos (Step 1, developing knowledge tool): To develop comprehensive videos we followed an iterative process. The research team and the video developer aimed to provide feedback throughout the development process. To enhance viewer engagement, we followed a story format to link all the videos, and incorporated the ICF and CP ideas into the story. The P-ICF videos were not prescriptive and did not contain any exercise programs, interventions, or medical advice. The videos were to be generic and highlight common issues and prevalent notions about the management of children with CP. The videos were to be informative and intended to encourage stakeholders to look beyond fixing the child and to focus instead on the child's overall development.

B) Identify problem, and determine know to do gap (Step 2): to identify the problems in viewing and understanding the videos; to explore stakeholders' knowledge needs; and to assess the simplicity and utility of the videos, the videos and a survey link were circulated among various parent and professional networks via social media and conference presentations. The online survey was developed using Google forms, and the survey link was incorporated into the P-ICF webpage. Viewers were advised to view all the videos and later answer the survey. The survey had 11 questions assessing the utility and needs of the consumers, and four demographic questions. We used a five-point Likert scale and open-ended comments to collect responses. We actively collected responses for six months (May 2016-Oct 2016). The detailed survey is attached as Appendix 1. An honorarium was given to survey respondents as remuneration for their time and effort. Ethical approval was received from McMaster University, Canada and Manipal University, India.

Results:

A) Video development and dissemination: The first author wrote the scripts and storyline for the videos and circulated it among the research team members for feedback and discussion. The P-ICF videos portray two fictional children, Paul and Sara. They have different levels of CP and both want to attend school. Sara's CP is more complex and has more challenges compared to Paul's. The videos illustrate what Paul's and Sara's parents and families can do to enable them to attend school and live meaningful lives. The focus of the videos was on highlighting the strengths of the child (what children "can do", as opposed to what children "cannot do") to enable parents and other consumers see the positive side of the child and foster hope among parents of children with CP. Videos were developed in plain language, as it makes the information more accessible for the general public (34); however, a few medical terms related to CP were retained as it helps to capture consumers' interest by providing in-depth information (35).

After incorporating the feedback, the scripts were sent for video development. A rough voiceover was included, and multiple versions of the rough draft of all the videos were circulated, viewed and discussed together by the research team and the video developer. Various aspects of the feedback collected were discussed between the first author and the video developer, and later incorporated into the videos. Lastly, a professional voiceover was integrated into the videos. To ease the understanding and for a better cultural reach, the voiceover was done in both North-American and South-Asian accents. The video contents are the same in both versions. The videos were developed over a period of eight months (Sept. 2015-May 2016).
A brief overview of the contents of the video modules is outlined below. The full scripts of the videos are included as Appendix 2.

Video 1, What is ICF? This video provides an overview of the ICF, its components and how parents can use the ICF concepts. The video is 3 min. 27 sec. long.

Video 2: Body Structure and Function (BSF) provides an overview of what BSF challenges can happen in CP, whether they can be corrected, and what parents can do to help their child. The video is 5 min. 23 sec. long.
Video 3: Activity and participation provides an overview of what activity and participation challenges happen in CP, and how parents can promote activity and participation in their children with CP. The video is 2 min.45 sec. long.
Video 4: Contextual factors provides an overview of environmental and personal factors. We designed two scenarios to illustrate how positive and negative environmental factors can influence children's functioning and development. The video is 5 min 24 sec. sec. long.
Video 5: How do different parts of the ICF work together? This module helps to tie up all the concepts mentioned above. The video is 2 min 41 sec long.

The final videos were posted on the *CanChild* website and on the first author's YouTube account on 1st May 2016. Media specialists created a web page to host the video and provided a link to the video on the *CanChild* homepage (https://canchild.ca/en/discover-canchild/the-icf-for-parents-p-icf). The research team circulated the video and survey links to their professional network via email, social media (Facebook, Twitter, LinkedIn, and ResearchGate) for a wider reach. The first author also displayed the videos at the annual Family Engagement Day organized *CanChild* Centre for Childhood Disability Research in April 2016, and at the European Academy of Childhood Disability conference in June 2016 in Stockholm, Sweden. The first author also re-posted the video and survey link on Facebook and Twitter, once every month for first three months.

B) **Viewers of videos:** as per YouTube statistics, over 6½ months (May 1, 2016-Nov 10, 2016) the videos received 17,950 views and were watched for 43,561 minutes (726 hours) across 136 countries. Approximately 80% viewers watched the videos on computer and 20% viewed videos on mobile devices and tablets. The YouTube channel has 47 subscribers as of Nov. 10, 2016. Figures 2 and 3 depict the number of views and the minutes watched for individual videos in both the accents.

Figure 2: Number of views on the video

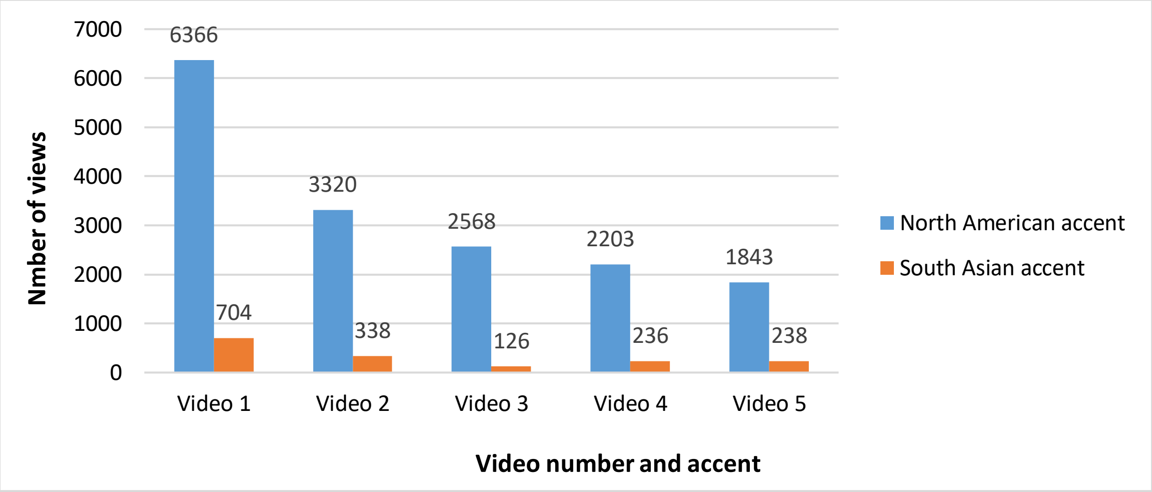
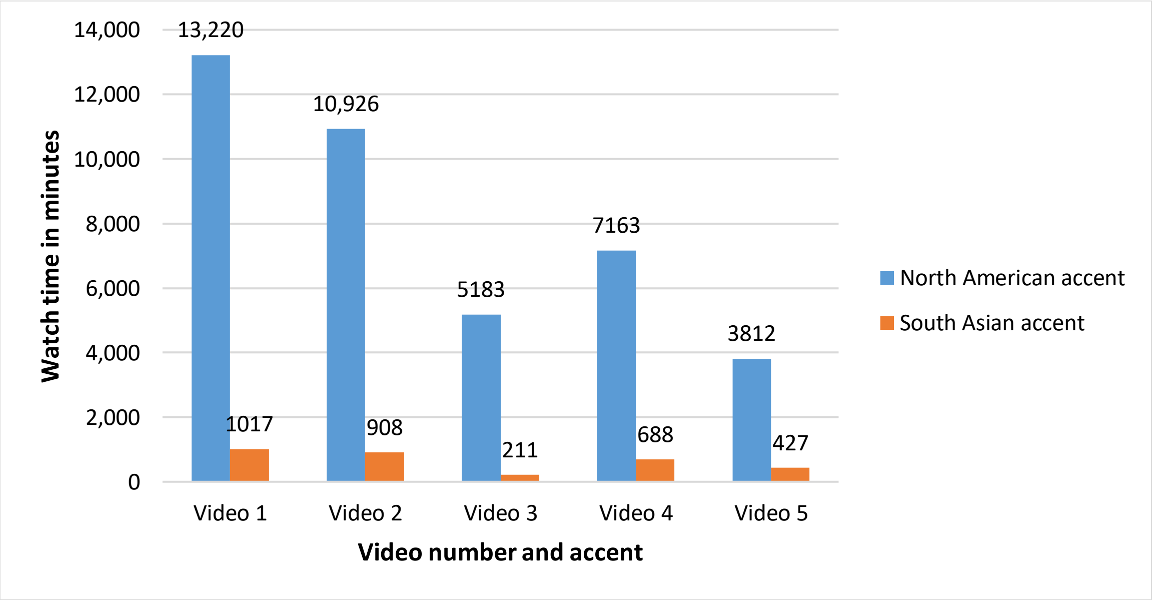
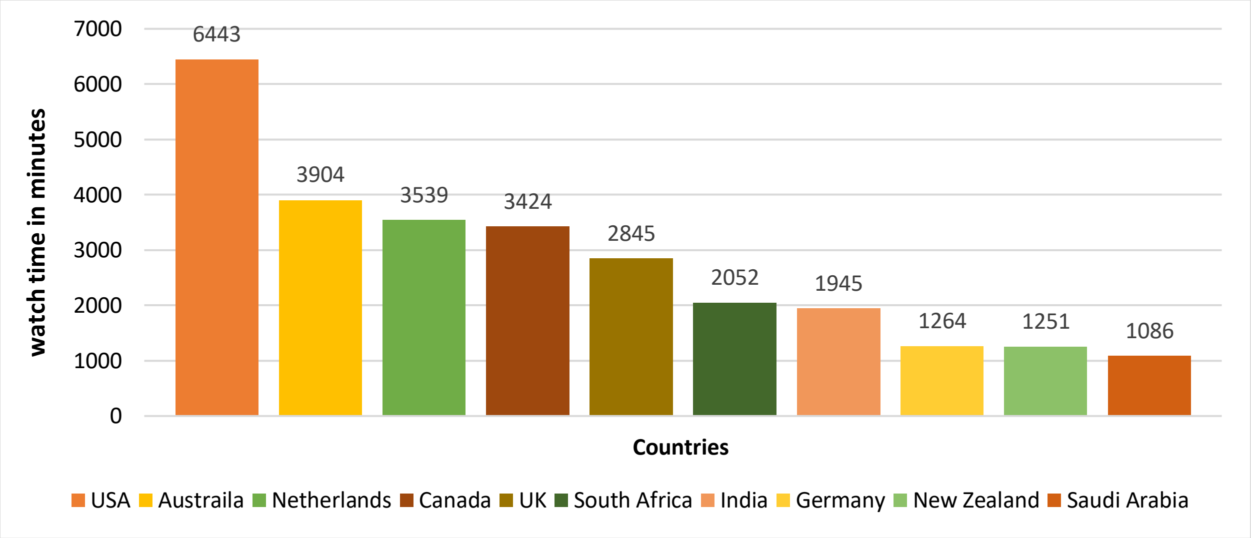


Figure 3: Minutes of video watched



Though the videos were watched in 136 countries (based on IP addresses), the majority of the videos were viewed in western countries. India and Saudi Arabia were the only Asian countries with a relatively high number of watch minutes. Figure 4 illustrates the top ten countries as per watch time in minutes.

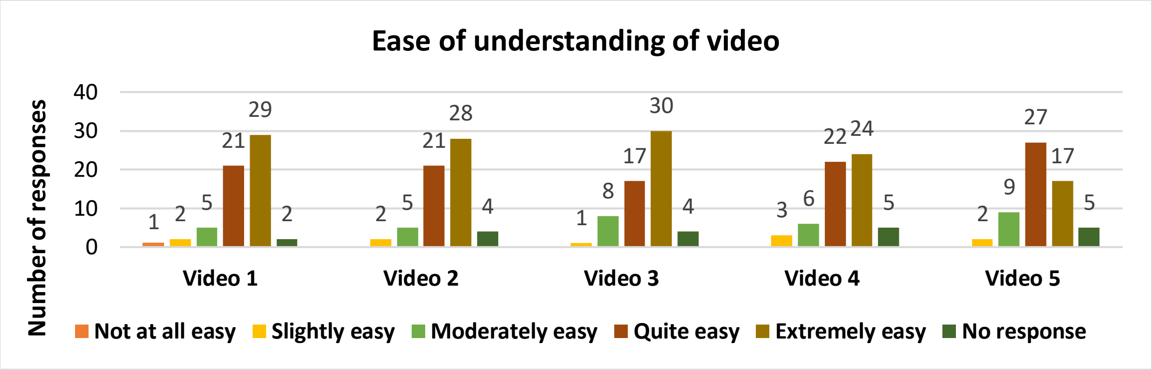
Figure 4: Top ten countries as per of watch time



C) Survey results: In six months (May 2016-Oct 2016), 60 survey responses were collected. Of the 60 respondents, 56 did not experience any technical problem in accessing and viewing the videos. Four respondents had minor problems, such as, they were unable to increase the viewing size of the video, the text too small to read, the video could not be streamed and found video blurry/unclear. The majority of respondents were healthcare professionals (n=41, 68%), followed by parents of children with CP (n=15, 25%), and individuals with CP (n=2, 3%). Two respondents did not answer this question. Forty-two respondents viewed the North American accent version (70%), 14 (23%) viewed South Asian version and 4 respondents (7%) did not specify the specific version they watched. Similar to video viewers, most survey responses came from the USA (24), India (13), Europe (10), Africa (3), Middle East (2) and Australia (2). Six respondents did not answer this question. Of 15 parents, 11 had children aged between 1-10 years, 2 had children aged 11 years, and one had an adult with CP aged 35 years.

Regarding *ease of understanding*, responses for ‘quite’ and ‘extremely’ easy to understand were as follows: 86% for video 1; 87% for video 2; 83% for video 3 and 4; and 80% for video 5. Figure 5 illustrates the complete survey responses for each video.

Figure 5: Ease of understanding of the video

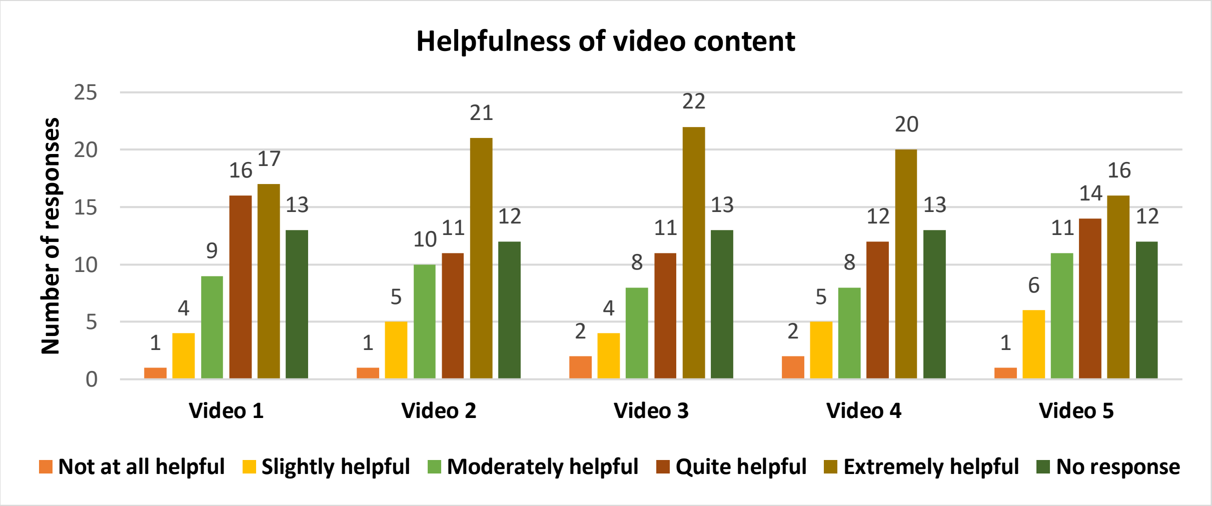


There were 17 open-ended responses to the *ease of understanding* component. Most responses were positive in nature. Critical comments and suggestions are summarized below. A complete list of respondent comments is listed in Appendix 3. One parent said, “The videos did a good job of describing the elements of the ICF and how they work together.” A HCP reported, “The video and examples given gave a clear understanding of all components of the ICF and how they work together.”

Negative comments focused on the need for more information or the way the information was presented. For example, a parent emphasized “Module 4 on contextual factors can also include environment and policies, at least the South-east Asia faces them more than developed nations. I suppose the social security and support systems too can be discussed if permitted”. A HCP said, “I had a strong feeling that the speed of the information flow was a bit too high (some parts of speech, text shifts, and content in animations).”

On the question of *helpfulness* of videos, the following percentages of respondents indicated the videos were ‘quite’ and ‘extremely’ helpful in managing CP for the videos: 70% for video 1; 66% for video 2; 70% for video 3; 64% for video 4; and 62% for video 5. Figure 6 illustrates the responses for individual videos.

Figure 6: Helpfulness of videos in managing Cerebral Palsy



There are 13 open-ended responses to the helpfulness component. Critical comments and suggestions are summarized below. Individual responses are attached as Appendix 3. Most responses were positive in nature. A parent said, “The videos do a good job of keeping it simple enough for many backgrounds and education levels.” Another parent suggested that videos will be helpful for new parents who are not familiar with ICF and CP. Negative comments suggested the need for modifying the videos to different cultures and populations. A parent said, “Certain examples need cultural relevance like accessible school buses in Indian conditions.” A HCP said, “In low and middle-income countries, where there is often a stigma against children with CP and where assistive devices are not available or affordable, some of the content of the videos is not relevant, but could be made so.” An adult with CP found videos helpful for young children, but not for adults.

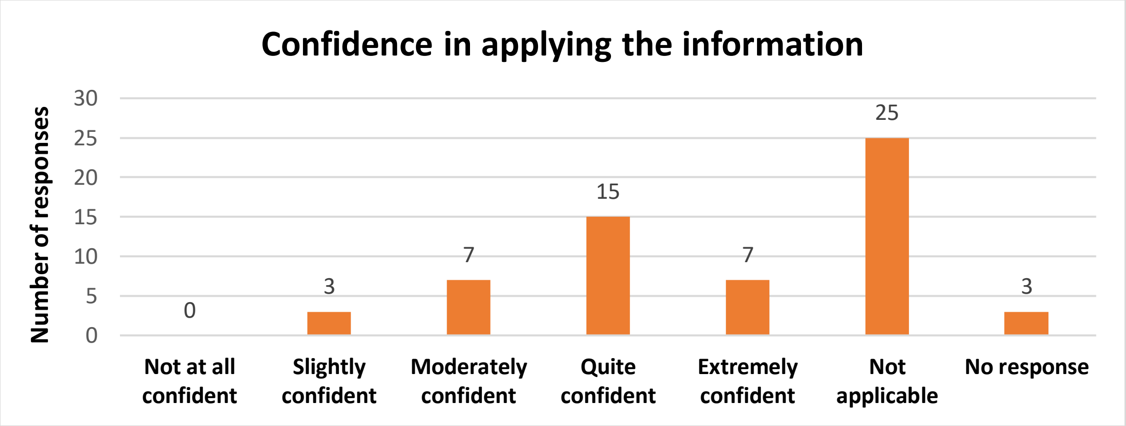
Regarding *interest*, following percentages of respondents indicated that they didn’t lose interest or only lost interest near the end: 83% in the first video; 85% in video 2; 87% in video 3; 90% in video 4; and 83% in video 5.

There are 13 open-ended responses to the *interest* component of the survey. Critical comments and suggestions are summarized below. Individual responses are attached as Appendix 3. Most respondents found the videos well connected and catchy. Negative comments focussed on fine editing of the videos and modifications for different stakeholders. For example, some respondents found background music, non-synchronised lip movements and similar voice in all the videos distracting. One parent requested modifying the videos to make them culturally sensitive and useful, and another suggested that parents (being adults) might not be interested in watching animated videos.

On the open-ended question of *lessons learned and the use of information* in child's rehabilitation, we received 20 comments, all positive. One parent said "We were of the opinion that making her physically capable should be our prime most goal. The videos made us realize overall development is the way to go". Another parent said, "It reinforced for me not to focus on trying to change or 'fix' my child, but instead focus on his strengths." Individual responses are attached as Appendix 3.

On the question of *confidence in implementing the ideas* in child's rehabilitation, we received 32 responses (53%). Out of 32, 22 respondents (69%) were 'quite' to 'extremely' confident in applying the ideas for rehabilitation of a child with CP. Figure 7 illustrates the responses for individual videos.

Figure 7: Confidence in applying the learned concepts for child's rehabilitation



We received nine comments about *confidence*, which were mixed in nature. Critical comments and suggestions are summarized below. Individual responses are attached as Appendix 3. A HCP said, "I would be using these videos as a teaching tool for therapists." Negative comments focus on help and collaboration needed among various stakeholders to implement the ICF ideas. A HCP said "… this explains the framework but what are the practical implications does it give to parents? The information feels very general and somehow needs to be taken down to earth for families".

On the question of *help needed from HCP in implementing the information*, we received 28 responses. Of these, 78% needed help from HCP and society. From HCP, respondents reported the need for more time, further information, resources and guidance, open-mindedness and education for HCP. From the community, respondents need support from the government, positive and supportive outlook, financial aid, better accessibility, and advocacy. Individual responses are attached as Appendix 3.

On the question of whether the videos help stakeholder to think differently about the child and therapy, we received 28 responses. Of these, 57% said that the videos make them think 'quite a bit' to 'extremely' differently. We received 13 comments, the critical comments and suggestions are summarized below, and the individual responses are attached in Appendix 3. A few parents suggested that these videos will be helpful for new parents. A parent said, "I was already thinking this way, but it confirmed that it is the right way to think about my child's disability. Promoting child development is everyone's ultimate goal!". A HCP said “Hopefully, parents may begin to recognize developmental and learning opportunities in numerous aspects of life – not only in therapy. But that is not expressed with enough clarity (in a down to earth way)”. Another HCP said, “Before we were focusing on impairments alone, now the whole focus shifted to participation.”

A few stakeholders suggested improvements be made to the videos. Many asked for videos to be translated into different languages, for example, Portuguese, Spanish, Bangla (used in Bangladesh), Arabic, Hindi and other Indian languages. A few requested fine editing; slowing of video speed; an option to silence the background music; contextually and culturally sensitive information; more environmental factors to be included in the video; shortening the videos; different voices for different videos; more examples in videos 2-5, adding children’s strengths in the body structure and function video; improving video 5 for more clarity; adding information for adults with CP; and including personal factors in the video.

Discussion:

This study illustrates successful implementation of a KT strategy that had a strong uptake and favorable end-user feedback. The short-term goals were to affect awareness of ICF principles and parental attitudes about how to optimize their child’s health in the presence of a CP diagnosis. The ultimate goal of KT is to change behavior and outcomes. These long-term outcomes are more difficult to assess in the near term, and cannot be predicted from the positive short-term process outcomes. We interpreted that the uptake of the P-ICF videos was positive given the extent of the observations over the period of six months. Further, stakeholders perceived the P-ICF videos positively and as a valuable learning tool and reported some of the anticipated attitudinal and awareness changes.

The high number of views on these videos seems to reflect people's interest in learning about the ICF ideas in the context of rehabilitation of children with CP. Despite a high number of views, we had fewer survey responses. Therefore, we cannot be confident that survey responses reflect the views of the majority of viewers. Previous research has established that engaging stakeholder helps to increase the quality, relevance, and utility of the KT tool, but further research is still needed to explore best methods of stakeholder engagement and how best to translate knowledge into clinical practice (30,36). Most views and survey responses were from Western countries rather than Asian and other countries. Most responses were from HCP, followed by parents of children with CP. The higher access and survey responses from Western countries could be due to multiple factors, one of which is undoubtedly the distribution networks we used. *CanChild* is an internationally recognized Canadian organization and the reach of its network is likely to be higher in North America. It is possible that parents and HCP in western countries are more familiar with the ICF concepts compared to parents and HCP in Asian and other countries and this may have motivated greater interest to explore knowledge in this area. Access and use of the Internet for searching health information differ among western and Asian countries (37), and could have also influenced the view statistics. Also, non-proficiency in the English language might also have affected the reach and interest of the videos among Asian and other countries. Translating the videos into different languages, and incorporating culturally acceptable familiar examples might help to engage stakeholders in other countries. As there is less access and use of the Internet in Asian countries compared to Western countries, more individualized, alternate ways such as focus groups, and setting up the videos in a clinic might be needed to gain parents' and stakeholders' views on the videos. Further coaching, hands-on and face-to-face efforts might be needed in Asian countries to engage stakeholders actively in using the ICF concepts for management of children with CP.

The KTA cycle is iterative. When developing the videos, we identified the lack of awareness of the social participation aspects of health in CP management as a gap in the literature and parental focus (unpublished work, under review). This phase of "identifying problem" guided our tool development. We also used the KTA cycle when evaluating the implementation of the videos. Reported implementation problems indicated that there were technical and contextual problems for a small subset of users. Regarding technical difficulties, some stakeholders felt that the videos were little fast, videos needed fine editing, and the background music was distracting. Future revisions will be made to the videos incorporating the requested changes. Additionally, we plan to include subtitles to all the videos. Subtitles will complement the audio-visuals, thus might help stakeholders to get a grasp of spoken words more easily.

The viewer comments indicated some areas that could be considered in future KT. A few parents were not clear of the purpose of the videos and needed an action plan; a few were of the opinion that the video content is more suitable for younger children and the videos might be of more help for new parents; many stakeholders requested more culturally appropriate examples in the videos. Considering the full spectrum of knowledge users is an important aspect of KT. Many stakeholders asked to include more examples in the videos to enhance clarity. The P-ICF videos were generic and highlighted common issues and prevalent notions about the management of children with CP. Balancing the need for brevity, comprehensiveness and relevance of information is one of the major challenges in optimizing KT. Feedback from knowledge users is a critical component of that process. Using the next step of the KTA cycle, "adapt knowledge to local context", in consultation with stakeholders, future work needs to create and evaluate a new set of videos for different stakeholders (for children with various age groups, in different languages with culturally appropriate examples, for HCP, and for community awareness).

We engaged stakeholders in the development of P-ICF videos as Knowledge Translation (KT) tools, which helps to increase the quality of the product, increases its relevance and helps to create more awareness (30-32). Education videos are useful in creating change in HCP knowledge, skills, capacity and practice; however, studies exploring KT approaches to incorporate evidence-based practice in clinical scenarios illustrate that a complex, multifaceted set of activities, changes, and advocacy is needed at multiple levels to see effective changes (23-25,38). The process is gradual; involves multiple stakeholders; happens over time, and need workforce, organizational will, and funds to sustain in the long term; and the strategies need customization based on stakeholders, target audience, and the available resources (36,39-41). Though respondents found the videos interesting and easy to understand, few were confident of applying the ideas into practice. Perhaps this is to be expected given the concepts were introductory, and the goals were awareness and attitudinal change. The videos were not designed to give users specific skills in implementing the knowledge. Implementing the P-ICF ideas into practice needs a collaborative effort from parents, HCP, healthcare institutions and organizations (hospitals, clinics, rehabilitation home). Parents requested further resources and help from HCP and community to implement the P-ICF ideas to their child's rehabilitation. Creating online communities of practice where researchers, clinicians and patients can communicate freely to share expertise, solution, and challenges might help to implement the P-ICF ideas into practice (42). The videos could serve as a launch point for multiple add-on KT strategies where parents would learn how to implement specific strategies to apply the ICF principles. Since the literature shows that multi-modal KT tends to be more efficient than an isolated strategy, the finding that parents are not confident about how to implement ICF indicates the need for multi-modal KT to change behavior and outcomes.

Our study had some limitations. First, we had a high number of non-responses for some questions. This could be due to the devices used by the respondents, as approximately 20% of the respondents used mobile devices and tablets to answer the questions. Mobile devices have a smaller screen size, and users had to scroll sideways to see all the response options. Smaller screen size and unfamiliarity with scrolling the screen sideways (as opposed to scrolling up and down) to view other options could have been a reason for the respondents leaving the questions unanswered. Use of smaller devices may also explain why some people thought that some information could be “bigger’. We also had less survey responses compared to the views on the videos. Future studies should use targeted strategies to get access to more respondents.

The YouTube statistics counts each individual view. People viewing the videos in a group online, for example, a teacher showing the videos in a classroom, will be counted as one view as the count is at the device level, not the person(s). We cannot account for number of viewers who might have downloaded the videos and viewed them individually or in groups offline. Thus, the actual number of views and related watch minutes might be higher than indicated count above.

Conclusion: We were able to use KT principles to create P-ICF videos that had strong uptake and were perceived by parents and HCPs as being relevant, easy to understand and a helpful learning tool. The videos may be useful on their own to increase awareness or change attitudes, they may need to be integrated into a multi-modal intervention to achieve behavior change or better health outcomes. To increase reach, consultation with stakeholders, translating the videos into different languages, and incorporating culturally acceptable examples might be needed. Future work is required to assess whether P-ICF videos or interventions that incorporate these can facilitate parents’ and HCPs’ behavior change and better health outcomes for children with CP.

Ethical approval: the study was approved by the McMaster University, Canada (project number 14-829) and Manipal University (IECKMCMLR 01-15/01), India.

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Chapter 7: DISCUSSION AND CONCLUSION

The overall purpose of this thesis was to advance knowledge about the information needs, research foci and potential for an ICF lens to inform management of children with CP, with a focus on India (a low-resource country) as an exemplar context where environmental factors vary in comparison to resource-rich countries where much of the predominant literature on CP management arises. However, the results of this research are considered as being generalizable to other countries, especially when considering how ICF encourages a comprehensive classification of environmental (contextual) factors that influence health. Further, even within resource-rich countries access to resources varies and understanding how this impacts management across countries can inform our understanding of how social disadvantage or cultural beliefs affect health processes and outcomes within countries. To meet this goal, I have presented an interconnected series of five papers, with each paper contributing uniquely towards the common theme.

The first study explored parents' perspectives on the management of their young children with CP in India and Canada. I used the ICF framework to categorize parents' perspectives, as collected by taped coded interviews, to generate clinically useful findings. The findings revealed that Indian parents were more focused on fixing body structure and function challenges compared to Canadian parents. Canadian children were also more active in their school and community compared to Indian children. Inaccessible communities, social beliefs, and lack of accessible services hindered participation of Indian children with CP in many age-appropriate activities. Both Indian and Canadian parents requested more information to help make their child functional.

The second study is a reflective paper emerging out of my experiences of interaction with Indian parents during the first study. This latter study is shaped by my understanding and knowledge of Indian culture and the healthcare system, and the experiences of working in India with children with disabilities. In the second paper, I discussed various factors that make it difficult to inform and change the perspectives of Indian parents towards their child with CP. I discussed the issues of limited literacy, poverty, a specific mindset, health education and the healthcare system as potential factors shaping parents' perspective towards their children with CP in India. I suggested reforms in the areas of medical education, public awareness, and healthcare regulations to make the environment more favorable for healthcare providers and researchers to engage in patient education.

Perspectives are shaped by the society in which we live. Healthcare providers, patients, and families live in the same society. It is logical to believe that perspectives of healthcare providers are shaped by families' perspective and vice versa. However, it is important for healthcare providers to utilize evidence-based treatment methods for management of children with CP. This leads to the third and fourth studies in this thesis. The third study reported a scoping review protocol, and the fourth study provided a scoping review exploring the nature and scope of research about the management of CP in India. The findings reveal that there is an increasing body of literature about CP management in India; however, the research is mostly quantitative and focuses on body structure and function. There is much less focus on interventions aimed to increase participation and modify the environment. The results led us into the fifth study, in which I developed plain-language videos about CP management using the ICF framework. These videos helped to inform parents and other stakeholders involved in the management of children with CP about the various areas that can be intervened to increase activity and participation among children with CP.

This body of work has the potential to advance the field of rehabilitation sciences in several areas. The findings will be useful to shape and inform future research projects in the area of childhood disability. I will discuss the implications in three areas.

I: Clinical implications:

I reported that Indian parents focus towards fixing their child, and children are more confined to home compared to Canadian children. The research in India about the management of CP also focusses on studying interventions at the body structure and function level. This is a significant cultural and social aspect/trend prevalent among stakeholders in India about the management of CP in India. It demonstrates that the focus of research topics aligns with the focus of parents and health care providers. While we cannot be sure of research drives focus, or follows the priorities set by clinicians, it suggests that moving the research and the attitudes of knowledge users is needed to improve outcomes for children with CP, particularly in India.

To broaden the focus of healthcare providers and to change parents' perspectives towards the management of children with CP, efforts at various levels are needed simultaneously. Healthcare providers have a professional responsibility to conduct evidence-based practice. In clinical practice, to encourage healthcare providers to look at ways to increase children's participation in age-appropriate activities (as opposed to normalizing movement patterns) efforts are needed to educate healthcare providers about the use of the ICF framework. Using Knowledge Translation strategies, education and hands-on efforts in the non-technical and engaging format are required to orient and encourage healthcare providers in India to look towards incorporating activity- and participation-based approaches.

Hands-on education (Anaby, Korner-Bitensky, Law, & Cormier, 2015) and tools like videos are effective in creating change in HCPs' knowledge, skills, capacity and practice (Camden, Rivard, Pollock, & Missiuna, 2015; Jeong, Law, DeMatteo, Stratford, & Kim, 2016; Missiuna et al., 2012; Russell et al., 2010). Healthcare providers and researchers having experience and knowledge of using the ICF framework can serve as knowledge brokers to help colleagues to understand and incorporate the ICF framework in clinical practice. This knowledge sharing might also contribute to creating a community of practice among healthcare providers and will further assist them to collaborate, thus creating research capacity and larger data sets, which can generate more robust evidence-based knowledge. Using the ICF framework can help healthcare providers to envision the many ways they can assist the child to participate actively in age-appropriate activities.

Patient education is an essential part of clinical practice, and simultaneous and similar efforts are needed to improve the theoretical, instrumental, and scientific relevance of these interventions. Parents know and want the best for their child. Parents and healthcare providers work in close collaboration and have the potential to influence each other's decisions. Informing and educating parents about their child's health should enable them to recognize their child's strengths and interests. The education might help parents to work towards building on children's existing strengths, and move away from the mindset of fixing the impairments and break the longstanding assumption of the need to "make the child normal." Helping parents understand children's strength might give them hope and courage to advocate for their child, thus creating a positive mental health. A shared understanding of goals through an ICF lens might help HCP engage in more effective goal-setting, communication and treatment consistency across clinic and home-programs. Since both health care providers and parents found the videos useful, this potential seems achievable. The videos might be considered basic level ICF-aligned training tools that could be used as start points for a variety of discussions or interventions.

II: Research implications:

There is a lack of qualitative studies regarding management of CP in India, with the focus being more on the body structure and function domain. There is a need to incorporate parents' and children's preferences and viewpoints while managing children with CP. Qualitative studies in Western countries illustrate that parents focus on variety of issues in rehabilitation of their children with CP (Piskur, Beurskens, Jongmans, Ketelaar, & Smeets, 2015; Reid et al., 2011; Vargus-Adams & Martin, 2011) and face multiple challenges during the process (Piskur et al., 2012; Resch et al., 2010). It is also important to explore and consider perspectives of children and youth with CP as these views often differ from their parents' views and priorities (Garth & Aroni, 2003; Lindsay, 2016). Increased use of qualitative studies can help healthcare providers in India to explore areas that are important to children with CP and their parents. Exploration of children's and parents' preferences might help healthcare providers and researchers to see beyond body structure and function domain, and focus on improving activity and participation in children with CP.

While our results are promising, they relate to uptake and attitudinal changes. What we hope to see in the future is the implementation of ICF in better communication, shared decision making, holistic treatment plans, community supports, and treatment outcomes, including satisfaction and quality of life for parents and children. This requires evidence from a wide range of studies that might build on this work to assess more comprehensive integration of ICF in the clinical process, in public health interventions, and in the evaluation of prognosis and outcomes. Since parents valued the knowledge provided by the videos, but were not confident about implementation in their own context, the next KT study might test a multi-modal intervention where the videos are augmented by a skills workshop and a peer support system where families could share strategies and resource. Using an RCT design to measure this approach against current standard practice would determine if there is a measurable benefit to this approach.

The scoping review suggested that many studies in India were published in predatory journals. This raises questions about the credibility of the research, and also about the reasons as to why Indian researchers choose to publish their research in predatory journals. Future research is needed to explore the potential reasons for selecting predatory journals by Indian HCP, and develop resources to educate Indian HCP about choosing between a predatory and non-predatory journal.

III: Policy implications:

Both Canadian and Indian parents expressed frustration with policies that were insufficient to meet the needs of their child. The Canadian context although more resource-rich was not always able to provide services in a timely way or the range of services needed. The Indian context reflected more widespread policy and resource challenges that might be expected in a developing nation. Many Indian children stayed at home due to lack of accessible infrastructure and human support. Social stigma around disability was more common in India. Moreover, the medical curriculum in India is traditional, and less focus is given to research, curriculum design, and resource development (Solanki & Kashyap, 2014; Supe & Burdick, 2006) which may explain the medicalized approach to CP management in India.

In India, the Persons with Disability Act mandates equality and participation in all areas of life for individuals with a disability. However, a recent study analyzing the trend for the education of children with disabilities in India highlights that due to an international push towards the education of children with disabilities, school enrollment rates have increased in the last decade (Singal, 2016). However, the lack of basic infrastructural necessities for the disabled, like accessible toilets and ramps; lack of expertise, skills and negative attitudes of teachers to educate and engage with children with disability; and low quality of education have led to many children not attending school in India (Sharma, Moore, & Sonavane, 2009; Singal, 2016). Despite the provision of "education for all" under the Persons with Disability Act, only children with less physical dependence and better language abilities can attend school regularly (Anish et al., 2013). These findings suggest that policies alone are insufficient to affect change. Although there are rules and guidelines to include children with disability in India, they are not implemented rigorously. This is likely at least partially a resource issue. A stricter watchdog system and greater advocacy from people with a special understanding of these issues might help in the strict implementation of laws in India and encourage governments to prioritize resources to the implementation.

In Canada, many children receive physiotherapy and occupational therapy within the school. In India, this model might be adopted to assist with better integration in schools. If the resources could be allocated to hire allied healthcare professionals along with teachers then this should increase the number of children with CP in school in India, and reduce the social exclusion reported by parents of children who were currently attending school. These professionals can help to integrate exercises, adaptive equipment, and other needed adaptations within the school curriculum and premises, thus allowing children to attend school and therapy at the same time.

There is a great need for reform in the medical curriculum in India, with an emphasis to educate and train healthcare providers to do evidence-based practice. Lack of research time and equipment, financial constraints, limited training and expertise in conducting and appraising research, organisational barriers, lack of will, service obligations and shortage of resources are commonly cited reasons for non-involvement in research by Indian healthcare providers (Alamdari, Venkatesh, Roozbehi, & Kannan, 2012; Sadana, D'Souza, Hyder, & Chowdhury, 2004). Even if most professionals are not going to be researchers, it is essential that they are exposed to 'critical appraisal' skills to enable them to be affecting consumers of the existing research literature and to be able to separate wheat from chaff. Increased collaboration with international institutions, and professionals having an education from resource-rich countries (as they understand the issues in both the countries), developing online tools (future work in progress) and hands-on workshops to help healthcare providers access, understand and implement the research evidence can help in engaging healthcare providers in understanding research activities. It is important to develop, revise and implement organizational practices and policies to develop human and institutional capacity to engage in scientific research in Indian healthcare institutions. This increased capacity might further promote the use of research evidence in clinical practice in India.

Parents in Canada were more aware of their need to advocate for their children. They advocated for local services, and to some extent for policy changes. The use of ICF language might be a common language that researchers, parents and policy makers might use to come to a shared understanding on issues or when considering policy changes. This was not explored in this study, but advocacy was an important theme. Indian parents were less likely to be assertive advocates for their child as the traditional medical hierarchy was more predominant. However, a potential outcome of training parents in India is that they would become effective advocates.

Limitations and future directions:

Although this thesis address Canadian and Indian contexts using an ICF lens, it was not possible to fully address either context or all important aspects. Further, limitations in how the studies were conducted should be considered when interpreting or applying the findings. The findings of the study exploring parents' perspectives of rehabilitation of their young children with CP are based on a sample of parents from Mangalore in the southern part of India. In India, health is the responsibility of state government, and there are variations in health resources and infrastructure across different states (Purohit, 2004). More nationwide studies are required to explore parents' perspectives in other states to get a broader picture. I also included only English-speaking parents of young children (2-10 years). Future work should include parents from non-English speaking areas and with adults/adolescents with CP. More representation from diverse parent groups will help to explore various factors shaping parents' perspectives in India. Management of CP requires a range of professionals and service providers. It is important to study perspectives of teachers and clinicians, and other service providers, to understand their views and the challenges they face while engaging in the management of children with CP. Perspectives from children and adults with CP in India should be explored in future studies. We also had children with a less severe form of CP in the Canadian sample. Future work should include parents' perspectives on children with severe levels of CP from resource-rich countries. Exploring perspectives and the factors shaping them will help us to find solutions to the challenges experienced, thus allowing service providers to provide family-centered service.

In the scoping review, I explored the state of the literature about research on management of CP in India. Future work is needed to explore clinical practice patterns about the management of CP in India (work in progress). Although our purpose was to describe the nature of the research enterprise, it was not possible for us to go further and do systematic reviews of the interventions used in India, due to limitations in the literature.

Using the P-ICF videos we tried to inform parents about the use of evidence-based techniques and resources for management of children with CP. Despite various efforts, we could only manage to get 13 responses from India (parents + professionals). Thus, despite our intent to engage and compare the developed and developing target audiences, we have limited data on the resource-limited countries. Beyond an online survey, future research should incorporate other measures like face-to-face interaction and finding key community leaders to engage better with Indian parents for a better and deeper response rate. This means we can be less confident the videos met the needs of both groups. Future work should focus on revising the P-ICF videos as per the feedback, and exploring the effectiveness of P-ICF videos in changing parents' capacity and perspectives towards their children.

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APPENDICES

Appendix 1

Definition of the ICF concepts

The ICF provides following definitions for its domains.[1]:

1. Body structures are defined as “anatomical parts of the body such as organs, limbs and their components”.
2. Body function is defined as “physiological functions of body system (including psychological functions).
3. Activity has been defined as “an execution of a task or an activity by an individual”, and activity limitation is defined as “difficulties an individual may have in executing activities”.
4. Participation has been defined as “an involvement in life situation”, and participation restriction is defined as “problems an individual may experience in involvement in life situations”.
5. Environmental factors are external factors and are defined as “the physical, social and attitudinal environment in which people and live and conduct their lives”. Examples of environmental factors include social attitudes, architectural, legal and social characteristics.
6. Personal factors are internal factors like age, gender, coping styles, social background, education, profession, past and current experience, overall behaviour pattern and other factors that influence how disability is experienced by an individual. Personal factors are considered as a background of individual’s life and living that are not a part of health condition, but can impact the functioning positively or negatively.[2]

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Appendix 2

Semi-structured interview guide to explore parent's perspective of their children with CP

In this study, I would like to know about how do you think about your child's abilities and disabilities and how do you help your child.

I will record the interviews, and do I have the consent to record?

1. Please tell me something about your child?
   Probes: How is a typical day for your child? What is your child engaged in during a typical day? What activities your child does (at home, school and community, play, social and cultural activities, recreation, personal care), communication with family and friends, fun and play activities, fitness etc., diagnosis?
   Independence in areas of : mobility, self-care, getting along (interaction), life activities (domestic, leisure, school), participation, cognition.
   What are the problems with the child? How do you think you can manage the problems? What do you think about the quality of life of your child?
2. How do you engage with your child's day to day activities? How are you helping in your child's rehabilitation? What are you doing to help in the rehabilitation of your child? What do you do to engage in your child's rehabilitation (to promote activity and participation)?
   Probes: promoting therapy, social exposure, school and community involvement, play with the child, what worked and what didn't, positive and negative effects on the child, fun activities.

   All of these questions will be probed by why question, for e.g. if parents say they are promoting therapy for the child, I would like to know what makes them promote therapy. This will help to understand what they engage in and why? what activities your child wants to do, and how do you or could you make the activity possible for your child?

3. What information/help would you like to receive to help your child? Why?

Appendix 3 Extracted data from studies for scoping review

S. no	Year	Title	Study Type	Population & Sample size	Indexing	Research question	Intervention	Outcomes reported	ICF domain intervened in experimental studies	ICF domain explored as an outcome in experimental studies	ICF domain studied in observation studies	Outcome measures used	Medical or Therapeutic intervention	Author qualifications (first author) & institute	Journal title
1	2015	A clinical study of autologous bone marrow mononuclear cells for cerebral palsy patients: a new frontier	Experimental	1.5 - 22 years, 40 CP children	Pubmed	To demonstrate the therapeutic benefits of cell therapy in combination with rehabilitation. The primary aim of the study was to evaluate the efficacy of intervention on CP children for the period of 6 months.The secondary aim was to evaluate in detail the effect of intervention on different types of CP.	1 dose of cell transplantation & standard neurorehabilitation. Cell therapy included intrathecal administration of autologous bone marrow mononuclear cells. Neurorehabilitation for 6 months included PT, OT, SLP, and psychological intervention.	Metabolic improvements in areas of the brain correlating to clinical improvements, Video recording and grading of the movement, neuroevaluation, improvement in walking, balance, speech, trunk control, tone, oromotor skills, speech	BSF	BSF, activity	NA	PET-CT scan to monitor the functional metabolic improvements in brain, video recording of the movements and user made criteria to assess these movements & walking, balance, speech, trunk control, tone, oromotor skills, speech	Medical	Department of Medical Services and Clinical Research, NeuroGen Brain & Spine Institute, Stem Asia Hospital and Research Centre, Mumbai. Neurosurgeons	Stem Cells International
2	2012	Administration of autologous bone marrow-derived mononuclear cells in children with incurable neurological disorders and injury is safe and improves their quality of life	Experimental	71 mixed patients, 20 with CP, 8-9 yrs	Pubmed	To demonstrate that the administration of autologous stem cells for incurable neurological disorders, intrathecal and intramuscular is safe, feasible, and has the potential to improve the quality of life of the patient.	Autologous Bone Marrow derived mono nuclear cell transplant and Rehab for 6 month-1 year. Stem cells	Muscle strength, tone, siezure freq., speech, gross motor function, balance	BSF	BSF	NA	FIM, MMT, MRI, NCV,	Medical	NeuroGen Brain & Spine Institute, Surana Sethia Hospital and Research Centre, Mumbai. Neurosurgeons	Cell transplantation

3	2010	A comparative study to study psycological status of mothers of children with cp & mother of normal children	Observation	30 Mother of CP patients. 2 -12 years	Google	To evaluate the depression and anxiety levels of mother having CP child compared to mothers of normal children	NA	Mothers depression and anxiety levels	NA	NA	Environmental factor	Beck deprression inventory, Sinha Anxiety Scale	NA	Dept. of Rehab sciences, Jamia Hamdard, New Delhi, Occupational therapist	The Indian Journal of OT
4	2014	Analysis of postural stability in children with cerebral palsy and children with typical development: an observational study	Observation	45 CP children (34 with spastic Diplegia, 11 with hemiplegia). 5 to 12 years, GMFCS Level 2 & 3	Pubmed	Using posturography to estimate the difference in balance control,while standing under conditions that would challenge visual and somatosensory inputs	NA	Posturography parameters	NA	NA	BSF	Posturography	NA	Department of Allied health sciences, Manipal University, Physiotherapist	Pediatric physical therapy
5	2015	Applicability of peabody developmental motor scales-2 in spastic diplegia : a single case study	Validity study	One child with this spastic diplegia, 9 months	Scopemed	Single case study has been taken to study the applicability of PDMS 2 in evaluating motor development in spastic diplegic children In India	NA	Different components of PDMS-2	NA	NA	NA	PDMS-2	NA	SDM College of physiotherapy, physiotherapist	International Journal of health sciences and research
6	2008	Approaches to therapy for children in India with cp	Narrative review	NA	Pubmed	Briefly describes various rehab approaches to CP treatment in India. Like PT, OT, SLP, special education	NA	NA	NA	NA	NA	NA	NA	Indian Institute of Cerebral Palsy, SLP	Journal of Pediatric Rehabilitation Medicine: An Inderdisciplinary Approach
7	2014	A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in western India	Qualitative	13 mothers, 4-6 yrs child age	Pubmed	To explore the psychosocial problems experienced by the parents of children with CP	NA	Social, financial and health problems experienced by mothers	NA	NA	Environmental factors	NA	NA	Pramukhswami Medical College, Gujrat, Pediatrics and community medicine	ISRN Family Medicine

8	2016	Articulatory working space area in children with cerebral palsy	Observation	20 CP children, 6-12 yrs	Scopemed	Study aimed at investigating difference across format frequencies and vowel working space area	NA	Vowel space area in individuals with CP was much reduced than normals indicating the restricted and narrowed range of tongue and jaw movements	NA	NA	BSF	NA	NA	Dept. of Speech & Language Pathology, JSS Institute of Speech & Hearing, Mysuru, SLP	International Journal of health sciences and research
9	2011	Assessment of the hand in cerebral palsy	Narrative review	N/A	Pubmed	Article focuses on the clinical examination, patient selection, and decision making while managing CP patients	NA	NA	NA	NA	NA	N/A	NA	Department of Plastic Surgery, Hand Surgery, Reconstructive Microsurgery and Burns Ganga Hospital, Plastic surgeons	Indian Journal of plastic surgery
10	2013	Association of timed “up and go” test with respect to gross motor function classification system level in children diagnosed as cerebral palsy	Observation	30 CP children of 4-12 years, GMFCS level I, II, and III.	DOAJ	To find score of TUG test with respect to GMFCS level	NA	TUG scores	NA	NA	Activity	TUG test, GMFCS	NA	Department of Physiotherapy, Padmashri Dr. Vittalrao Vikhe Patil Foundation’s Campus, Maharashtra, India Physiotherapists	International Journal of Health & Allied Sciences
11	2015	A study of audiological profile of children with cerebral palsy	Epidemiology	117 children of 2-10 years	Medknow	To determine the frequency and type of hearing impairment in children with cerebral palsy. From Oct. 2011-Apr. 2013	NA	Types of hearing impairment. Eg. Sensorineural, conductive, and mixed hearing impairment	NA	NA	NA	Audiometry	NA	Department of Audiology, Ali Yavar Jung National Institute for the Hearing Handicapped, Mumbai SLP	Indian Journal of Cerebral Palsy

12	2013	A study of feeding problems in children with cerebral palsy	Observation	33 mothers and children aged 7 months - 8 yrs	Scopemed	To find out the magnitude and extent of feeding problems in children with cerebral palsy	NA	Sucking and swallowing problems, inability to self feed, prolong feeding time, improper feeding positions, coughing and chocking during feeding , vomiting, recurrent chest infections, oral motor dysfunction, drooling, cry / strong extensor thrust during feeding	NA	NA	BSF, activity	GMFCS, Gisel and Patrick’s feeding behavior skill score	NA	SBB College of Physiotherapy, Gujrat, Physiotherapist	National Journal of Integrated Research in Medicine
13	2014	A study on the awareness, beliefs, and service utilization among families of children with cerebral palsy in Jalandhar district of Punjab	Observation	248 children, 3-13 years	Medknow	To explore the awareness, beliefs, concerns and socioeconomic status of the family of children with cerebral palsy, and examine the influence of these factors on the service utilization pattern	NA	Parents awareness, beliefs & service utilization trends	NA	NA	Environmental factors	socioeconomic scale developed by Aggarwal et. Al.	NA	Department of Physiotherapy, Lyallpur Khalsa College, Jalandhar, Physiotherapist	CHRISMED Journal of Health and Research
14	2013	A study to find the effect of myofascial release on chest expansion in cerebral palsy children	Experimental	50 children, 5 to 12 years	Scopemed	Find the effect of myofascial release on chest expansion in cerebral palsy	Myofascial release	Chest measurements	BSF	BSF	NA	NA	Therapeutic	D.Y. Patil College of Physiotherapy, Physiotherapist	International Journal of Current Research and Review
15	2012	Availing services for developmental disabilities: parental experiences from a referral center in developing country	Observation	74 children with CP. 4 monhs-14 yrs	Pubmed	To identify the problems faced by parents of children with developmental disabilities in availing rehabilitative services and to find their satisfaction level.	NA	Problems in transporting, finances	NA	NA	Environmental factors	NA	NA	Department of Pediatrics, Maulana Azad Medical College, Delhi, pediatricians	Indian Journal of pediatrics

16	2014	Barriers to early diagnosis, intervention and social integration of children with developmental disabilities: a qualitative study from rural villages and a poor urban settlement of bangalore, south india	Qualitative	Parents of 32 children. 2-15 yrs	DOAJ	1. To identify barriers to early identification, appropriate treatment and rehabilitation of children with developmental disabilities, as perceived by parents 2. To determine barriers to diagnosis and provision of appropriate care to children with developmental disabilities,as perceived by doctors. 3. To identify barriers in providing inclusive education to these children,as perceived by teachers. who live in rural and urban areas of Bangalore	NA	Physician (lack of knowledge & resources), parent(financial problems, mythts and stigma) and teacher (apprehension and attitude) related barriers	NA	NA	Environmental factors	NA	NA	Community Health Department, Bangalore Baptist Hospital, Bangalore, physicians	Disability, CBR and Inclusive Development
17	2005	Bedtime diazepam enhances well-being in children with spastic cerebral palsy	Experimental, RCT	120 children, below 5 years	Pubmed	Assess the use of bedtime diazepam on burden of caring, Child behavior & child's ADL activities	Bedtime oral diazepam	Parent reported burden of care & child behaviour profile, tone and spasm reduction	BSF	Activity, BSF & environmental factor	NA	Researcher developed questionnaire	Medical	Christian Medical College, Vellore, Pharmacology	Pediatric rehabilitation
18	2014	Body mass index in children with cerebral palsy	Observation	50 CP children, 1 to 18 years	Scopemed	To analyze body mass index of children with CP	NA	BMI values	NA	NA	BSF	GMFCS	NA	GMERS Medical College, Gandhinagar, SBB College of Physiotherapy, Physiotherapist	National Journal of Integrated Research in Medicine
19	2010	Botulinum toxin type a in subjects with spastic cerebral palsy from eastern India	Experimental	63 spastic CP, 1-19 years	Pubmed	Study was undertaken to determine the response of BTXA in our subjects with cerebral palsy in respect of reduction of tone, diminution of pain, improvement of limb position, gait and functional skill.	Botox injection	Tone, pain & functional status	BSF	BSF & activity	NA	Modified ashworth scale, visual analog scale, ROM, Physician rating scale for gait, tone rating scale, global functional assessment scale	Medical	Department of Neurology, Department of physiotherapy Bangur Institute of Neuroscience & Psychiatry, Kolkata, neurologist	Journal of Pediatric Neurology
20	2008	Burden of caring: families of the disabled in urban India	Qualitative	Parents of 14 to 25 years old CP children	Pubmed	To examine the experience of caregiving in families of young children with cerebral palsy	NA	Individual and social dimension of disability	NA	NA	Environmental factors	NA	NA	Department of Community Health and Social Medicine, Jawaharlal Nehru University, New Delhi, physicians	Indian Journal of Gender Studies

21	2016	Caregiver-reported health-related quality of life of children with cerebral palsy and their families and its association with gross motor function: a south Indian study	Observation	3-10 years old CP children	Pubmed	To determine the health-related quality of life of children with cerebral palsy and their families and its correlation with gross motor function.	NA	Lifestyle assessment questionnaire-CP	NA	NA	QOL	Lifestyle assessment questionnaire-cerebral palsy, to assess quality of life of children and their families	NA	Department of Paediatrics, Indira Gandhi Institute of Child Health, Bengaluru, pediatricians and pediatric neurologists	Journal of Neurosciences in Rural Practice
22	2015	Cerebral palsy: antenatal risk factors	Epidemiology	Mother of 100 CP children	DOAJ	To study the different antenatal maternal risk factors associated with cerebral palsy in the study group.	NA	Antenatal risk factors	NA	NA	NA	NA	NA	Andhra Medical College, Department of orthopedics, anesthesiology, pediatrics	Journal of Evolution of Medical and Dental Sciences
23	2005	Cerebral palsy-definition, classification, etiology and early diagnosis	Narrative review	NA	Pubmed	Briefly describe different types of CP and their treatments	NA	NA	NA	NA	NA	NA	NA	Department of Developmental Pediatrics, Bangalore Children's Hospital, pediatricians	Indian Journal of Pediatrics
24	2012	Cerebral palsy in children: an overview	Narrative review	NA	Pubmed	Brief synopsis of etiology, classification, diagnosis and management of cerebral in children.	NA	NA	NA	NA	NA	NA	NA	Department of Paediatric Orthopedics, CNBC, Geeta Colony, Delhi	Journal of Clinical Orthopaedics and Trauma
25	2007	Cerebral palsy: interictal epileptiform discharges and cognitive impairment	Narrative review	NA	Pubmed	This paper is intended to strengthen the earlier postulation made by the author emphasizing the role of IEDs in cognitive impairment and their subsequent timely treatment to obtain improvement in cognitive functioning in CP.	NA	NA	NA	NA	NA	NA	NA	Physiology Department, G.R. Medical College, Gwalior	Clinical Neurology and Neurosurgery
26	2015	Cerebral palsy: risk factors, comorbidities and associated mri findings, a hospital based observational study	Epidemiology	57 CP patients	Scopemed	To study the various risk factors, comorbidities and MRI findings in patients with cerebral palsy patients.	NA	Types of CP, associated risk factors & MRI findings	NA	NA	NA	NA	NA	Department of Pediatrics, Government Medical College, Srinagar	International Journal of Contemporary Pediatrics

27	2013	Changes in the clinical spectrum of cerebral palsy over two decades in north india—an analysis of 1212 cases	Epidemiology	1212 children with CP, 1-2 yrs	Pubmed	We evaluated the clinical profile, etiological factors and co-morbidities of children with CP in North India, and compared with our previous study	NA	Types of CP, causes, comorbidities	NA	NA	NA	NA	NA	Department of Pediatrics, Postgraduate Institute of Medical Education and Research, Chandigarh	JOURNAL OF TROPICAL PEDIATRICS
28	2012	Children with developmentaldisabilities in india: age of initial concern and referral for rehabilitation services ,and reasons for delay in referral	Observation	103 children with CP, 2.75 mean age	Pubmed	To identify the age at first concern and age at referral for rehabilitation services in children with developmental disabilities in India	NA	Age of first concern & referral, and reasons for delay in referral (assuarnace by physicians and family members), non-referral	NA	NA	Environmental factors	Researcher developed questionnaire	NA	Child Development Center, Maulana Azad Medical College and associatedLok Nayak Hospital, Bahadur Shah Zafar Marg, New Delhi	Journal of Child Neurology
29	2015	Clinical outcome with botulinum toxin-a in spastic cerebral palsy children with equinus gait	Experimental	22 Spastic CP children, Age 2-8 years	Medknow	Analysis of spastic equinus gait, ankle movements, and spasticity change	Botulinum Toxin-A injected in gastrocnemius	Temporospatial parameters of gait, spasticity & ROM	BSF	BSF, Activity	NA	Modified Ashworth Scale, ROM, gait parameters	Medical	Department of Physical Medicine and Rehabilitation, AIIMS, PMR	Astrocyte
30	2008	Clinical profile of special children at asha centre	Epidemiology	13 CP children, no age mentioned	Pubmed	To study the clinical profile and underlying etiological factors in CP children at ASHA center	NA	Causes and comorbidities	NA	NA	NA	NA	NA	(Paediatrics), Armed Forces Medical College, Pune, Pediatricians	Med J Armed Forces India
31	2015	Clinical profile, predisposing factors, and associated co-morbidities of children with cerebral palsy in south India	Epidemiology	100 CP cases, No age mentioned	Pubmed	To study clinical patterns, predisposing factors and comorbidities in children with CP	NA	Percentage of different types of CP, antenatal complications and comorbidities	NA	NA	NA	NA	NA	Department of Pediatrics Neurology, Indira Gandhi institute of child health, bangalore, Pediatricians	Journal of Pediatric Neurosciences

32	2009	Communication functions, modalities, and maternal responses in children with severe speech and physical impairment	Observation	10 mother children, 2-4 yrs	Pubmed	To explore the different kinds of functions and modalities used by children with severe speech and physical impairment (SSPI) and cerebral palsy (CP) during communicative interactions with their mothers; and the choice of modalities to indicate different functions. Furthermore, this study attempted to investigate if mothers displayed identifiable responsive styles during these interactions	NA	Communication function, choice of modality	NA	NA	Activity and participation, Envt. Factor	Evaluation of the recorded video by two judges	NA	All India Institute of Speech and Hearing Manasagangothri, Mysore, SLP	Asia Pacific Journal of Speech, Language, and Hearing
33	2013	Comparative assessment of therapeutic response to physiotherapy with or without botulinum toxin injection using diffusion tensor tractography and clinical scores in term diplegic cp children	Experimental	36 children with CP, 2-8 yrs	Pubmed	To compare the effects of combined therapy [botulinum (BTX) plus physiotherapy] with physiotherapy alone using diffusion tensor imaging (DTI) derived fractional anisotropy (FA) values of motor and sensory fiber bundles and clinical grade of the disability to see the value of BTX in term children with spastic diplegic cerebral palsy (CP).	Botox injections, physiotherapy	MRI values, GMFM	BSF	BSF, Activity	NA	MRI values, GMFM	Medical	Magnetic Resonance Section, Department of Radiodiagnosis, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow, radiologists	Brain and Development
34	2016	Comparison between task -oriented training and pnf exercises on lower extremity function in cerebral palsy-a rct	Experimental,RCT	30 CP children, 5-12 yrs	OMICS	To compare the effect of Task-Oriented Training and Proprioceptive Neuromuscular Facilitation exercises on lower extremity function in children with cerebral palsy	Task oriented training, PNF exercises	Pediatric berg balance scale, 10 m walk test, Gait parameters	Activity, exercises	BSF, Activity	NA	Pediatric berg balance scale, 10 m walk test, Gait parameters	Therapeutic	Department of Physiotherapy, School of Allied Health Sciences, Sharda University, physiotherapists	Journal of Novel Physiotherapies
35	2011	Comparison of energy expenditure in community ambulating spastic diplegic children with and without walker: a cross-sectional study	Experimental	25 CP children, 5-17 yrs	Google	To compare energy expenditure of ambulation with and without walker on outdoor uneven surface and indoor even surface in children with spastic diplegia	Walker	Physiological cost index values	Environmental factors	BSF	NA	Physiological cost index	Therapeutic	Physiotherapy, Department of allied sciences, Manipal university, physiotherapists	Physiotherapy and Occupational Therapy Journal

36	2015	Comparison of postural instability between the spastic diplegic and hemiplegic children with cerebral palsy	Observation	100 CP children, 5-12 yrs	Medknow	To compare the postural instability between the children with cerebral palsy having spastic diplegia and hemiplegia	NA	Early Clinical Assessment and Balance (ECAB) scale and Pediatric Reach Test (PRT).	NA	NA	BSF	Early Clinical Assessment and Balance (ECAB) scale and Pediatric Reach Test (PRT).	NA	Department of Physiotherapy Pediatric Neurology, Sancheti Hospital, Shivaji Nagar, Pune, Maharashtra, physiotherapists	Indian Journal of Cerebral Palsy
37	2016	Comparison of self-concept of children with cerebral palsy and children without impairments	Observation	56 CP children, 10-16 yrs	Medknow	To compare the selfconcept of children having cerebral palsy with the children having no impairment	NA	Harter's Self Perception Profile for Children (SPPC)	NA	NA	Environmental factors (childs PF)	Harter's Self Perception Profile for Children (SPPC)	NA	Department of Pysiotherapy, Sancheti Institute College of Physiotherapy, Pune, Maharashtra, India, physiotherapists	Indian Journal of Cerebral Palsy
38	2006	Compliance with walking aid use in children with cerebral palsy in India	Observation	50 CP children, 6-16 yrs	Pubmed	To Assess the compliance with the walking aid	NA	Distance walked, %age use walking aid	NA	NA	Environmental factors (child's PF)	Log entry of Distance walked, %age use walking aid	NA	Department of Physiotherapy, Manipal College of Allied Health Sciences, physiotherapist	American Journal of Physical Medicine & Rehabilitation
39	2014	Correlation between motor impairment and participation in children with cerebral palsy	Observation	20 CP children, Five years+	Scopemed	To find out the co-relation between motor impairment and participation in children with cerebral palsy	NA	PEDI and GMFCS	NA	NA	Activity	PEDI	NA	S.B.B. College of Physiotherapy, V.S. General Hospital, Ellis Bridge, Gujarat, physiotherapists	International Journal of Contemporary Pediatrics
40	2014	Correlation of functional independence and quality of life in school aged children with cerebral palsy	Observation	46 CP children, 4-12 yrs	Scopemed	To examine the correlation between functional independence and quality of life in school-aged children with cerebral palsy	NA	FIM, Wee-FIM, CP-QOL scores	NA	NA	Activity, QOL	FIM, Wee-FIM, CP-QOL	NA	S.B.B. College of Physiotherapy, V.S. General Hospital Campus, Ellis Bridge, Gujarat, physiotherapists	International Journal of Contemporary Pediatrics
41	2014	Correlation of gross motor function with abiloco-kids questionnaire for assessing locomotion ability in children with cerebral palsy	Observation	18 CP children, 6-15 yrs	Scopemed	To correlate ABILOCO-Kids questionnaire with GMFM for assessing locomotion ability in children with CP	NA	ABILOCO-Kids questionnaire & GMFM	NA	NA	Activity	ABILOCO-Kids questionnaire & GMFM	NA	S.B.B. College of Physiotherapy, V.S. General Hospital, Ellis Bridge, Ahmedabad-380006, Gujarat, physiotherapists	International Journal of Contemporary Pediatrics

42	2010	Correlation of quantitative sensorimotor tractography with clinical grade of cerebral palsy	Observation	39 CP children, 3-12 yrs	Pubmed	To determine whether tract-specific diffusion tensor imaging measures in somatosensory and motor pathways correlate with clinical grades as defined using the Gross Motor Function Classification System (GMFCS) in cerebral palsy (CP) children.	NA	Ashworth scale, gait video recording, MRI values	NA	NA	BSF	Ashworth scale, gait video recording,	NA	Department of Radiodiagnosis, anesthesiolog, Neurology. Sanjay Gandhi Postgraduate Institute of Medical Sciences; Radiologists, India	Neuroradiology
43	2016	Coupling effect of neuromuscular electrical stimulation on glutei and transcutaneous electrical nerve stimulation on hip adductors in scissoring gait	Experimental	30 CP children, 4 to 11 years	Medknow	To study the coupled effect of neuromuscular electrical stimulation (NMES) on glutei and transcutaneous electrical nerve stimulation (TENS) on hip adductors in improving gait parameters	NMES & TENS	Modified Ashworth scale, AROM, Voluntary control grading, gait parameters	BSF	BSF, activity	NA	Modified Ashworth scale, AROM, Voluntary control grading, gait parameters	Therapeutic	Department of Physiotherapy,Department of Neurosurgery Nizam's Institute of Medical Sciences, Hyderabad, Physiotherapists	Indian Journal of Cerebral Palsy
44	2011	Depression and quality of life in mothers of children with cerebral palsy	Observation	30 mother of CP children	Scopemed	To evaluate depression and quality of life in mothers of children with cerebral palsy.	NA	BDI and SF 36 scores	NA	NA	Environmental factor, QOL	BDI-II to measure the level of depression, SF 36 for QOL	NA	S.B.B.College Of Physiotherapy, Gujarat, Department of Physiology, Government Medical College, physiotherapists	National Journal of Integrated Research in Medicine
45	2013	DTI correlates of cognition in term children with spastic diplegic cerebral palsy	Observation	22 CP, 22 healthy controls, 4-12 years	Pubmed	To correlate cognitive functions with diffusion tensor imaging derived metrics in spastic diplegic children	NA	Indian children intelligence Test to quantify cognition and DTI to quantify microstructural changes in various white matter regions	NA	NA	BSF	Revised Amsterdamse Kinder Intelligence (RAKIT) Test.43 The Indian Children Intelligence Test (ICIT), MRI findings	NA	Department of Radiodiagnosis, Sanjay Gandhi Post Graduate Institute of Medical Sciences, Uttar Pradesh, radiologist	European Journal of Pediatric Neurology
46	2014	Effectiveness of myofascial release on spasticity and lower extremity function in diplegic cerebral palsy: randomized controlled trial	Experimental, RCT	30 CP children, 2-8 yrs	OMICS	To find out the effectiveness of Myofascial Release in combination with conventional physiotherapy on spasticity of calf, hamstring and adductors of hip and on lower extremity function in spastic diplegic subjects	Myofascial Release	Modified ashworth scale, tardieu scale, GMFM	BSF	BSF, Activity	NA	Modiefied ashworth scale, tardieu scale, GMFM	Therapeutic	College of Physiotherapy, Narhe, Pune, Physiotherapists	International Journal of Physical Medicine & Rehabilitation

47	2012	Effectiveness of play therapy over conventional physiotherapy in spastic diplegic cerebral palsy children	Experimental	30 CP children, 3-7 yrs	Scopemed	To examine the effectiveness of play therapy together with conventional therapy to improve the hand function ability in children with spastic diplegic cerebral palsy.	Conventional PT vs play exercises (Playing with Dough, sand, water)	Box and Block test and Nine Hole Peg test scores	Activity	Activity	NA	Box and Block test and Nine Hole Peg test	Therapeutic	Department of Physiotherapy, College of Applied Education and Health Sciences, Ch. Charan Singh University, Meerut, Physiotherapist	National Journal of Integrated Research in Medicine
48	2014	Effect of ankle foot orthosis on energy expenditure index and gait speed in spastic cerebral palsy children : an observational study	Experimental	21 CP children, 6.85 yrs mean age	Scopemed	To determine whether use of AFO affect the gait speed & energy expenditure in cerebral palsy children or not	Walk with & without AFO	Energy expenditure index and gait speed	Environmental factors	Activity, BSF	NA	10 m walk test, heart rate, and gait speed	Therapeutic	S.B.B. College of Physiotherapy, V.S. General Hospital, Ellis Bridge, Gujarat, Physiotherapists	International Journal of Contemporary Pediatrics
49	2014	Effect of anterior chest wall myofascial release on thoracic expansion in children with spastic cp	Experimental	12 CP children, no age mentioned	Scopemed	To see the effect of MFR on chest wall movements	Myofascial release	Pre-and posttest chest expansion scores at Axila, xiphoid and sub-costal areas	BSF	BSF	NA	Pre-and posttest chest expansion scores at Axila, xiphoid and sub-costal areas	Therapeutic	S.B.B. College of Physiotherapy, V.S. General Hospital, Ellis Bridge, Gujarat, physiotherapist	International Journal of Contemporary Pediatrics
50	2015	Effect of auditory & visual biofeedback with electrical stimulation of the tibialis anterior muscle on active rom & selective motor control of ankle of children with spastic cp	Experimental	30 CP children, 4 to 10 years	Scopemed	To investigate the efficacy of using biofeedback and neuromuscular electrical stimulation applied ontibialis anterior in children with cerebral palsy. The present work was designed to compare the effect oftreatment with or without biofeedback applied to children with diplegic CP	NMES & biofeedback	ROM, Voluntary muscle control, GMFM score	BSF	BSF, Activity	NA	GMFM, ROM and VMC	Therapeutic	Shri U.S.B. College of Physiotherapy, Rajasthan, National Centre for Nanoscience and Nanotechnology, Vidyanagari Campus, Kalina, Santacruz (East), University of Mumbai, Swami Vivekanand National Institute of Rehabilitation Training and Research, Orissa, India.	International Journal of Physiotherapy and Research

51	2016	Effect of cage therapy using advanced spider suit compared to traditional physical therapy on gross motor function in children with cerebral palsy – an indian experience	Experimental	10 CP children, 4 to 8 years	OMICS	To find out the Effect of Cage Therapy using Advanced Spider Suit Compared to Traditional Physical Therapy on Gross Motor Function in Children with Cerebral Palsy	5 weeks of cage therapy	GMFM Scores Pre-and post	BSF, Activity	Activity	NA	GMFM	Therapeutic	Cloudnine Hospital, Jayanagar, bangalore, Pediatrician	International Journal of Neurorehabilitation
52	2015	Effect of dynamic sitting balance on upper extremity motor skills in children having spastic diplegia : a correlational study	Experimental, RCT	30 CP children, 2-8 years	Medknow	To study the effect of dynamic sitting balance on upper extremity skill in children having spastic diplegia	Dynamic sitting exercises on Swiss ball, wobble board	Pre-and post-Scores on Quest, pediatric reach, sitting assessment scale	Activity	Activity	NA	Quest, pediatric reach, sitting assessment scale	Therapeutic	Department of Physiotherapy, Nizam's Institute of Medical Sciences, Panjagutta, Hyderabad, Department of Neurosurgery, physiotherapist	Indian Journal of Cerebral Palsy
53	2014	Effect of high frequency tens versus sham tens on spastic plantar flexors in children with cerebral palsy	Experimental	34 CP children, 5.36 yrs mean age	Scopemed	To evaluate the Effect of high TENS with conventional therapy in comparison to sham TENS with conventional therapy on spasticity of plantar flexors in cerebral palsy children	TENS	Spasticity, range of motion, GMFM	BSF	BSF	NA	Modified Ashworth scale, GMFM, ROM	Therapeutic	S.B.B college of physiotherapy ,Vadilal sarabhai hospital, Gujarat, physiotherapist	International Journal of Physiotherapy and Research
54	2014	Effect of modified constraint induced movement therapy on hand function of hemiplegic cerebral palsy	Experimental	10 CP children, 2-8 yrs	Scopemed	To determine the effectiveness of modified CIMT on hand function of hemiplegic CP children	CIMT	Pre-and post-values on Quest, pediatric motor log activity	Activity	Activity	NA	Quest, pediatric motor log activity	Therapeutic	Sigma Institute of Physiotherapy, Bakrol, Vadodara, Physiotherapist	International Journal of Current Research and Review
55	2011	Effect of modified suit therapy in spastic diplegic cerebral palsy - a single blinded randomized controlled trial	Experimental, RCT	30 CP children, 4 to 12 years	DOAJ	To determine the effect of modified suit therapy in gross motor function of spastic diplegic children	Suit therapy for 2 hours daily for 3 weeks	Pre-and post GMFM' scores	Activity	Activity	NA	GMFM	Therapeutic	KJ Pandya College of Physiotherapy, Sumandeep University, Vadodara, Mobility India, Bangalore.	Online Journal of Health and Allied Sciences

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56	2016	Effect of neuromuscular electrical stimulation on gluteus maximus and quadriceps in cerebral palsy children with crouch gait	Experimental	40 CP children, 5-11 yrs	OMICS	To investigate the effects of NMES on Gluteus maximus and Quadriceps strength in cerebral palsy children with crouch gait, and the subsequent effect on their gross motor function	NMES	Muscle strength, GMFM	BSF	BSF, activity	NA	ROM, GMFM	Therapeutic	Swami Vivekan and National Institute of Rehabilitation Training and Research, Olatpur, Cuttack, India, physiotherapist	Journal of Neurological Disorders
57	2008	Effect of serial casting in spastic cerebral palsy	Experimental	22 CP children, 3-8 yrs	Pubmed	To evaluate the effect of serial casting in spastic children in terms of increase in range of motion, reduction of spasticity and improvement in ambulation	Serial Casting	ROM, spasticity, video recording of walking	BSF	BSF, activity	NA	Modified Ashworth scale	Therapeutic	Department of Physical Medicine and Rehabilitation, SMS Medical College, Jaipur, orthopedic surgeon	Indian Journal of Pediatrics
58	2016	Effect of vibrotactile stimulation on motor performance in a child with cerebral palsy: a case study	Experimental, Case study	One CP child nine years of age	Medknow	To report unexpected quick and highly effective result of vibrotactile stimulation on gross motor ability in a child with cerebral palsy.	Vibration sense	GMFM scores Pre-and post	BSF	Activity	NA	GMFM	Therapeutic	Department of Neurosciences, PDVVPF's College of Physiotherapy, Ahmednagar, Maharashtra, physiotherapist	Indian Journal of Cerebral Palsy
59	2015	Effects of modified constrained induced movement therapy to improve the upper limb functional activities and gross manual dexterity on hemiparetic cerebral palsy children	Experimental	10 CP children, 8 to 12 years	OMICS	To find out the effects of modified Constraint induced Movement therapy (modified CIMT) to improve the upper limb functional activities and gross manual dexterity among the children with hemiparetic cerebral palsy	Modified CIMT	Peadiatric Motor Activity Log, box and block to assess gross manual dexterity pre-and post	Activity	Activity	NA	Peadiatric Motor Activity Log, box and block to assess gross manual dexterity	Therapeutic	RVS College of Physiotherapy, Coimbatore, Tamilnadu, Physiotherapist	International Journal of Neurorehabilitation

60	2013	Efficacy of modified constraint induced movement therapy in improving upper limb function in children with hemiplegic cerebral palsy: a randomized controlled trial	Experimental, RCT	31, 3-8 year old CP children	Pubmed	To evaluate the efficacy of 4 weeks of modified constraint induced movement therapy (mCIMT) in improving upper limb function in 3–8 years old children with hemiplegic cerebral palsy.	Modified CIMT	Pre-and post quest scores	Activity	Activity	NA	Quest	Therapeutic	Department of Pediatrics, All India Institute of Medical Sciences, New Delhi, Department of Physical Medicine and Rehabilitation, pediatricians	Brain and Development
61	2016	Efficacy of supracondylar knee ankle foot orthosis for hyperextended knee and heel rise in spastic cerebral palsy: a pilot clinical trial	Experimental, Pilot RCT	6 CP children, 5 years plus	Medknow	To check the efficacy of bilateral molded SKAFO for knee hyperextension and heel rise for Cerebral palsy in terms of gait parameters and energy expenditure	Bilateral SKAFO	Observation gait analysis, physiological cost index (energy expenditure)	Environmental factors	BSF, Activity	NA	Observation gait analysis, physiological cost index	Therapeutic	Department of Prosthetics and Orthotics, Swami Vivekanand National Institute of Rehabilitation Training and Research, Cuttack, Prosthetist and orthotist	Indian Journal of Cerebral Palsy
62	2013	Elementary school enrolment and its determinants among children with cerebral palsy in Thiruvananthapuram district, Kerala, India	Observation	3-12 yrs, 86 CP children	Pubmed	To find out the proportion of children with CP who are enrolled for some kind of formal education and to study the determinants of the same	NA	Number of children enrolled in the school and their determinants	NA	NA	Environmental factors	NA	NA	Department of Community Medicine, Government Medical College, Thiruvananthapuram, Kerala, physicians	Journal of Neurosciences in Rural Practice
63	2007	Epiphyseal separations in spastic cerebral palsy	Experimental, Case series	4 CP children, 1.5-5 yrs	Pubmed	We report nine epiphyseal separations involving the distalfemur and proximal humerus in four severely affectedchildren with spastic quadriplegic cerebral palsy	Jointly positioning, splinting, vitamin C	Bone healing	BSF	BSF	NA	Decrease symptoms and bone healing	Medical	Bai Jerbai Wadia Hospital, Mumbai, Orthopaedic Surgeon	Journal of Pediatric Orthopaedics

64	2014	Evaluating the effectiveness of community physiotherapy in terms of functional independence for locomotor disabled through rehabilitation camps in Himachal Pradesh	Experimental	14 CP adults, 18 years +	DOAJ	To examine the effectiveness of community physiotherapy services in relation to progress in ADLs of the locomotor disabled persons	Physiotherapy advice and exercises	FIM	Activity	Activity	NA	FIM scores Pre-and post	Therapeutic	Composite Regional Centre for Persons with disabilities, Himachal Pradesh, physiotherapist	International Journal of Physiotherapy and Research
65	2014	Family awareness of legislative issues on child with cerebral palsy: cross sectional survey	Observation	224 Adult family members	DOAJ	To find out family awareness of legal rights of person with disability to ensure dignity and legal rights	NA	%age of people aware or not aware	NA	NA	Environmental factors	Researcher made survey	NA	SPB Physiotherapy College, Surat, Saveetha College of physiotherapy, Chennai, physiotherapist	International Journal of Physiotherapy and Research
66	2016	Family life of caregivers: a descriptive study of disruption of family activities, leisures and interaction of caregivers of children with cerebral palsy	Observation	65 primary caregivers of CP children	DOAJ	To study family life of caregivers who provide primary care to children with Cerebral Palsy	NA	Disruption of family life of caregivers (care of burden)	NA	NA	Environmental factors	Family burden interview schedule developed by Shaila Pai and R.L. Kapur	NA	Department of Physical Medicine & Rehabilitation, All India Institute of Medical Sciences (AIIMS), New Delhi, physicans	Al Ameen Journal of Medical Sciences
67	2015	Feasibility of multisensory training and its effects on balance control in school going children with cerebral palsy	Feasability study	17 CP children, 6-16 yrs	Medknow	To test the feasibility of administering multisensory training in school going children with cerebral palsy and its effects on balance control as measured by Balance Evaluation Systems Test (BESTest)	Sensory based balance training encompassing inputs from visual, vestibular, and proprioceptive systems NA	Pre-post BESTest scores	NA	NA	NA	BESTest	Therapeutic	Department of Physiotherapy, School of Allied Health Sciences, Manipal Hospital, Manipal University, Bengaluru, Physiotherapists	Indian Journal of Cerebral Palsy
68	2015	Feeding difficulties among children with cerebral palsy: a review.	Narrative review	NA	Scopemed	To review the studies conducted among children with cerebral palsy to assess their feeding problems and its impact on child's growth and nutritional status	NA	NA	NA	NA	NA	NA	NA	Department of Food and Nutrition, Lady Irwin College, New Delhi, dietician	International Journal of Health Sciences & Research

69	2013	Four years follow up of dyskinetic cerebral palsy (choreoathetoid) - a single case study	Experimental, case study	1CP child, 18 months	Scopemed	Evaluated a child with Dyskinetic Cerebral Palsy on PDMS and treated	Physiotherapy	PDMS scores pre-post	Activity	Activity	NA	PDMS-2	Therapeutic	SDM College of Physiotherapy, Dharwad, Karnataka. Physiotherapist	International Journal of Health Sciences & Research
70	2012	Goal oriented activity towards life skill training: preliminary indications of a task-intensive approach to manage cerebral palsy	Experimental	10 CP adults	DOAJ	To devise a viable programme of intervention for older people with Cerebral Palsy	Exercises	ROM, strength, particpation preferences	Activity	Participation	NA	NA	Therapeutic	Department of Physiotherapy, MCOAHS, Manipal University, Karnataka, Physiotherapists	Disability, CBR & Inclusive Development Journal
71	2012	Habitual anterior dislocation of the hip in cerebral palsy: a case report	Experimental, Case study	1,7 yr old CP child	Pubmed	Gave adduction and internal rotation brace & counselling for not dislocating the hip habitually	Brace and counselling	Reduction in pain and other symptoms	Environmental factors	BSF	NA	NA	Therapeutic	Bai Jerbai Wadia Hospital for Children, Parel, Mumbai, orthopedic surgeons	Journal of Pediatric Orthopaedics
72	2012	Handedness in diplegic cerebral palsy	Observation	111 CP children and 444 age matched control	Pubmed	To determine if the frequency of left-handedness is high in children with spastic cerebral diplegia	NA	%age of children left handed	NA	NA	Activity	The handedness of each child was assigned on the basis of responses to questions on the hand preference for writing and drawing, feeding and throwing a ball	NA	Paediatric Orthopaedic Service, Kasturba Medical College, Manipal, Occupation Therapy Department, department of Community Medicine, orthopedic surgeon	Developmental Neurorehabilitation
73	2014	Health-related quality of life in children with cerebral palsy and their families	Observation	Mothers of 100 CP children, 3-10 yrs	Pubmed	To determine the health-related quality of life in children with cerebral palsy and their families	NA	Lifestyle Assessment Questionnaire – Cerebral Palsy (LAQ-CP) scores	NA	NA	QOL	Lifestyle Assessment Questionnaire – Cerebral Palsy (LAQ-CP)	NA	Santosh College of Physiotherapy, Santosh Medical College and Hospital, Ghaziabad, and Child Development Center, Maulana Azad Medical College, New Delhi, physiotherapist	INDIAN PEDIATRICS

74	2016	Higher levels of caregiver strain perceived by indian mothers of children and young adults with cerebral palsy who have limited self-mobility	Observation	Mother's of 62 CP children, 2-21 yrs	Pubmed	Describe and compare the caregiver strain experienced among Indian mothers of children and young adults with cerebral palsy (CP) living in low resource settings.	NA	Caregiver strain index scores	NA	NA	Environmental factors	Caregiver strain index & GMFCS	NA	Ashok & Rita Patel Institute of Physiotherapy, Charotar University of Science and Technology, Changa, Gujarat, MSAJ College of Physiotherapy, Chennai, , Department of Physical Therapy and Rehabilitation Sciences, Drexel University, Philadelphia, physiotherapist	Physical & Occupational Therapy in Pediatrics
75	2014	Impact of an educational film on parental knowledge of children with cerebral palsy	Experimental	53 parents of children with CP	Pubmed	To evaluate the parental knowledge of CP and assess the impact of an educational programme on it.	Educational film	Pre-and post-parent knowledge	Environmental factors	Environmental factors	NA	Researcher made questionnaire	Therapeutic	Vardhman Mahavir Medical College and Safdarjung Hospital Dept. of Pediatrics, Delhi, Pediatricians	International Journal of Pediatrics
76	2008	Impact of an educational program on parental knowledge of cerebral palsy	Experimental	26 parents of children with CP	Pubmed	To investigate parental knowledge of cerebral palsy, and to evaluate the impact of an educational intervention on it.	Structured educational program	Pre-and post-parent knowledge	Environmental factors	Environmental factors	NA	Researcher made questionnaire	Therapeutic	Division of Pediatric Neurology, Department of Pediatrics, Lokmanya Tilak Municipal Medical College & General Hospital, Mumbai, pediatrician	Indian Journal of Pediatrics
77	2016	Impact of physiotherapy service utilization on physical and functional status of children with cerebral palsy in Jalandhar, Punjab, India	Observation	248 children with CP	Medknow	Report describes the impact of physiotherapy service utilization on the physical and functional status of children with cerebral palsy.	NA	%age of children not receiving physiotherapy, GMFM & QUEST scores of children getting and not getting Physiotherapy	NA	NA	BSF, activity	GMFM, ROM, GMFCS, and quest	NA	Department of Physiotherapy, Lyallpur Khalsa College, Jalandhar, Department of Physiotherapy, Punjabi University,Physiotherapist	CHRISMED Journal of Health and Research

78	2015	Improved quality of life in a case of cerebral palsy after bone marrow mononuclear cell transplantation	Experimental, Case study	One CP child 12 year age	Pubmed	To study the benefits of Cell therapy we have administered autologous bone marrow mononuclear cells (BMMNCs) to a 12-year-old CP case	Autologous bone marrow mononuclear cells	FIM, ROM, Muscle strength, balance, walking stability, Repeat pet scans	BSF	BSF, Activity	NA	FIM, MRI scans	Medical	Department of Medical Services and Clinical Research, NeuroGen Brain and Spine Institute, StemAsia Hospital and Research Centre, Navi Mumbai, Department of Research and Development, Department of Neurorehabilitation. Neurosurgeons	CELL JOURNAL
79	2014	Indian children with developmental disabilities: early versus late referral for intervention	Epidemiology, study of five years	2222 Children with developmental disability	Pubmed	To study the age at referral, of children with neurodevelopmental disabilities to Child Development and Early Intervention Clinic and compare the neuromorbidity and socio-economic profile of the early and late presenters	NA	Demographic status, age of presenting at the clinic	NA	NA	NA	DSM criteria, global development delay, IQ tests	NA	Department of Pediatrics, Maulana Azad Medical College and Associated Lok Nayak Hospital, New Delhi 110002, India	Indian Journal of pediatrics
80	2005	Instrumented gait analysis for planning and assessment of treatment in cerebral palsy	Observation, Case study	2 CP children	Pubmed	We record our experience of how gait analysis has been useful in the treatment of two children with cerebral palsy, one with spastic hemiplegia and one with spastic diplegia	NA	How to use gait analysis to plan surgeries on muscles, improvements in walking speed	NA	NA	BSF, Activity	Physiological cost index	NA	Department of Physical Medicine and Rehabilitation, Christian Medical College, Vellore,PMR	Indian Journal of Orthopaedics
81	2009	Inter-rater reliability of the top down motor milestone test: a cross-sectional study	Reliability study	15 CP children and their parents	Pubmed	To assess the inter-rater reliability of the Top Down Motor Milestone Test	NA	Inter-rater reliability	NA	NA	NA	Top Down Motor Milestone Test	NA	Department of Physiotherapy, Kasturba Medical College, Manipal University, India	Clinical Rehabilitation
82	2015	Journey of a child with spastic diplegic cerebral palsy from doldrums to hope	Experimental, Case study	1 CP child, 9 yr	Medknow	This case study describes the physical therapy of a 9 year old male child with spastic diplegic cerebral palsy with the aim to improve his gross motor function and social skills	Physiotherapy was performed by giving sessions of Roods approach, sensory integration, and static weight	Pre-post GMFCS scores	Activity	Activity	NA	GMFCS	Therapeutic	Maharishi Markandeshwar Institute of Physiotherapy and Rehabilitation, Haryana, Physiotherapists	Indian Journal of Cerebral Palsy

							bearing exercise for 9 months								
83	2005	Lower limb alignment in cerebral palsy	Experimental	365 lower limbs in 220 patients were operated by various methods described for hip, knee and ankle joint.	Pubmed	To assess the results of various surgical procedures described.	Surgery	The results were rated as excellent, good, fair and poor according to the criteria proposed by Sidney Keats et al and Green et al	BSF	BSF	NA	Criteria proposed by Sidney Keats et al and Green et al	Medical	Physical Medicine & Rehabilitation Department, Swami Vivekanand National Institute of Rehabilitation Training and Research, Cuttack, PMR	Indian Journal of Orthopaedics
84	2011	Magnetic Resonance Imaging, risk factors and co-morbidities in children with cerebral palsy	Observation	102 CP children till 15 yrs	Pubmed	To observe various risk factors, associated co-morbidities and compare clinical findings with information available from brain MRIs in a study sample	NA	Various abnormalities seen on MRI and %age of children having them	NA	NA	BSF	MRI findings	NA	Department of Pediatrics/Radiodiagnosis Institute of Medical Sciences, Banaras Hindu University, Varanasi, pediatricians	Journal of Neurology
85	2010	Management of severe crouch gait in children and adolescents with cerebral palsy	Experimental	17 CP children, 10-17 yrs	Pubmed	We devised a different protocol of treatment aimed at correction of the flexion deformity of the knee, weakening of the hamstrings, and augmenting the power of the knee and hip extension, which we used on 17 children with severe crouch.	Surgery	Changes in Functional mobility, ROM, muscle strength	BSF	BSF, activity	NA	Modified ashworth scale, functional mobility scale, muscle strength, visual & video gait analysis, physiological cost index	Medical	Paediatric Orthopaedic Service, Kasturba Medical College, Manipal, Karnataka, orthopedic surgeon	Journal of Pediatric Orthopedics
86	2014	Management of tone and hand functions in cerebral palsy: inhibitive weight bearing splint as an adjunct modality	Experimental	10 cp children, 6 mnts- 2 yrs	DOAJ	To evaluate the efficacy of the inhibitive weight bearing splint for cerebral palsy patients in management of tone and hand functions	Weight-bearing splint	EDPA scores Pre-and post, tone	Environmental factors	BSF, activity	NA	Erhardt's Development Prehension Assessment (EDPA) Scale, hand tracing, functional activity	Therapeutic	Department of Physiology, CIMS Bilaspur, Physiologist	Journal of Evolution of Medical and Dental Sciences

87	2014	Maternal stress and mother-child interaction style among the mothers of cerebral palsy children – a qualitative study	Observation	38 CP children, 5-12 yrs	DOAJ	To study the relationship between parenting stress and mother-child interaction style among the mothers of cerebral palsy children	NA	Correlation of mother's stress level and style of child interaction	NA	NA	Environmental factors	Parenting Stress Index Short-Form, Video recording of mother child interaction, Maternal Behavior Rating Scale	NA	Research Scholar (Psychology) SHIATS Faculty & Incharge Dept of Psychology SHIATS, Allahabad, psychologists	American Journal of Engineering Research
88	2007	Measurement of the angle of plantar flexion: an objective way of assessing muscle relaxation in children with spastic cerebral palsy	Experimental, RCT	180 CP children	Google	To study the efficacy of diazepam as a muscle relaxant in spastic cerebral palsy, we compared the Ashworth scale score to the Angle of plantar flexion score in monitoring muscle relaxation.	Bedtime diazepam or placebo	Difference in muscle tone	BSF	BSF	NA	Ashworth scale	Medical	MBBS, MD (Pharmacology), Department of Pharmacology, Christian Medical College & Hospital, Vellore, Tamilnadu	Indian Journal of Physical Medicine and Rehabilitation
89	2012	Mental health and quality of life of caregivers of individuals with cerebral palsy in a community based rehabilitation programme in rural Karnataka	Observation	Caregiver of 23 CP children	DOAJ	To assess the mental health status and quality of life of caregivers of persons with disabilities	NA	Scores on GHQ and WHO-QOL brief	NA	NA	Environmental factors, QOL	General health questionnaire, WHO-QOL brief	NA	Department of Community Health, St John's Medical College, Bangalore, physicians	Disability, CBR & Inclusive Development
90	2012	Multi-disciplinary therapeutic intervention programmes for athetoid cerebral palsy child in clinical settings: a case report	Experimental, Case study	one 14 year CP child	Scopemed	This case report intends to address the importance of multi-disciplinary therapeutic intervention programmes for children with athetoid cerebral palsy	Physiotherapy treatment	Pre-and post GMFM 'scores	Activity	Activity	NA	GMFM	Therapeutic	Composite Regional Centre for Persons with Disabilities, Under Ministry of Social Justice & Empowerment, Sundernagar, Himachal Pradesh, Physiotherapist	International Journal of Therapies and Rehabilitation Research

91	2011	Multilevel orthopedic surgery for crouch gait in cerebral palsy: an evaluation using functional mobility and energy cost	Cohort study, Observation, retrospective, cohort included CP children who had surgery in 1 year	18 CP children	Pubmed	We retrospectively evaluated the effect of surgery on the mobility and energy consumption at one year or more with the help of validated scales and scores	Surgery and rehabilitation	Improvements in functional mobility, walking distance, energy expenditure	NA	NA	BSF, activity	Functional mobility scale, functional assessment questionnaire, GMFCS, physiological cost index	NA	Ganjwala Orthopaedic Hospital, Ahmedabad, Gujarat, Orthopedic surgeon	Indian Journal of Orthopaedics
92	2015	Multilevel soft tissue with bony corrective surgery in lower limb deformities as one sitting procedure in spastic cerebral palsy: an experience from free disabled surgical camps	Experimental	30 CP patients, 4-16 yrs	DOAJ	To assess the results of multilevel soft tissue with bony corrective surgery procedure on static deformities and contractures in lower limbs with patients of spastic cerebral palsy	Surgery	Improvement in walking and GMFCS	BSF	Activity	NA	GMFCS	Medical	Department of Orthopaedic, Government Chhattisgarh, Institute of Medical Sciences, Bilaspur, Chhattisgarh. orthopedic surgeon	Journal of Evolution of Medical and Dental Sciences
93	2012	Musculoskeletal disorders in caregivers of children with cerebral palsy following a multilevel surgery	Observation	257 Parents of CP children who underwent surgery, 117 parents of CP but ambulatory children	Pubmed	To identify prevalence and risk factors of musculoskeletal disorders among the caregivers of cerebral palsy children	NA	Scores on Caregiver strain index and its association with child's level of cooperativeness	NA	NA	Environmental factors	Caregiver Strain index, BORG scale,	NA	RECOUP Neuromusculoskeletal Rehabilitation Centre, Bangalore, orthopedic surgeon	Work
94	2011	Myositis ossificans of bilateral hip joints in a patient with diplegic cerebral palsy	Experimental, Case study	1 CP child of six years	Pubmed	We report a boy with diplegic cerebral palsy who developed MO of his bilateral hip joints after initiating physiotherapy.	Aspirin tablets	Decrease in pain and increasing mobility in hip	BSF	BSF	NA	NA	Medical	Department of Pediatrics, Maulana Azad Medical College, New Delhi, Department of Orthopedics, pediatrician	Journal of Clinical Neuroscience

95	2012	Neurofacilitation of developmental reaction (nfdr) approach: a practice framework for integration / modification of early motor behavior (primitive reflexes) in cerebral palsy	Experimental, RCT	30 CP children, 6 months-2 yrs	Pubmed	To see the efficacy of Neurofacilitation of Developmental Reaction (NFDR) approach over Neurodevelopmental Therapy (NDT) for integration / modification of early motor behavior (Primitive Reflexes) in CP	NFDR & NDT	Scores on GMFM and modified Ashworth scale, pre-and post	Activity	BSF, activity	NA	GMFM, Modified Ashworth scale	Therapeutic	Department of Physical Medicine and Rehabilitation, Rehabilitation and Artificial Limb Centre (RALC), Chhatrapati Shahuji Maharaj (CSM) Medical University (Erstwhile King George Medical College and University), Lucknow, PMR	Indian Journal of Pediatrics
96	2013	Neuroimaging in cerebral palsy - report from north India	Observation	98 children, No age mentioned	Pubmed	We studied the clinico-radiological profile of children diagnosed as CP. Relevant investigations were carried out to determine the etiology.	NA	MRI abnormalities	NA	NA	BSF	MRI	NA	Department of Pediatrics, University College of Medical Sciences, Delhi, Pediatrician	Iranian Journal of Child Neurology
97	2012	Neurological disorders and barriers for neurological rehabilitation in rural areas in Uttar Pradesh: a cross-sectional study	Observation	26 CP children	Pubmed	To find out the neurological disorders and barriers for neurological rehabilitation in rural areas in Uttar Pradesh	NA	Financial, transport, awareness, negligence problems	NA	NA	Environmental factors	Researcher developed questionnaire	NA	Department of Physiotherapy, College of Applied Education and Health Sciences, Meerut, Physiotherapist	Journal of neurosciences in rural practice
98	2010	Neurophysiologic findings in children with spastic cerebral palsy	Observation	15 CP children, 4 months-10 years	Pubmed	To investigate the relationship between abnormal VEP and BAEP findings with different clinical parameters in children with spastic cerebral palsy	NA	VEP & BAEP vlaues	NA	NA	BSF	NA	NA	Department of Physiology, Opthalmology, Pediatrics, Anatomy, Mahatma Gandhi Institute of Medical Sciences, Sevagram, Wardha, Physician (ophthalmologist)	Journal of Pediatric Neurosciences

99	2012	Occupational therapy psychoeducational group: empowering caregivers of children with cerebral palsy	Experimental	16 parents of children with CP	Google	To assess the knowledge and understanding of CP among caregivers, parameters that affect learning, judge the efficacy of a psychoeducational program	Education program	Increase in parents knowledge after education	Environmental factors	Environmental factors	NA	Researcher developed questionnaire	Therapeutic	G.S Medical College, occupational therapist, Mumbai	The Indian Journal of Occupational Therapy
100	2015	One stage soft tissue release, open reduction, femoral shortening, osteotomy and peri acetabular augmentation for spastic dislocated hip- early results	Experimental	24 children with CP	Medknow	We evaluated the clinical and radiological results of one stage correction of hip dislocation for cerebral palsypatients. Chart review of patients underwent hip surgery in six years	Hip surgery	ROM, GMFCS, pain, various hip indexes pre-and post	BSF	BSF	NA	ROM, GMFCS, pain, various hip indexes	Medical	Swami Vivekanand National Institute of Rehabilitation Training and Research, Olatpur, Bairoi, Cuttack, Orissa, orthopedic surgeon	Indian Journal Cerebral Palsy
101	2011	Outcome of selective motor fasciculotomy in the treatment of upper limb spasticity	Experimental	20 CP patients, 5-35 yrs	Pubmed	To assess the outcome of selective motor fasciculotomy in relieving upper limb spasticity	Selective motor fasciculotomy	Pre-and post-changes in Modified Ashworth Scale, Selective Voluntary Control Grade, Wee FIM Scores	BSF	BSF, activity	NA	Modified Ashworth Scale, Selective Voluntary Control Grade, Wee FIM Scale and hand function evaluation	Medical	Department of Neurosurgery, Nizam's Institute of Medical Sciences, Hyderabad, Neurosurgeons	Journal of Pediatric Neurosciences
102	2015	Parents' expectations from rehabilitation services for their children with cerebral palsy: a retrospective study	Retrospective chart review	3960 Children with CP	Medknow	To observe whether the expectations of the parents change across age, as recorded in chief complaints, in a way that psychological disorders are late to be detected and are generally not recognized by parents and medical professionals. charts observed for patients in two years	NA	Increasing psychosocial difficulties with age	NA	NA	Environmental factors, personal factors	Developmental screening test, Malin's Indian adapted version of Vineland Social Maturity Scales	NA	Department of Rehabilitation Psychology, National Institute for the Mentally Handicapped, Secunderabad, rehabilitation psychologist	Indian Journal Cerebral Palsy
103	2006	Parent-to-parent counseling -a gateway for developing positive mental health for the parents of children that have cerebral palsy	Experimental	50 parents of CP children	Pubmed	The aim of the study is an attempt to minimize the gap between caregivers and the affected child through an exchange of knowledge and experience within the therapeutic group interactions	Counseling by senior parents having children with CP to new parents having children with CP	Satisfaction with the program, decreasing anxiety levels, change the style of child interaction, parents motivation levels	Environmental factors	Environmental factors, personal factors	NA	Researcher developed questionnaire	Therapeutic	National Institute for the Orthopaedically Handicapped, Kolkata, orthopedic surgeon	International Journal of Rehabilitation Research

		with multiple disabilities													
104	2014	Percutaneous adductor release in nonambulant children with cerebral palsy	Experimental	64 hips in 32 patients, 2-14 yrs	Pubmed	To evaluate the results of percutaneous adductor release under general anaesthesia.	Percutaneous adductor release	Various hip angles pre-and post surgery	BSF	BSF	NA	Hip angles	Medical	SMS & RI Sharda University, Uttar Pradesh, orthopedic surgeon	Journal of the Nepal Medical Association
105	2015	Perinatal risk factors in cerebral palsy: a rehab center based study	Epidemiology	307 CP children, no age mentioned	Medknow	To describe the distribution and to explore perinatal risk factors among children with cerebral palsy	NA	Prenatal risk factors	NA	NA	NA	Researcher developed questionnaire	NA	Department of Public Health, Sam Higginbottom Institute of Agriculture Technology and Sciences, Allahabad, Department of Pediatric Orthopedics, Community Medicine, Physiotherapy, Samvedna Trust, MLN Medical College, Allahabad, Uttar Pradesh, physician	Indian Journal Cerebral Palsy
106	2015	Physical profile of children with cerebral palsy in Jalandhar district of Punjab India	Epidemiology	248 CP children, 3-13 yrs	Medknow	This report describes the physical and functional status of children with CP in Jalandhar district of Punjab and examines its association with biological and social factors	NA	Types of CP and associated comorbidities	NA	NA	NA	Physical examination of child and parent interview, GMFCS	NA	Department of Physiotherapy, Lyallpur Khalsa College, Jalandhar, Punjab, 2 Department of Physiotherapy, Punjab University, physiotherapist	Indian Journal of Cerebral Palsy

107	2007	Physiological cost index in cerebral palsy: its role in evaluating the efficiency of ambulation	Reliability study	100 Normal children 7-15 yrs, 277 CP children	Pubmed	To evaluate whether the Physiological Cost Index (PCI) can be used as a reliable index of efficiency of gait and as an outcome measure in cerebral palsy	NA	PCI values, ICC	NA	NA	NA	PCI	NA	Department of Physiotherapy, Manipal College of Allied Health Sciences, Manipal, physiotherapists	Journal of Pediatric Orthopedics
108	2012	Positron emission tomography-computed tomography scan captures the effects of cellular therapy in a case of cerebral palsy	Experimental,Case study	One CP child, 2 year age	OMICS	To show functional Improvements and correlated structural changes in the brain seen by PET scans six months after cell therapy	Cell therapy	MRI values and structural changes	BSF	BSF	NA	MRI	Medical	Department of Medical Services and Clinical research, NeuroGen Brain and Spine Institute, Surana Sethia Hospital and Research Centre, Mumbai, physicians	Case Reports in Neurological Medicine/Journal of Clinical Case Reports
109	2013	Positron emission tomography—computer tomography scan used as a monitoring tool following cellular therapy in cerebral palsy and mental retardation—a case report	Experimental, Case study	1 adult 20 years old with CP	Pubmed	Examined a maximally rehabilitated, 20 year old male suffering from CP. He had diplegic gait and Intelligence Quotient (IQ) score of 44 with affected fine motor activities, balance, speech and higher functions.	Cell therapy, autologous bone marrow derived mononuclear cells followed by rehab	Structural changes in the brain and improvements in FIM	BSF	BSF, activity	NA	FIM, Modified Ashworth scale	Medical	Department of Medical Services and Clinical Research, Department of Research and Development, Department of Neuro-Rehabilitation, NeuroGen, Brain and Spine institute Private limited, Mumbai, Neuropathologist	Case Reports in Neurological Medicine
110	2013	Postural sway in dual-task conditions between spastic diplegic cerebral palsy and typically developing children	Observation	83 CP children, 8-17 yrs	Scopemed	To identify whether dual-task conditions affect the postural control of children with spastic diplegic cerebral palsy	NA	Velocity of movements in posturography	NA	NA	Activity	Static posturography	NA	MPT (Pediatric Neurosciences) is Lecturer, Alva's college of Physiotherapy, Karnataka, Physiotherapist	International Journal of Health and Rehabilitation Sciences

111	2011	Prevalence of cerebral palsy in children < 10 years of age in R.S. Pura town of Jammu and Kashmir	Epidemiology	NA	Pubmed	To determine the prevalence of cerebral palsy in children aged <10 years	NA	A total of 11 cases of cerebral palsy were ascertained yielding a crude prevalence rate of 2.27/ 1000 in the age group of <10 years	NA	NA	NA	NA	NA	Dr. Rajendra Prasad Government Medical College, Kangra, Himachal Pradesh, Acharya Shri Chander College of Medical Sciences, Sidhra, Jammu, Department of Education, University of Jammu, physicians	JOURNAL OF TROPICAL PEDIATRICS
112	2005	Prevention of developmental disabilities	Narrative review	NA	Pubmed	Narrative review of prenatal, natal and postnatal causes and prevention of developmental disabilities	NA	NA	NA	NA	NA	NA	NA	Departments of Pediatrics, All India Institute of Medical Sciences, New Delhi, pediatrician	Indian Journal of Pediatrics
113	2013	Problems of families with cerebral palsy-strategies and recommendations for interventions in rural India	Epidemiology	283 CP children	Google	To ascertain the demographic features of the childrenwith cerebral palsy with reference to their age, sex, caste,religion, type of family, size of family.2. To examine the process of onset of cerebral palsy withreference to mother's recognition of the symptoms,3. To learn the process of diagnosis and the extent of cerebral palsy with reference to the place of diagnosis, ageat the time of diagnosis, extent of cerebral palsy; and theassociated problems;4. To examine the status and characteristics of the familiesliving with the children of cerebral palsy with reference tothe type family, income levels.5. To find out the services available to the children of cerebral palsy.	NA	Percentage of children having CP, how many attending different therapies and education	NA	NA	NA	Researcher developed questionnaire	NA	Physician, hyderabad	Indian Journal of Applied Research

114	2014	Profile of childhood health conditions referred to physiotherapy and attributing factors to disablement	Mixed Methods	Five children with CP and their caregivers in a qualitative study	DOAJ	To profile the prevalence of childhood health conditions and the factors that contribute to the disablement process leading to disability among children who visit a tertiary referral hospital in Mysore.	NA	Prevalence of CP, & problems experienced by mothers (society and family attitudes, financial, architectural barriers), less awareness among doctors, non-cooperation form school	NA	NA	Environmental factors	Semistructured interviews	NA	JSS College of Physiotherapy, Mysore, Karnataka, Physiotherapist	Disability, CBR & Inclusive Development Journal
115	2012	A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in western india	Qualitative	13 parents	Pubmed	To explore the psychosocial problems faced by the parents of childrenwith cerebral palsy (CP) in rural and urban settings	NA	Qualitative themes of financial, social, health, support problems, lack of trained staff	NA	NA	Environmental factors	NA	NA	Department of Pediatrics, Pramukhswami Medical College, Karamsad, Gujarat Central Research Services, Charutar Arogya Mandal, HM Patel Academic Center, Karamsad, Gujarat, Department of Community Medicine, Pramukhswami Medical College, Karamsad, Gujarat, physicians	ISRN Family Medicine
116	2005	Recent advances in management of cerebral palsy	Narrative review	NA	Pubmed	Narrative review of different therapies in CP	NA	NA	NA	NA	NA	NA	NA	Dept. of Peadriatic orthopedics and rehabilitation, bangalore childrens hospital, orthopedic surgeon	Indian Journal of Pediatrics
117	2012	Referral profile of a child development clinic in Northern India	Epidemiology	792 children referred	Pubmed	To delineate the demographic and clinical profile of children referred to a Child Development Clinic (CDC) of a tertiary care public hospital in India	NA	%age Of children having CP	NA	NA	NA	DSM-IV criteria	NA	Child Develo pediatricianpment Clinic, Department of Pediatrics, Maulana Azad Medical College and associated Lok Nayak	Indian Journal of Pediatrics

														Hospital, Bahadur Shah Zafar Marg, New Delhi, Pediatrician	
118	2015	Relation of quality of upper limb to independent gross motor and manual ability function in children with spastic diplegia	Observation	30 CP children, 4-8 yrs	Medknow	To find the relation of the quality of upper limb function to independent gross motor and manual ability function in children with spastic diplegia	NA	Correlation between quest & GMFCS, MACS & PEDI	NA	NA	Activity	GMFCS, MACS, QUEST, PEDI	NA	Sancheti Institute College of Physiotherapy, Sancheti Hospital, Pune, physiotherapist	Indian Journal of Cerebral Palsy
119	2012	Reliability of "modified timed up and go" test in children with cerebral palsy	Reliability study	30 CP children, 4-12 yrs	Pubmed	To assess the intrarater reliability of TUG test incerebral palsy children.	NA	ICC values	NA	NA	NA	TUG test	NA	PDVVPF's College of Physiotherapy,Ahmednagar, Ravi Nair College of Physiotherapy, Sawangi M, Wardha, Physiotherapist	Journal of Pediatric Neurosciences
120	2012	Responsiveness of edinburgh visual gait score to orthopedic surgical intervention of the lower limbs in children with cerebral palsy	Responsiveness	50 CP children, 6-19 yrs	Pubmed	To report the responsiveness and minimal clinically important difference of the Edinburgh Visual Gait Score (EVGS), used to measure gait deviations in children with cerebral palsy	NA	Minimal clinically important difference	NA	NA	NA	Edinburgh Visual Gait Score	NA	Department of Physiotherapy, Manipal College of Allied Health Science, Manipal University, Karnataka, physiotherapist	American Journal of Physical Medicine & Rehabilitation
121	2015	Results of selective motor fasciculotomy in spastic upper limbs due to cerebral palsy (a review of 30 children and adults)	Experimental	30 CP patients, 5-35 yrs	Pubmed	To assess the outcome of selective motor fasciculotomy in relieving upper limb spasticity	Selective motor fasciculotomy	Pre-and post-changes in Modified Ashworth Scale, Selective Voluntary Control Grade, Wee FIM Scores	BSF	BSF, activity	NA	Modified Ashworth Scale, Selective Voluntary Control Grade, Wee FIM Scale and hand function evaluation	Medical	Department of Neurosurgery, Nizam's Institute of Medical Sciences, Panjagutta, Hyderabad, neurosurgeon	Indian Journal of Cerebral Palsy

122	2014	Short term effect of myofascial release on calf muscle spasticity in spastic cerebral palsy patients	Experimental	18 CP Children	Scopemed	To study the short term effect of stretching and MFR/ stretching alone on calf muscle spasticity in spastic diplegic patients	Myofascial release	Decrease in spasticity based on Ashworth scale	BSF	BSF	NA	Modified Ashworth scale,	Therapeutic	Physiotherapist, Shree M P Shah Govt. Medical College, Pandit Nehru Marg, Jamnagar, Gujarat, Physiotherapist	International Journal of Health Sciences and Research
123	2015	Single event multi level orthopedic surgery in a teenager having spastic triplegic cerebral palsy	Experimental, Case study	One CP child 18 year age	Medknow	Single Event Multilevel Orthopedic Surgeries (SEMLOS) were performed in both the lower limbs and in right upper limb with derotational osteotomy on right proximal femur and fixation with DHS.	Surgery	Improvement in walking and finger opening	BSF	Activity	NA	GMFCS	Medical	Faculty of Health Sciences, Sam Higginbottom Institute of Agriculture Technology and Sciences, Uttar Pradesh, Therapist Incharge, Samvedna, Allahabad, physiotherapist	Indian Journal Cerebral Palsy
124	2015	Single photon emission computed tomography scan as a diagnostic tool in children with cerebral palsy treated with human embryonic stem cells	Experimental	88 CP patients,2 months-18 yrs	OMICS	The present study was conducted to evaluate the diagnostic modality of Single Photon Emission Computed Tomography (SPECT) scan that can assess the patient with CP before and after hESC (human embryonic stem cells) therapy	Human Embryonic Stem Cells Injection	Improvements in areas of brain visible via scans	BSF	BSF	NA	SPECT scan, GMFCS pre-post	Medical	Nutech Mediworld, New Delhi, Department of Statistics, Retired Additional Secretary, Ministry of Home Affairs, Government of India, Department of Nuclear Medicine, Mahajan Imaging Centre, Rajan Dhall Hospital, New Delhi Mahajan Imaging Centre, New Delhi, physicians	Nuclear Medicine & Radiation Therapy
125	2008	Single-stage multilevel soft-tissue surgery in the lower limbs with spastic cerebral palsy: experience from a rehabilit	Experimental	34 CP patients, 4-16 yrs	Pubmed	To assess the effect of singlestage multilevel softtissue surgery (Single Event Multiple Level Resections, SEMLR) on deformities and locomotion in patients with cerebral palsy with static contracture(s) in lower limbs	Surgery	GMFCS and physical examination Pre- and post	BSF	BSF, activity	NA	GMFCS	Medical	Department of Psychiatric and Neurological Rehabilitation, National Institute of Mental Health and Neuro Sciences (NIMHA	Indian journal of orthopaedics

		ation unit												NS), Bangalore, Department of Neurology, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore, neurologist	
126	2014	Sleep disorders in children with cerebral palsy and its correlation with sleep disturbance in primary caregivers and other associated factors	Observation	50 CP children, aged 6.5-15 yrs, 50 mothers	Pubmed	To observe prevalence of sleep disturbance (SD) in cerebral palsy (CP) children in a specific age-group and its correlation with SD in primary caregivers and other associated factors.	NA	scores of SDCS & PSQI	NA	NA	BSF, Environmental factors	Sleep Disturbance Scale for Children (SDSC) in CP children, Pittsburgh Sleep Quality Index (PSQI) in caregivers	NA	PMR, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore	Annals of Indian Academy of Neurology
127	2015	Socio-demographic profile of cerebral palsy affected patients: an Indian scenario	Epidemiology	307 parents	Scopemed	This study was conducted with the aim of describing existing demographic profile of patients and their families coming to the rehab center for treatment	NA	Demographics	NA	NA	NA	NA	NA	Dept of Public Health, Faculty of Health Sciences, SHIATS, Allahabad; Dept. of Community Medicine, MLN Medical College, Allahabad; Pediatric Orthopedic surgeon, Trishla Orthopedic Clinic and Secretary samvedna Trust, Allahabad; Dean Faculty of Health Sciences & Director University Health Services, SHIATS, Allahabad; Assistant Professor, Dept of Public Health, Faculty of Health Sciences, SHIATS,	International Journal of Current Research and Review

														Allahabad; Physiotherapist, Koree Physiocare, Ghaziabad. physicians	
128	2007	Stress among mothers of children with cerebral palsy attending special schools	Observation	Mothers of children with CP	DOAJ	To assess the stress experienced by mothers of children with cerebral palsy attending special schools in Kerala	NA	The scores on the questionnaire	NA	NA	Environmental factors	The Questionnaire on Resources and Stress	NA	Lecturer in Physiotherapy, School of Medical Education Mahatma Gandhi University, Kerala, Physiotherapist	Asia Pacific Disability Rehabilitation Journal
129	2016	Structural and perfusion abnormalities of brain on mri and technetium-99m-ecd spect in children with cerebral palsy	Observation	56 CP children, 1-14 yr age	Pubmed	To demonstrate structural and perfusion brain abnormalities	NA	Changes in brain structures	NA	NA	BSF	NA	NA	Department of Pediatrics, Military Hospital, Jabalpur, Department of Pediatrics, Narayana Hrudayalaya, Bangalore, Department of Pediatrics, Indira Gandhi Medical College, Shimla, Department of Radiodiagnosis, Command Hospital, Southern Command, Pune, Department of Obstetrics and Gynaecology, Indira Gandhi Medical College,	Journal of Child Neurology

														Himachal Pradesh, Department of Nuclear Medicine, Indira Gandhi Medical College, Shimla, Physicians	
130	2009	Study of clothing preference of cerebral palsy children according to their physical limitation	Observation	15 CP girl children, 8-12 yrs	Google	To explore problems in donning and doffing of the garments experienced by the mothers of cerebral palsy children and their suggestions with regard to types of neckline, sleeve, placket opening as well as fasteners.	NA	Mother's preferences and clothing	NA	NA	Environmental factors (personal factor)	Researcher develop survey	NA	Department of Textiles and Apparel Designing, University of Agricultural Sciences, Dharwad	Karnataka J. Agric. Sci
131	2012	Supracondylar femoral extension osteotomy and patellar tendon advancement in the management of persistent crouch gait in cerebral palsy	Experimental	14 CP children, 11-16 yrs	Pubmed	We evaluated outcome of supracondylar femoral extension osteotomy (SCFEO) and patellar tendon advancement (PTA) in the treatment of crouch gait in patients with cerebral palsy.	Surgery	Pre-and post scores on Functional mobility scale, observational gait analysis, various radiographic analysis, GMFCS, VAS, MMT	BSF	BSF, activity	NA	Functional mobility scale, observational gait analysis, various radiographic analysis, GMFCS, VAS, MMT	Medical	Department of Physical Medicine and Rehabilitation, Swami Vivekan and National Institute of Rehabilitation, Training and Research, Orissa, Department of Physiotherapy, Swami Vivekan and National Institute of Rehabilitation, Training and Research, Orissa, PMR	Indian Journal of Orthopaedics
132	2014	Test-retest reliability of six minute walk test in spastic ambulatory children with	Reliability study	18 CP children, 4-14 yr	Scopemed	To assess the test-retest reliability of 6MWT in children with ambulatory spastic cerebral palsy.	NA	Reliability scores	NA	NA	NA	Six minute walk test	NA	S.B.B. College of Physiotherapy, V.S. General Hospital, Ellis Bridge, Ahmedabad,	International Journal of Contemporary Pediatrics

		cerebral palsy												physiotherapist	
133	2015	The effect of a circuit training program on functional performance in children with spastic cerebral palsy – a quasi-experimental pilot study	Experimental	10 CP children, 6-11 yrs	Scopemed	To investigate the effects of a circuit training regimen on static and dynamic motor function of children with spastic CP.	Circuit exercise training for 6 weeks	GMFM Scores Pre & post	Activity	Activity	NA	GMFM	Therapeutic	Lecturer, Alvas College of Physiotherapy, Mangalore, Baskaran Chandrasekaran, MPT Senior Physiotherapist, Department of Pulmonary Rehabilitation, PSG Hospitals, Tamil Nadu Mahalakshmi Venugopalan, MPT Professor, PSG College of Physiotherapy, Tamil Nadu, Ashokan Arumugam, MPT, PhD Assistant Professor, Department of Physical Therapy, College of Applied Medical Sciences, Majmaah University, Kingdom of Saudi Arabia, physiotherapist	International Journal of Health and Rehabilitation Sciences
134	2005	The efficacy of diazepam in enhancing motor function in children with spastic cerebral palsy	Experimental,RCT	180 CP children, less than 12 yrs	Pubmed	Studies the clinical efficacy of a low dose of diazepam in enhancing movement in children with spastic cerebral palsy	Diazepam	Changes in tone, range of motion, Spontaneous movements	BSF	BSF	NA	Ashworth scale	Medical	Developmental Paediatrics Unit and Department of Biostatistics, Christian Medical College & Hospital, Tamil Nadu, physician	Journal of Tropical Pediatrics

135	2012	Therapeutic potential of autologous stem cell transplantation for cerebral palsy	Experimental, case study	One child of six years of age	Pubmed	Study evaluates the safety and efficacy of autologous bone-marrow-derived mononuclear cell (BMMNCs) transplantation in CP	Stem cell therapy	The structural changes in the brain, improvements in function	BSF	BSF, activity	NA	GMFCS Pre-and post	Medical	StemOne Biologicals Pvt. Ltd., Pune, Shitole Hospital, Rajarampuri 1st Lane, Near Janata Bazar, Kolhapur, physician	Case Reports in Transplantation
136	2014	Therapeutic potential of human embryonic stem cell transplantation in patients with cerebral palsy	Experimental	91 CP children, 30 days-18 yr.	Pubmed	To explore the efficacy and safety of human embryonic stem cell (hESC) therapy in patients with CP.	Stem cells	GMFCS pre-and post, structural changes in the brain	BSF	BSF, activity	NA	GMFCS	Medical	Nutech Mediworld, H-8, Green Park Extension, New Delhi, Pediatrician, Max Hospital, Saket, New Delhi, ministry of Home Affairs, Government of India, physician	Journal of Translational Medicine
137	2011	The relation of patient satisfaction and functional and cosmetic outcome after correction of the wrist flexion deformity in cerebral palsy	Experimental	15 CP patients	Pubmed	Wrist flexion deformity in cerebral palsy is treated with flexor carpi ulnaris to extensor carpi radialis brevis transfer. The aim of the study was to assess the outcome of this procedure and analyse the determining factors for patient satisfaction.	Wrist surgery	Correlations between cosmesis & satisfaction	BSF	Activity, personal factor	NA	House classification for function, Likert scale for satisfaction, Johnstone scale for cosmesis	Medical	Department of Plastic Surgery, Hand Surgery, Reconstructive Microsurgery and Burns, Ganga Hospital, Coimbatore, surgeons	The Journal of Hand Surgery
138	2008	Treatment-induced plasticity in cerebral palsy: a diffusion tensor imaging study	Experimental	8 CP children, 3-12 yrs	Pubmed	To study the effects of combined therapy on motor function in children with spastic cerebral palsy, using diffusion tensor imaging, and we determined if the improved motor function after intervention was associated with improved diffusion tensor imaging measures of the corticospinal tract.	Botulinum injection followed by PT	pre-post scores on video gait analysis, GMFCS, modified ashworth scale, tardieu scale, structural changes in the brain	BSF	BSF, activity	NA	video gait analysis, GMFCS, modified ashworth scale, tardieu scale	Medical	Richa Trivedi, PhD*, Rakesh K. Gupta, MD*, Vipul Shah, MS†, et al. Radiodiagnosis; Sanjay Gandhi Post Graduate Institute of Medical Sciences; Lucknow, physicians	Journal of Pediatric Neurology

139	2007	Treatment of interictal epileptiform discharges in cerebral palsy patients without clinical epilepsy: hope for a better outcome in prognosis	Narrative review	NA	Pubmed	Review of IED in CP patients	NA	NA	NA	NA	NA	NA	NA	Physiology Department, G.R. Medical College, Gwalior, Madhya Pradesh	Clinical Neurology and Neurosurgery
140	2015	Trends of cerebral palsy in Rajasthan, India	Epidemiology	240 children with CP	DOAJ	To determine the incidence of etiological factor and clinical features of children with cerebral palsy (CP) in Rajasthan from 2010-2014	NA	Various etiological factors	NA	NA	NA	NA	NA	PG Department of Pediatrics Ayurveda, National Institute of Ayurveda, Rajasthan, Physicians	International Journal of Advanced Ayurveda
141	2011	Upper extremity constraint-induced movement therapy in infantile hemiplegia	Experimental, case study	1 cp child, 5 yrs	Pubmed	We report the effects of constraint induced movement therapy in a five year old female child with infantile hemiplegia on improvement of upper extremity motor skills.	CIMT	QUEST scores pre-post	Activity	Activity	NA	QUEST	Therapeutic	Department of Physiotherapy, Sikkim Manipal Institute of Medical Sciences, Gangtok, Physiotherapists	Journal of pediatric neurosciences
142	2011	Utility of combined hip abduction angle for hip surveillance in children with cerebral palsy	Observation	113 CP children, 2-11 yrs	Pubmed	To assess the utility of Combined hip abduction angle (CHAA) in the clinical setting to identify those children with CP who were at greater risk to develop spontaneous progressive hip lateralization.	NA	Sensivity and specificity for CHAA	NA	NA	BSF	radiographic measures, GMFCS	NA	Orthopaedic Department, K.J.Somaiya Medical College, Hospital & Research Centre, Oshiwara, Mumbai Paediatric Orthopaedic Surgeon,	Indian Journal of Orthopaedics
143	2008	Vagal nerve stimulation: exploring its efficacy and success for an improved prognosis and quality of life in cerebral palsy patients	Narrative review	NA	Pubmed	In this paper, the author proposes Vagal Nerve Stimulation technique implantation in CP patients on account of its dual therapeutic effectiveness, i.e. anti-epileptic and IED-suppression.	NA	NA	NA	NA	NA	NA	NA	Physiology Department, G.R. Medical College, Gwalior 474001, MP, physician	Clinical Neurology and Neurosurgery

144	2012	Virtual reality based therapy for post operative rehabilitation of children with cerebral palsy	Experimental	16 Cp children,	Pubmed	To understand the effect of Virtual reality based therapy	Virtual reality	MACS and pediatric balance score pre-post	Activity	Activity, BSF	NA	MACS and pediatric balance	Therapeutic	RECOUP Neuromusculoskeletal Rehabilitation Centre, Bangalore, orthopedic surgeon	Work

Appendix 4: Survey questions for P-ICF video evaluation

Survey on International Classification of Functioning, Disability and Health (ICF) and Cerebral Palsy video series

This survey is designed to help us understand your views on the videos we are producing. Your responses will help us to make the videos better for parents, families and friends to understand children with Cerebral Palsy. This survey requests feedback on the five videos that you viewed. We want to know if you find the videos clear, easy to understand, and useful. Please choose one best response for each multiple choice question. The survey should take approximately 10 minutes to complete.

Part A: Technical problems

1a. Did you have any difficulty while viewing the videos?

Answer: No ☐ (move to question number 2)

Yes ☐ (move to question number 1b)

1b. Please tell us in which video(s) you faced the problem? Check <u>all</u> that apply.

☐ Video 1 (What is ICF)
☐ Video 2 (What is BSF)
☐ Video 3 (What is A & P)
☐ Video 4 (Contextual factors)
☐ Video 5 (We see the parts: how do they work together)

1c. Please tell us what problem you faced?

For example, unable to see or hear, unclear sound or video, difficulty in understanding any word, other technical problems:

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Part B: Understanding

Q. 2 How easy was it to understand:	**Not at all easy**	**Slightly easy**	**Moderately easy**	**Quite easy**	**Extremely easy**
Video# 1 (What is ICF)					
Video# 2 (What is BSF)					
Video# 3 (What is A & P)					
Video# 4 (Contextual factors)					
Video# 5 (We see the parts: how do they work together?)					

Make a comment on your choice:
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Part C: Helpful

Q. 3 How helpful do you think these videos are for informing you on how you manage your child's health?	**Not at all helpful**	**Slightly helpful**	**Moderately helpful**	**Quite helpful**	**Extremely helpful**
Video# 1 (What is ICF)					
Video# 2 (What is BSF)					
Video# 3 (What is A & P)					
Video# 4 (Contextual factors)					
Video# 5 (We see the parts: how do they work together?)					

Make a comment on your choice:

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Part D: Interest

Q. 4 Did the following videos hold your interest? If not, how far into the video did you start to lose interest?	**1 minute into the video**	**2 minute into the video**	**3 minute into the video**	**Near the end**	**I didn't lose interest at all, it was very interesting**
Video# 1 (What is ICF)					
Video# 2 (What is BSF)					
Video# 3 (What is A & P)					
Video# 4 (Contextual factors)					
Video# 5 (We see the parts: how do they work together?)					

Make a comment on your choice:
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Part E: Learning and application

5. What was one thing you learned from watching these videos? How would you use this information in your child's rehabilitation?

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6. How confident do you feel about your ability to implement the ideas/knowledge you learned in these videos in your child's rehabilitation?

☐ Not at all confident
☐ Slightly confident
☐ Moderately confident
☐ Quite confident
☐ Extremely confident

Make a comment on your choice:
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7. Do you feel you need any help from healthcare professionals to implement the ideas in these videos with your child?

Answer: Yes ☐ (move to question number 8)

No ☐ (move to question number 9)

8. What help would you need from healthcare professionals in implementing the ideas in these videos to assist with your child's rehabilitation?

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9. Other than healthcare professionals, what other supports would you need to implement the ideas in the videos?

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10. Did the videos help you to think differently about your child and your child's therapy?

☐ Not at all
☐ Slightly
☐ Moderately
☐ Quite a bit
☐ Extremely

Make a comment on your choice: (What was it that you thought before, and how do you think about your child's therapy now?)

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Part F: Modification

11. These videos will be used to inform other parents about the ICF, Cerebral Palsy and its management. With that in mind, what would you suggest we add, or delete, or modify in the videos? ***Please specify the video number.***

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Part G: Relation

12. What is your relation to the child in your family with Cerebral Palsy?

☐ Mother
☐ Father
☐ Grandparent
☐ Sibling
☐ Other (Please specify)

13. How old is your child?
Answer: ……………

14. When was your child diagnosed with Cerebral Palsy?
Answer: ………………..

15. I live in……………….

Part H: Contact details

Your help will enable us to enhance the quality of the videos. If you are interested to help us further with your ideas in developing these videos, please provide us with your contact details.

Name:…………………………………………………………

Email:…………………………………………………………

Phone number: ……………………………………………….

Thank you for taking time to complete this survey. If you have questions about the survey please ask Pranay Jindal, doctoral student at School of Rehabilitation Sciences and CanChild Centre for Childhood Disability Research, McMaster University by contacting at jindalp@mcmaster.ca.

Appendix 5: P-ICF video scripts

Video 1: What is ICF?

Video Scene 1: Show Paul's **mother** and Sara's **father** talking to each other in a doctor's clinic. Show Sara and Paul in parents' lap.

Paul's mother: Hello, how are you?

Sara Father: We are fine, thank you. How are you?

Paul's mother: We are good too. Paul has Cerebral Palsy. He has difficulty walking by himself. I am not sure what can I do for managing his Cerebral Palsy?

Sara Father: I see!! Sara also has Cerebral Palsy, and has difficulty walking by herself and talking. I also have questions about managing her Cerebral Palsy. Let us consult the doctor together.

Video Scene 2: both families in doctor's office.

Doctor talking: Hello!! What brings you all here today?

Sara's father: Hello doctor!! As you know, Sara has Cerebral Palsy. We were wondering about the treatment options for Sara, and what can we do to manage her Cerebral Palsy.

Paul's mother: So were we. But Paul and Sara have different abilities and needs. We are also wondering what therapy they would need? Will it be different for each of them?

Doctor: you are right!!Every child and family with Cerebral Palsy is unique and has different abilities and needs. Treatments or therapies that work for one child or in one situation may not be the right thing for other children or in any other situation. To help kids function well in day to day life, it is important that families and health care providers, like us, understand a child's unique strengths and challenges and focus on these in therapies. Successful intervention in Cerebral Palsy needs collaboration with health care professionals, family and the community services. Our ultimate goal is to enable children to grow and develop to their best capacity, regardless of how they do things!

Sara’s Father: There are so many things that influence therapy and Sara’s progress. How do I understand what to do for my child’s management?

Doctor: Let us go a little back in time, in 2001, the World Health Organization designed an approach to health that aims to identify and understand each child and family’s unique functional abilities and needs. It is called the International Classification of Functioning, Disability and Health, or “the ICF” in short.

The ICF divides a health condition, for example, in your child’s case, Cerebral Palsy into 3 interconnected parts. These parts are connected in such a way that, if you influence one part, all the other parts change to adjust.

a) First, the body structure and function, which explains how body parts work,
b) Second, the activity and participation, which explain what people do, and how they engage with the world
c) And third, the contextual factors, which include environmental and personal factors that help people function

So, using the ICF approach to view your child’s health might help you to:

a) Understand your child’s strengths and challenges, and see a broader picture of your child’s development.
b) Communicate and advocate better about your child’s functional needs to the health care professionals and community, and,
c) Make informed decisions and engage actively in your child’s health care.

Doctor: I will discuss each one of them individually to help you understand better.

Video 2: Body Structure and Function (BSF)

What is "Body Structure and Function"?
The ICF defines body *structures* as "body parts," for example, legs, hands, mouth, brain, eyes, and muscles. Body *functions* are the "things that our body parts do." For example, we move the muscles around our eye to see in different directions; we move our leg muscles to move around; we move our tongue to speak; and we feel pain or touch against our skin.

What happens to Body Structure and Function in Cerebral Palsy? To understand this, let's meet Paul. Paul is diagnosed with Cerebral Palsy and loves to go for a walk with his parents. Let's see what body structure and function challenges Paul has, and what can we do about them.

In Paul's case, the body structure problem challenge is "the impairment to his brain" that caused him Cerebral Palsy. The brain impairment is permanent and does not get worse over time. The brain impairment affects some of the functions of the body. For instance, the signals from Paul's brain to move his leg muscles may not clearly tell the leg muscles to move. This makes it hard for Paul to move his legs in a coordinated way, and makes walking more difficult for him than for typically-developing kids.

Impairments to other parts of the brain might also make it more difficult for people with Cerebral Palsy to learn, understand and problem solve as easily as other people.

Can Paul's Body Structure and Function problems challenges be corrected?
Therapies like muscle stretching, strengthening, surgeries, injections like Botox, and casting all aim to influence the body structure and function. However, because every child is different, treatments that work for one child or in one situation may not be useful for Paul's situation. For instance, exercises can help to make the leg muscles stronger, but this might not necessarily help Paul to walk better. Also, if a child has difficulty in understanding, it might be hard for the child to know why they should do exercises.

Focussing ***only*** on changing the body structure and function challenges may take a long time even for some partial improvement. And, while waiting for his muscles to get stronger, Paul may miss out on great fun and play activities that he loves and are essential for his overall development. In fact, we do not yet know how to 'fix' things like the brain.

So what can Paul's parents do?

Try always to think first and foremost about Paul's overall development. For optimal development and function, Paul needs the opportunity to play and interact with friends and family along with medical care and therapy as needed. This means **not focusing only** on trying to change the body structure and function, but also on looking at other things that can help Paul to develop.

Consider an example: many people use glasses to help them see. Glasses do not "fix" the problem of the eye, but help us to *function* effectively by enabling us to see more clearly. Similarly, we do not need to fix Paul's body or brain to help him walk move around, or to enable him to do so many other things. Research shows very little **functional** benefit from **just** focusing on trying to fix body structure and function challenges. Children benefit equally from therapies aimed at improving their ability to play and learn through changes in their environment or changes in the body structure and function. (Click the link at the end of video to read more).

So, we encourage parents like Paul's to understand that medical care cannot **fix** Paul's Cerebral Palsy, but doctors and therapists can help to promote his development and functioning. We encourage parents to move beyond just trying to make their child to do things like everyone else, i.e. making the child "normal". Rather, we want parents to focus on child's abilities, strengths and interests, and give their child the opportunities to play, go to school, and have fun with family and friends – the same things experienced by other children. (Click the link at the end of video to read more).

So, parents: we believe that it is very important for kids to have opportunities to 'do' and to 'be functional' in their own ways, without necessarily doing things 'nicely' or 'normally'.

To learn more on how to help your child be more active, please see the next module on 'Activity' and 'Participation'.

Video 3: Activity and participation

What is activity and participation?

The ICF defines “Activities” as completion of tasks that we do every day: for example, walking, talking, playing, and eating. “Participation” means to be involved in life situations. For example: **walking** to move around, to play, or to go to school; and **talking** to develop relationships with family and friends.

What are the challenges with activity and participation in Cerebral Palsy?

To better understand this, let us meet Sara. Sara has weak leg and back muscles, and impairment to the brain, which are **body structure and function** challenges. Sara’s **body structure and function** challenges make walking and talking difficult for her. This is called **activity limitation** in ICF. The activity limitation leads to her non participation in social activities, like going to school, which is called **participation restriction** in ICF.

What can Sara’s parents do to promote Sara’s activity and participation?

We want to think about how best to encourage and enable Sara to play, go to school, and have fun with family and friends. Medical care and therapists can help Sara move around by providing supports like a motorized wheelchair. To help Sara talk, she can type on her computer ‘talker’ that will sound out the words for her family and friends. Therapy in this case enhances both mobility and communication. Using her wheelchair and her computer, Sara can go to school and learn new things, make new friends and play with them, and can engage in experiences similar to other children of her age. Participation in school and community life will help Sara become more active and independent, and may help improve her body structure and function. Increased independence will boost Sara’s self-confidence and self-esteem and will help her and her family to achieve a better quality of life.

To learn more about ways to increase your child’s participation in home and community, please see the next module on contextual factors.

Video 4: Contextual factors

What are contextual factors?

Contextual factors are things about a person or their environment that can positively or negatively affect functioning in daily life. The ICF divides these factors into **personal** and **environmental** factors**. Personal** factors are individual characteristics of the person such as their age, personality, beliefs, education and gender. **Environmental** factors are things around the person, such as the physical and social environment; for example, accessibility of infrastructure and attitudes of family and society.

How can contextual factors influence my child's functioning?

Challenging environmental factors can make functioning difficult in some areas of your child's life; on the other hand, supportive environments can help children function better and have more fun. To understand this more, let us meet Sara and see how supportive and challenging contextual factors can influence Sara's overall development and her desire to go to school. Sara has weak leg and back muscles. This makes it difficult for Sara to walk independently. Impairment to Sara's brain has also affected her speech, which makes talking to family and friends difficult for her. Due to difficulty in walking and talking, Sara is missing out on important activities like going to school, making friends and playing with them.

Scenario 1 (challenging contextual factors hindering participation): Sara's parents might be having feelings of shame or guilt for Sara's Cerebral Palsy. These feelings might be stronger if society also has a stigma towards disability. Sara's parents might not have sufficient finances to support Sara's health care needs. These factors might prevent Sara's parents from seeing a health professional. This might lead to Sara being confined to home and poorer health and lack of opportunities for optimal development. Sara's deteriorating health might cause more worries, leading to stress, poor social and work life, and poor mental health for Sara's parents. Thus, we see how negative contextual factors can hinder Sara's development and the quality of life for her and her family.

Scenario 2 (positive contextual factors favouring participation): Sara is an **enthusiastic** girl and wants to go to school. Her parents optimistic outlook might encourage them to see a therapist to facilitate Sara's desire to go to school. Sara's therapist should think of Sara's overall development, and might give her a wheelchair to help her move around. The therapist can refer

Sara's parents to other healthcare professionals like an occupational therapist, counsellor, social worker and speech therapist. All health care professionals can help parents in managing Sara's Cerebral Palsy, and can suggest ways to help Sara become functional and join school. Social worker and counsellor can help parents in managing emotional issues and finding community services. The Occupational therapist can recommend ways for Sara's parents to make their house more accessible for Sara to move around and function better. For help in talking, speech therapist can give Sara a computer talker.

The school can provide Sara with an accessible school bus, infrastructure, classroom, and a school aide where she can learn and move freely like other children. Teachers, friends, staff, and people in the community can keep a positive outlook towards Sara, encourage and provide her with opportunities to learn and play, and be patient with her while she is learning to use her wheelchair and the computer talker in the new environment. The community can advocate for accessible roads, transportation, and community services where Sara and other children can live and move freely. Governments can help societies by providing financial support and enforcing laws to create accessible communities and support services needed to accommodate Sara's needs. Media services can help Sara and her family by spreading awareness about Cerebral Palsy. Thus, we see how positive contextual factors can help Sara and her family live a meaningful life that is essential for her development and allows her to participate fully in life activities.

Video 5: How do different parts of the ICF work together?

Paul's mother to doctor: Doctor we have now understood the three components of the ICF, but still cannot understand how they relate to each other? Could you please give an example?

Doctor: Sure!! We know that Paul and Sara both have Cerebral Palsy. Consider sending Paul and Sara to a school, and see how all the ICF components relate to each other.

Both Paul and Sara are enthusiastic, curious and like to play. Paul and Sara have weakness in their leg muscles, which makes walking difficult for them. Impairment to Sara's brain also makes talking difficult for her. As you families have both come to me to discuss your child's health, this shows your health seeking behaviour, and an optimistic outlook towards your child's health. Though both Sara and Paul have difficulty walking by themselves, they have different needs and abilities, thus would need different kinds of treatment. Paul can walk with a walker, but Sara would need a motorised wheelchair to help her move in the home, community and school. Sara can use a computer talker to communicate easily with friends and family. Accessible communities, transportation, and supportive attitude of people will help them to engage in experiences similar to other children.

In the school, along with other children, Paul and Sara might be involved in activities like colouring, crafts and other play activities. Going to school will provide opportunities for Paul and Sara to meet other children, to make friends, develop social relations and communication skills. Increased participation in school activities might help Paul and Sara to develop stronger muscles and better balance. These are things that improve with practice, and enable Paul and perhaps Sara even more, to be active and independent in their lives. Paul and Sara can also take some therapy to strengthen muscles and improve balance.

Thus, we see progress in Paul's and Sara's development by enabling them to attend school using technology. Here Paul and Sara are not simply having specific 'therapies', but in fact, there may be more changes in Paul's and Sara's life within a school than there would be in 'therapy' alone. All this will promote child 'development' – everyone's ultimate goal!

Paul's mother to doctor: Thank you, doctor!! We now understand how to use the ICF for managing our children's health.

Appendix 6: Responders comments on open-ended questions

How easy was it to understand the videos?

1. The video and examples given gave a clear understanding of all components of the ICF and how they work together. (healthcare provider)
2. It was a little awkward at first, but it picked up very quickly
3. Very clear straight forward messages. The most challenging video is the final one. It might be that I viewed it on a very small screen, but think it important to emphasize the key words of the ICF in the narrative plus text enhancement on the screen to draw the elements together well. Is excellent really - perhaps just one or two additional visual devices
4. I was left wondering what parents would get out of this? the bottom line is who cares? why do I need to know the terms and various things like this? I am not really needing a new set of terms like this. what is the purpose?
5. The videos did a good job of describing the elements of the ICF and how they work together!
6. Video 2 speaks of body structure: instead of saying structure is leg hand eye. Why don’t you put it as brain, eye, muscles etc. also along with structure you can very well explain function in such a case. because, immediately the video jumps to function part of brain. Module 4 on contextual factors can also include environment and policies, at least the South-east Asia faces them more than developed nations. I suppose the social security and support systems too can be discussed if permitted
7. It needs little modification if it needs to be used in Indian conditions
8. It was clear enough
9. The mouths did not match up with words spoken, a lot of drifting during video.
10. The video series were quite easy to understanding. Good explain with the pictures
11. As I am a professional with previous insights in ICF, I have difficulties to imagine if parents would find the information easy to understand. But I had a strong feeling that the speed of the information flow was a bit too high (some parts of speech, text shifts and content in animations).
12. It's very easy to understand
13. I am a physiotherapist and had previous knowledge of the ICF
14. I think that the language used on the videos is very easy to understand.
15. Video 5 contents are not so clear in comparison to the video 4. I doubt that families may find these contents so useful
16. Understood what was said

How helpful do you think these videos are for informing you on how you manage your child’s health?

1. The ICF seems to be more of a diagnostic tool, and parents will know it colloquially rather than as a professional, but it is still essential to understanding treatment choices. I think the videos do a good job of keeping it simple enough for many backgrounds and education levels.

2. I can't see any way that this helps me parent. And from our perspective we can offer all of our children a decent life. So, it might relate to other people-I am not sure who would find it useful really sorry.
3. As a parent, I am familiar with the ICF, and have been successful in managing my child's condition, but I think these videos would be particularly helpful for someone who is not familiar with the ICF, and each of the components.
4. Certain examples need cultural relevance like accessible school buses in Indian conditions
5. Would like to know organizations or agencies that can help to integrate these
6. Good
7. Very helpful
8. Only first video was available for viewing so cannot compare on this survey
9. For the young children is good but on the long term it says nothing. On the long term when the children were adults there becomes other problems were not talking about. Then is there no helping hand.
10. I think the videos are very helpful for parents and for educating professionals working in developed countries. However, in low and middle income countries, where there is often stigma against children with CP and where assistive devices are not available or affordable, some of the content of the videos is not relevant, but could be made so.
11. The language uses too much jargon. Plain English is needed.
12. Some of the contextual factors are not appropriate in the situations where i work with parents of children with CP, seeing the hi-tech devices recommended would make people demotivated because how can they help their kids without access to computers to communicate and electric WCs
13. Very helpful and useful

Did the following videos hold your interest? If not, how far into the videos did you start to lose interest?

1. This is very interesting to me.
2. But I am also committed to the need for excellent education
3. Great job on all of the videos!
4. There is an ease of understanding as well a flow in the videos. Good job.
5. It is easy to follow for professionals who are familiar with these concepts. Needs simplification for Indian Scenario
6. Parents of such children are very short on time. They would prefer a human face talking them thru to little bit animation to explain things. That would be comforting too. Personally, I feel animation is good for children. If you have human face a doctor or therapist talking thru would be best.
7. Difficult for common man
8. Paid attention all through it was catchy enough
9. I think first video is a good start but needs some cleaning up in editing video.
10. It was good but a little bit the same

11. I did keep focus as my aim was to listen and understand who these videos informed parents on ICF. I had to make two breaks in between viewing the two last videos as the speed and similarities in intonation and voices made it difficult to stay focused.
12. I do have a great difficulty with the very strident music that is incessant. It would be great if there was the option to turn this off completely
13. This is a potentially very useful series of videos

What was one thing you learned from watching these videos? How would you use this information in your child's rehabilitation?

1. Keep the child more active along with other kid is equally important as another rehab program
2. All CP children don't have the same needs
3. My child does not have CP but we can certainly use the approach in working on issues we have at school and at home.
4. It is important to focus on how to improve child life situations rather than concentrating on impairments alone
5. I am a professor of a Public University in Brasil. I work with children with CP and happily the ICF´s approach is in our daily routine.
6. People attitudes affect my child
7. To ask for a more individualized plan of care
8. It reinforced for me not to focus on trying to change or 'fix' my child, but instead focus on his strengths.
9. I am a parent-professional & have implemented it in personal life & have been teaching parents for more than a decade
10. NA as I am already using services.
11. Better understanding that CP is a broad spectrum
12. That every child with CP is different & Health Care Providers should respect that
13. To identify the patient's functional needs
14. We were of the opinion that making her physically capable should be our prime most goal. The videos made us realize overall development is the way to go.
15. Got ideas to make things simpler for parents with CP
16. How to explain to parents about ICF
17. Things that the parents should try to make their child do, to participate in all play activities or their interest act, they should not force to do nicely or like another normal child
18. As a physiotherapist and involved in training of therapists, the importance of connect all areas of the ICF
19. I will use this information to give better information for parents about ICF and to explain about personal differences between children.
20. Improve on rehabilitation for CP based on this new concept ICF

How confident do you feel about your ability to implement the ideas/knowledge you learned in these videos in your child's rehabilitation?

1. As applicable as it is, I will keep the ICF in mind
2. Excellent videos developed by CanChild
3. How and what would I implement?
4. People living in most metropolitan cities would have these services available to them. But people from diverse backgrounds, poor socio economic background and many migrants would benefit from this videos more.
5. I have applied the ICF to my practice, without truly knowing that I was applying the principles.
6. Nil
7. I am self an adult with CP
8. It is very difficult to take the perspective of parents and try to understand if this information assists parents in rehabilitation of their child and increases their confidence. When listening, I thought - ok this explains the framework but what are the practical implications does it give the parents? The information feels very general and somehow needs to be taken down to earth for families.
9. I would be using these videos as teaching tool for therapists
10. I think that we need to understand at what stage families' will be able to watch videos and help plan their questions/thoughts
11. I am a Physical Therapist on Brazil, who studies a lot about ICF and CP.
12. Worthwhile

What help would you need from healthcare professionals to implement the ideas in these videos to assist with your child's rehabilitation?

1. Information and guidance that whom to approach for activity's participation in school and community.
2. Guidance
3. Speech Language Pathologist to incorporate more activities and participations instead of focusing solely on body functions.
4. Health care professional have better ideas and skills to improve child's overall participation
5. Explanation about how this will help our child and families. I am still not sure why this is important.
6. A more individualized plan of action
7. They would need to be open to the concept of not only trying to 'fix' what is wrong, or what is not working normally. I would hope that health care professionals would be on board with this.
8. Procedure to link assistance
9. For them to listen
10. Their professional help and guidance is necessary for the child's growth.
11. How to make other videos like this in other languages?
12. Time with healthcare profession

13. Education and awareness should be key to rehabilitation

Other than healthcare professionals, what other supports would you need to implement the ideas in the videos?

1. School personals have a key role in make more facilities to accommodate kids with differential abilities.
2. From community
3. Easier accessibility to resources
4. Support from government
5. I would need to know what it is I am supposed to be implementing?
6. A positive outlook, and supportive family and friends, who are willing to work with me and my family.
7. Financial aid sources
8. Maybe a Personal/Life Coach
9. Speech, physiotherapy, OT, special education
10. Technical support, to make a video
11. How to implement this with patients?
12. Advocacy and active involvement of caregivers at every stage of development of the child.

Did the videos make you think differently about your child and your child's therapy?

1. We are near the end of the journey, and I can see this as being more important to the beginning.
2. There are many factors that must be considered to further support the development of my child
3. Before we were focusing on impairments alone now the whole focus shifted to participation
4. I have been working with the ICF model in terms of both practice and research.
5. It was interesting to watch, but I have no idea of the next step.
6. I was already thinking this way, but it confirmed that it is the right way to think about my child's disability. "Promoting child development is everyone's ultimate goal!"
7. Because I had previous knowledge and received services and followed what was offered so these videos. But to a new family they would be of benefit.
8. It would be helpful if the survey covered professional opinion as well as parent.
9. Counselling is very important
10. Hopefully parents may begin to recognize developmental and learning opportunities in numerous aspects of life - not only in therapy. But that is not expressed with enough clarity (in a down to earth way).
11. As a physiotherapists and trainer of trainers, I Still come across professionals who work too much in the "Medical Model" of rehabilitation. The ICV and the videos are useful tools to highlight the "Social Model"
12. Watching this video as a healthcare professional, I will be biased to my answers. I think it would be useful to have a focus group to answer the questions from the parental perspective rather than professional

13. I have always thought of a holistic approach during the rehabilitation process, so this video is a reminder and booster

These videos will be used to inform other parents about the the International Classification of Functioning, Disability and Health, Cerebral Palsy and its management. With that in mind, what would you suggest we add, or delete, or modify in the videos? Please specify the video number.

1. No, they were all helpful and relevant
2. Can emphasize how to address the psychological factors or behavior issues with cerebral palsy
3. Add 2 more
4. In the first video, I don't think the long lead in with the families is necessary.
5. Improve video 5 in a better way
6. It would be extremely important to be able to provide the videos in other languages. I would be very happy to contribute, from our University, with the translation into Portuguese of Brazil.
7. I think that the part with 'normal' in it is a clumsy section. don't know what video, just felt a bit uncomfortable
8. I didn't see anything that I would change!
9. Module 2, speaking from a therapist point of view, the structures involved would be muscles and brain rather than leg hand eye etc. over all for patient understanding it looks good. Module 4 on contextual factors can also include environment and policies, at least the South-east Asia faces them more than developed nations. i suppose the social security and support systems too can be discussed if permitted
10. Simplification. I need to show it to our parents for their opinion
11. In environmental factor part, you should add another factor, not only school or family.
12. They are all good
13. make them little short, add human faces not just animation and remove some repetitions of highly technical /scientific words. Make it more applied language
14. Don't think the accents are necessary
15. Some more examples may be helpful in video2-5.
16. Nothing really, but the Health Care Workers need to be better educated
17. None
18. Only saw first video. Content good for introduction to CP, but editing makes viewing sometimes difficult. There was a lot of drifting, shadows on speech bubbles distracting, mouths not moving together with words sometimes bothersome.
19. You might add more specific case histories. Videos were a bit generic.
20. Simple and it has covered all the points
21. information is repeated, narration is fast in all videos, please highlight important information. sometimes narration was monotonous
22. Say at last that you all your life searching to look how to do things. After the child years, there is no therapies to help you with the problems such like pain.
23. Slow down the speed a bit to allow all kind of parents to digest the multi-channeled information. Encourage the idea that despite of body structures and functions opportunities to be active and participate in a variety of situations is as valuable for

development and learning as various therapies. Life should be fun and meaningful together with others - not only focus on diagnosis and therapies.
24. According to the need of Rehabilitation we can modify
25. An option to remove the music
26. The language used is rather full of jargon and needs to be put into plain everyday usage English. It would be extremely helpful if the videos could be adapted to be appropriate for low resourced countries and use culturally appropriate images.
27. Suggestion given for the context video. Generally, be aware of the lack of hi tech (sometime any at all) devices in many contexts
28. Just keep the beginning video for parent’s general information and then add others as needed
29. Maybe you could include the description of personal factors, such as motivation, age, sense of efficacy, self-esteem, to help individualizing parents' understanding (videos 4 and 5)
30. Video 5 should be more clear and detailed
31. Clarity

General comments, not related to any question.

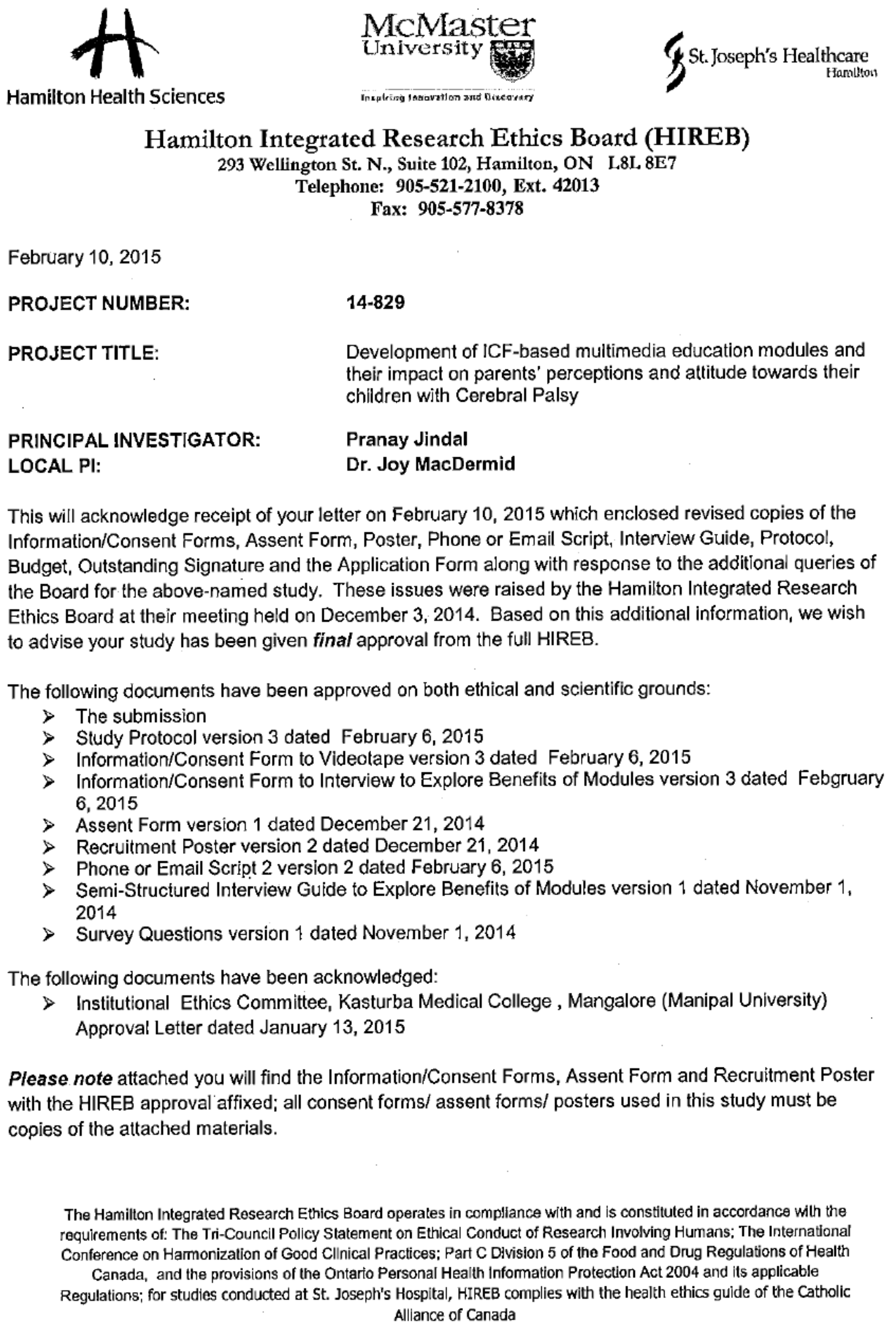
1. (From a Healthcare professional) I enjoyed watching them. Great (and important) work! The message is really good and important; i.e. most important is not the separate factors, but the development of the child broadly, with a focus on family, friends and fun! Two suggestions from my point of view:
   a) The module Body Functions only describes challenges and weaknesses. I would suggest to include some strengths too (every child has specific strengths in body functions too)
   b) The module Contextual factors now only discusses challenging factors related to the parents. I would suggest to add some challenging examples from other social environmental factors and physical environmental factors

2. (From a parent) I like the style of the videos. They are really easy on the eye. As a fan of the F Words, I think the complex ICF language used in your videos kind of clashes with the simple visuals, but that might just be because I prefer the Function, Friends, Fun etc. Very simple words to describe the domains. I was wondering why, throughout, the children are described as wanting to go to school? It led me to think it meant that they couldn't currently go to school because of their disabilities. Have I understood this right? If so, I'm really concerned with the message this sends; that disabled children don't have an automatic right to go to school if they are disabled. I think the thing the characters want to do should be something that isn't a basic right, for example go skiing, or sailing. Do you see what I mean? I understand why you've done it in separate modules, and I like the separation, but I don't really get a feel for what the videos actually do for parents. What help do they provide, other than saying we shouldn't try to fix the cerebral palsy, but to change the environment to make it easier for the child to

participate. (I get this.) So, when the videos talk about getting therapy or powerchairs, I worry that parents might say how the hell do we do that? We've tried to get this but the waiting list is 6 years long etc. How could the videos empower parents to challenge the services which ignore their requests for the therapy and equipment to help their child participate? Finally, and I know I've probably come across as being really critical (I hope my feedback is useful, without offending you), in the module which talks about contextual factors, it made me quite annoyed that the negative contextual factors were very much focusing on parents, and not on people such as therapists, clinicians, teachers, social workers who make the things happening around the family worse than any guilt the parent might be feeling. This is really an area that has been researched a lot, and there is a lot of evidence to show that too often the family (more often than not, the mother) is blamed for negative relationships, being 'difficult' etc., when a lot of the time it's because the clinician/professional/whatever you want to call them, have poor skills in being person/family centered. (Don't worry I'm not cross with you!) I'd really like to see videos such as yours to show how the ICF can be used to reinforce the rights of children, for example using the UNCRC or UNCRPD

3. (From a parent) These videos are extremely basic. They don't allow you to write anything into the comment section- technical problem. I don’t understand why they always say CP does not get worse, but our child has!! and we've worked hard with our child. When we stop doing intensive therapy, our child deteriorates dramatically. They seem to suggest that by giving therapy, you're going to lose years of schooling. That is simply not true. And anyway, anytime we did pull our child out of school to access intensive therapy, her schooling as a flow on effect actually benefitted enormously. They used too many able body examples. For example, when they were saying about Sara getting better balance, they showed an able-bodied person walking along a balance beam. Ha ha what a crock! They indicated that the child would get an aide at school-this is simply not what happens in the real world. Conductive Education in its true form; not the watered-down versions we see in Australia; actually, does encompass psychology teaching and the three main therapies. It works. Our child made close on miraculous gains in a matter of weeks.
4. (From a Healthcare professional) I have done some guesses with regard to how parents may experience the information. The difficulty is that parents are extremely different and perceive information differently. I have tried to think of how parents could digest this kind of information and use it in their everyday life with their child with disability. Therapy is necessary and a diagnosis assists understanding of the child's needs but I think it is so important to emphasize to parents that there are hidden development and learning opportunities in so many everyday situations where the child is active and participate (on their own or assisted by others). An important message is thus that not only therapy sessions and school provide their child with developmental and learning opportunities. That insight may assist parents in recognizing how they can use their everyday environment to support their child and thereby decrease their bad consciousness for not

doing enough "therapy" with their child. I feel that this message exists in the fifth video but it is very general and might thus be hidden to many parents.



Hamilton Health Sciences
McMaster University
Inspiring Innovation and Discovery
St. Joseph's Healthcare Hamilton

Hamilton Integrated Research Ethics Board (HIREB)
293 Wellington St. N., Suite 102, Hamilton, ON L8L 8E7
Telephone: 905-521-2100, Ext. 42013
Fax: 905-577-8378

February 10, 2015

PROJECT NUMBER:	**14-829**
PROJECT TITLE:	Development of ICF-based multimedia education modules and their impact on parents' perceptions and attitude towards their children with Cerebral Palsy
PRINCIPAL INVESTIGATOR:	**Pranay Jindal**
LOCAL PI:	**Dr. Joy MacDermid**

This will acknowledge receipt of your letter on February 10, 2015 which enclosed revised copies of the Information/Consent Forms, Assent Form, Poster, Phone or Email Script, Interview Guide, Protocol, Budget, Outstanding Signature and the Application Form along with response to the additional queries of the Board for the above-named study. These issues were raised by the Hamilton Integrated Research Ethics Board at their meeting held on December 3, 2014. Based on this additional information, we wish to advise your study has been given ***final*** approval from the full HIREB.

The following documents have been approved on both ethical and scientific grounds:

- The submission
- Study Protocol version 3 dated February 6, 2015
- Information/Consent Form to Videotape version 3 dated February 6, 2015
- Information/Consent Form to Interview to Explore Benefits of Modules version 3 dated Febgruary 6, 2015
- Assent Form version 1 dated December 21, 2014
- Recruitment Poster version 2 dated December 21, 2014
- Phone or Email Script 2 version 2 dated February 6, 2015
- Semi-Structured Interview Guide to Explore Benefits of Modules version 1 dated November 1, 2014
- Survey Questions version 1 dated November 1, 2014

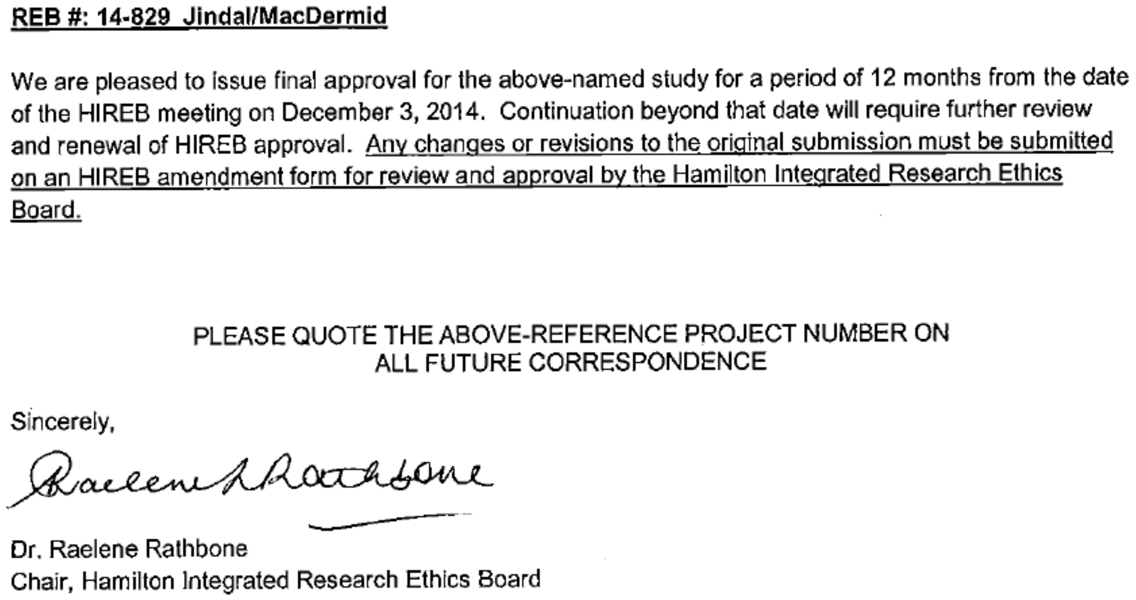
The following documents have been acknowledged:

- Institutional Ethics Committee, Kasturba Medical College , Mangalore (Manipal University) Approval Letter dated January 13, 2015

Please note attached you will find the Information/Consent Forms, Assent Form and Recruitment Poster with the HIREB approval affixed; all consent forms/ assent forms/ posters used in this study must be copies of the attached materials.

The Hamilton Integrated Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada, and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations; for studies conducted at St. Joseph's Hospital, HIREB complies with the health ethics guide of the Catholic Alliance of Canada

Ethics approval



REB #: 14-829 Jindal/MacDermid

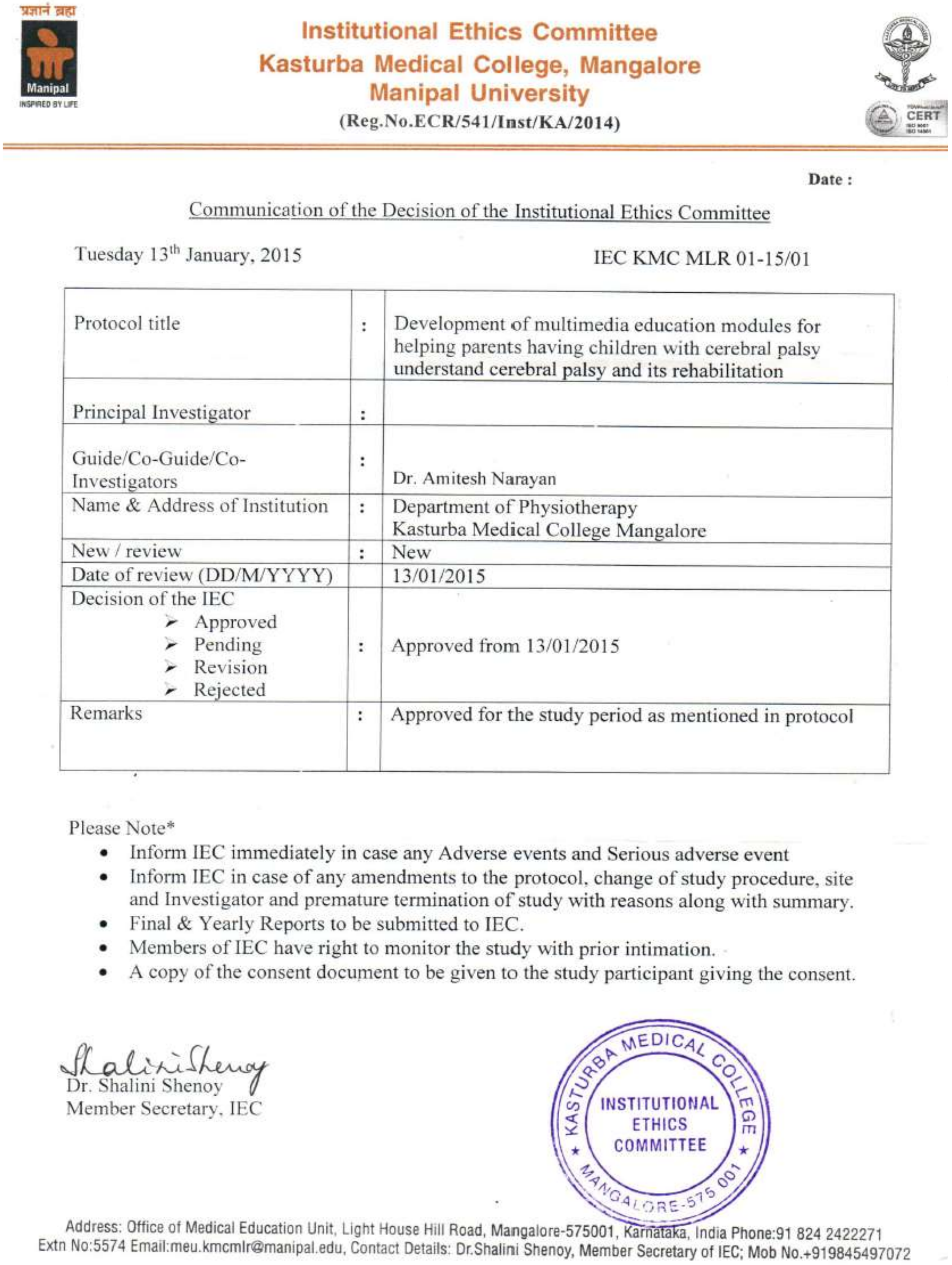
We are pleased to issue final approval for the above-named study for a period of 12 months from the date of the HIREB meeting on December 3, 2014. Continuation beyond that date will require further review and renewal of HIREB approval. Any changes or revisions to the original submission must be submitted on an HIREB amendment form for review and approval by the Hamilton Integrated Research Ethics Board.

PLEASE QUOTE THE ABOVE-REFERENCE PROJECT NUMBER ON
ALL FUTURE CORRESPONDENCE

Sincerely,

Raelene L Rathbone

Dr. Raelene Rathbone
Chair, Hamilton Integrated Research Ethics Board



Institutional Ethics Committee
Kasturba Medical College, Mangalore
Manipal University
(Reg.No.ECR/541/Inst/KA/2014)

Date :

Communication of the Decision of the Institutional Ethics Committee

Tuesday 13th January, 2015

IEC KMC MLR 01-15/01

Protocol title	:	Development of multimedia education modules for helping parents having children with cerebral palsy understand cerebral palsy and its rehabilitation
Principal Investigator	:	
Guide/Co-Guide/Co-Investigators	:	Dr. Amitesh Narayan
Name & Address of Institution	:	Department of Physiotherapy Kasturba Medical College Mangalore
New / review	:	New
Date of review (DD/M/YYYY)		13/01/2015
Decision of the IEC ➢ Approved ➢ Pending ➢ Revision ➢ Rejected	:	Approved from 13/01/2015
Remarks	:	Approved for the study period as mentioned in protocol

Please Note*

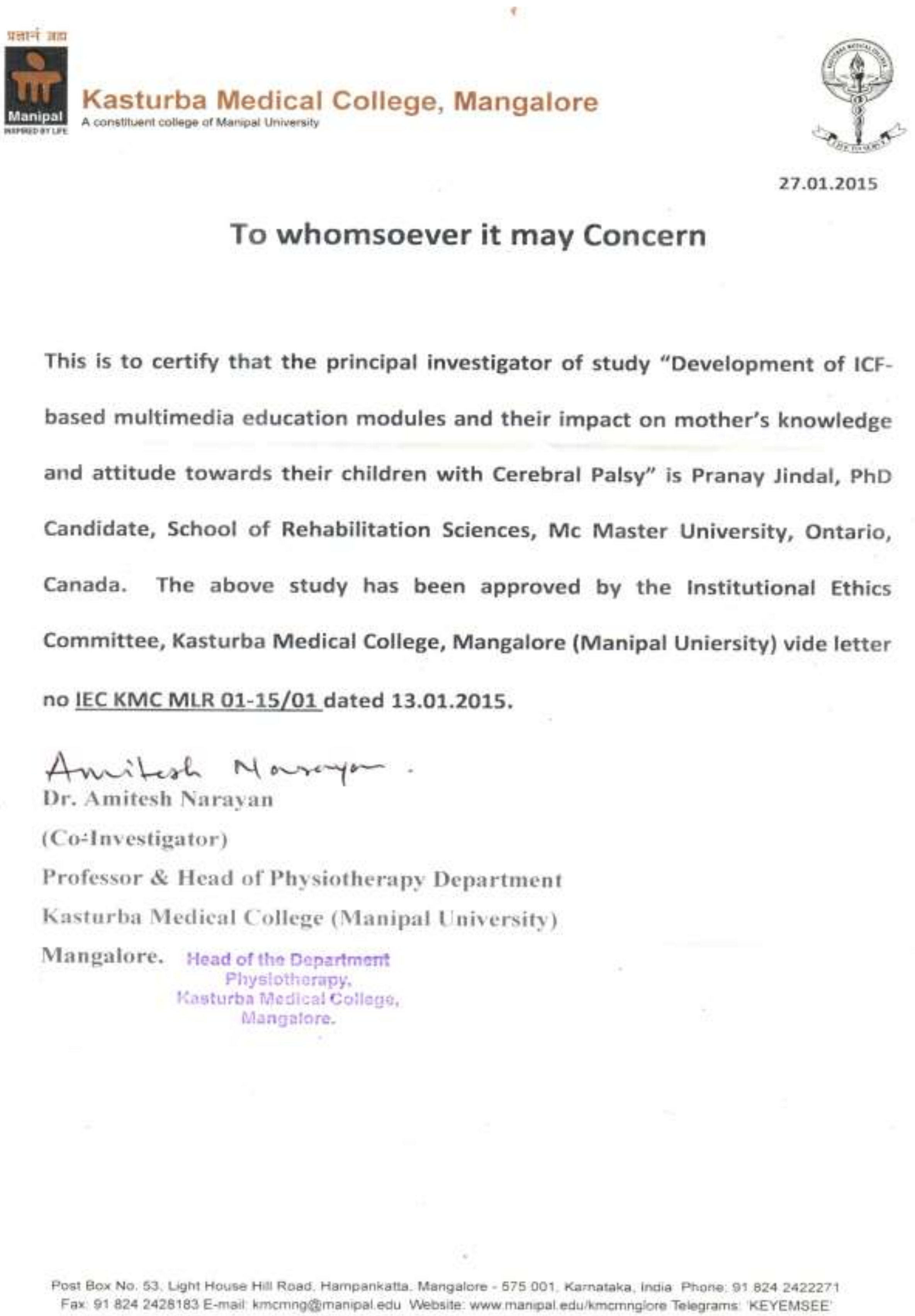
- Inform IEC immediately in case any Adverse events and Serious adverse event
- Inform IEC in case of any amendments to the protocol, change of study procedure, site and Investigator and premature termination of study with reasons along with summary.
- Final & Yearly Reports to be submitted to IEC.
- Members of IEC have right to monitor the study with prior intimation.
- A copy of the consent document to be given to the study participant giving the consent.

Shalini Shenoy
Dr. Shalini Shenoy
Member Secretary, IEC

INSTITUTIONAL ETHICS COMMITTEE

Address: Office of Medical Education Unit, Light House Hill Road, Mangalore-575001, Karnataka, India Phone:91 824 2422271
Extn No:5574 Email:meu.kmcmlr@manipal.edu, Contact Details: Dr.Shalini Shenoy, Member Secretary of IEC; Mob No.+919845497072

Ethics approval



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A constituent college of Manipal University

27.01.2015

To whomsoever it may Concern

This is to certify that the principal investigator of study "Development of ICF-based multimedia education modules and their impact on mother's knowledge and attitude towards their children with Cerebral Palsy" is Pranay Jindal, PhD Candidate, School of Rehabilitation Sciences, Mc Master University, Ontario, Canada. The above study has been approved by the Institutional Ethics Committee, Kasturba Medical College, Mangalore (Manipal Uniersity) vide letter no IEC KMC MLR 01-15/01 dated 13.01.2015.

Amitesh Narayan.
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