Identifying barriers to occupational and physical therapy services for children with cerebral palsy

Elizabeth A. Cada\textsuperscript{a,∗} and Roberta Kuchler O'Shea\textsuperscript{b}
\textsuperscript{a}Department of Occupational Therapy, Governors State University, University Park, IL, USA
\textsuperscript{b}Department of Physical Therapy, Governors State University, University Park, IL, USA

Abstract. Project Export/Cerebral Palsy Project was a three-year study funded by the National Institute of Health (1R24 MD000509-01) to investigate barriers to adequate and appropriate therapy services for children and adults with Cerebral Palsy who are living in the south metropolitan region of Chicago. This study examined barriers individuals with Cerebral Palsy (CP) and their families encounter when accessing Occupational Therapy (OT) and Physical Therapy (PT) services in the region. The study utilized a 3-tiered investigation system (survey, educational forum, and focus groups) that provided families and community therapists opportunities to identify barriers that impact access to evaluations and ongoing therapy services for individuals with Cerebral Palsy.

The findings revealed a multitude of barriers identified by family and therapist participants. These barriers included, but are not limited to, financial resources, availability of therapists, convenient appointment times, and transportation issues. The educational forum and focus groups were effective in identifying knowledge gaps regarding Cerebral Palsy and strategies for accessing therapy in the region. Future plans include continuing collaborative initiatives for families and therapy providers. These include community educational forums that are accessible and provide relevant information, opportunities for networking, and advocacy information. The findings of the study will also be utilized to help occupational and physical therapists develop and implement alternative models of service delivery that provide greater access to therapy services for individuals with Cerebral Palsy.

Keywords: Cerebral palsy, occupational therapy, physical therapy, barriers to therapy services

1. Introduction

The Project Export/Cerebral Palsy project was a three-year study funded by the National Institute of Health (1R24 MD000509-01) to investigate barriers to adequate and appropriate occupational and physical therapy evaluation and services for children with Cerebral Palsy living in the south metropolitan region of Chicago. This geographical area, which includes the far south suburbs of Chicago, is comprised of a somewhat random mix of urban, suburban and rural environments. Similar to the environs, diversity is also seen in both the population and economic conditions of its residents. An additional preeminent characteristic of the region is ongoing and rapid socio-economic change, with the paradox of both growth and decline occurring in communities in close proximity to each other.

For statistical purposes, we considered the south metropolitan region of Chicago to consist of 20 townships, 5 in the southernmost part of Cook County, Illinois and the remaining 15 in the eastern part of Will County, Illinois. Table 1 presents a demographic profile of the south metropolitan region of Chicago, compiled from data from a 2000 Census of the US Popula-
The symptoms of CP are diverse, and consequently the disabling impact of this disorder varies widely [10]. CP is a permanent but non-progressive lesion in a single or multiple locations in the immature brain. Despite the static brain lesion, progressive musculoskeletal changes can be seen. These include spasticity, atypical gait patterns, decreased muscle mass, and ataxia in one or more extremities. However, CP is associated with a variety of co-morbidities and secondary conditions such as seizures, spasms, epilepsy, speech and communication disorders, learning disabilities sensory impairments, and hearing and vision issues which may intensify as the individual ages [16].

The prevalence of CP among children increased from the mid-1960s to the mid-1980s [4,8,11]. This increase is thought to be largely a consequence of medical advances that increased the survival rate of babies with low birth weight. Recent decreases in the prevalence of CP among children has only partially offset the increases of earlier years [10].

Cerebral Palsy cannot be cured. However, the disabling effects of CP can be reduced through a variety of treatments and therapies, e.g., physical and occupational therapy; speech therapy; drugs to control seizures, relax muscle spams, and alleviate pain; surgery to release tight muscles and correct anatomical abnormalities; braces and other orthopedic devices; wheelchairs and rolling walkers; communication aids; etc. [10].

The investigators undertook this study with three assumptions. The primary assumption is that interdisciplinary research is valuable [2,3,5,8]. The second is that what constitutes a barrier for children with cerebral palsy and their families when seeking occupational and physical therapy services may be different for each family [9,12,14]. Thirdly, occupational and physical therapists have their own perceptions about why families cannot or do not access therapy services [1,7].

2. Method

This study utilized a three-tiered system which included a survey, educational forum, and focus groups.
to gather data on why families have difficulty accessing providers. Throughout the data collection process, families and therapy providers had several opportunities to identify barriers to therapy evaluations and ongoing therapy services for children with cerebral palsy.

The first year of the project was devoted to developing relationships with therapy service providers and families in the south metropolitan region of Chicago. During this year a small advisory group was developed which consisted of families, representatives from the south metro region health care community, community health care activists, school system and early intervention therapy providers. Through discussion with the advisory group the investigators gained valuable insight into some of the issues related to therapy service availability and delivery in the region.

Based on a review of the literature and information gathered anecdotally from families and providers, the investigators developed two survey instruments. One survey was developed for families and the other for therapy providers. The surveys were piloted with a small group of therapy providers and families. The instruments were available in English, Spanish and Polish.

The surveys for the therapists were distributed via mail and directly to those therapists employed in early intervention programs, public school systems, community based outpatient agencies and hospitals in the south metropolitan region. The surveys developed for the families were distributed via therapy providers. A total of 346 surveys were distributed to families and 300 surveys to therapy service providers with two postal mailings. The surveys did not request any identifying information and were returned directly to the investigators via a postage paid envelope. Forty five (13%) families and eighty seven (29%) therapy providers returned the survey.

During the first year of the project, through dialog with the advisory group and other encounters with the community it became apparent that families and health care providers were keenly interested in learning about resources regarding CP. Both the families and providers shared anecdotal stories of experiences with healthcare providers who were not able to provide information about new treatment options and the services available for children with CP in the south metro region. More importantly families wanted general information about CP and the implications of a diagnosis of CP over the lifetime. Based on the need for information, the advisory group assisted the investigators in planning an education forum.

The primary goal of the educational forum was to provide current information about CP to health care providers, families, and the community at large. The
secondary goal of the forum was to create networking opportunities for the participants. The investigators felt that educational forum might provide an additional opportunity to distribute surveys to those individuals who had not yet participated in the study. The forum was advertised to the community in a variety of ways including sending flyers to be distributed at agencies that provided healthcare services, to early intervention and public school system providers, community service agencies, announcements in local newspapers and word of mouth. Transportation to the forum which was held at a central location in the region was provided for those who requested it. One hundred people attended this forum, 55 therapy providers, 35 family members and 15 community members which included health professionals. Participants were asked to complete a simple pre and post test to assess their knowledge about CP before and after the forum. There were several additional questions that gave the participants an opportunity to describe barriers to accessing therapy services and gauge their satisfaction with the forum.

At the conclusion of the forum, the investigators identified ten individuals that were willing to serve as focus group facilitators. They included 4 community members, 3 therapy providers, and 2 family members who were willing to assist the investigators in gathering additional data for the study from local community based focus groups. The purpose of adding focus groups to the study was to identify families of children with CP who had not yet accessed therapy services and to gather greater insight into the experiences of families who had or were currently receiving services south metro region.

A half-day training session was provided for the focus group facilitators that included an overview of the project, instructions for recruiting participants, how to conduct the focus group, key questions and data collection. At the conclusion of the training session, the participants were equipped to facilitate five focus groups in the region.

Four focus groups were conducted at the end of the second year of the project, and 13 families participated. The focus groups were held in a variety of settings in the local communities. Each session was appropriately two hours in duration and had 2 to 3 participants, consisting of mothers, guardians appointed by the state, and fathers or extended members of the family that provided child care and. All those who participated were given a gift certificate to a local store as a small token of appreciation. The facilitators took notes and audio taped each session. The tapes were transcribed and analyzed for themes.

2.1. Findings

The data were gathered via three mechanisms: a survey tool, a pre and post test for participants at the educational forum, and a series of focus groups. The survey gathered data regarding two distinct steps in therapy service delivery: making the initial appointment for an evaluation; and scheduling and participating in on-going therapy sessions. For the purposes of this study, scheduling an appointment for an evaluation was considered a one-time occurrence, scheduling and participating in ongoing therapy sessions was considered an ongoing process. The surveys were designed to be sensitive to these two aspects of therapy service delivery occurrences because the researchers believed that the barriers to these two types of services are likely to be different.

The family survey had closed and open ended questions contained in the three sections: the first section requests demographic information about the family which includes race/ethnicity, SES information, how medical services are funded, number of children with disabilities, the age when the respondent first noticed that child had developmental issues and the age when the child received the diagnosis of CP. The second section focuses on questions regarding who referred the child with CP for services, where and the type of setting that provides services, what services they child receives. The third section contains questions regarding perceived barriers for therapy evaluations and services, who provides care giving or other assistance to the family and several open ended questions that ask about future expectations or needs for services and changes that the respondent would like to see in the current service delivery systems.

The provider survey also had both closed and open questions contained in three sections. The first section seeks information about the provider's current practice including, case load, ages of children seen for therapy, number of visits/length of time child is served per week, the setting(s) in which the therapy service is provided, other services offered in those settings, patient funding sources, and referral sources. The section mirrored the questions that were asked in the third section of parent survey regarding barriers that the family experience seeking therapy evaluations and services. The third section gave the respondents the opportunity to respond to open ended questions regarding their views of family support systems, what makes it possible for a family attend appointments, how do families gath-
er knowledge of CP and ways to reduce the barriers families are experiencing.

Therapist and family survey responses, in percentages, were compared for ranking, and t-tests were utilized to determine whether differences in variable ranking were statistically significant.

The demographic data from the family survey is similar to that of the south metro region Table 2. Eighty-eight percent of the respondents to the family survey were single-child families whose only child had a diagnosis of CP. The majority of children, 71% received a diagnosis of CP from 0–6 months of age and 18% from 6–12 months of age. Seventy-five percent of the children were referred to a therapy provider by their physician. When referred for therapy services, 33% of the families’ initial contact was with a community-based therapy clinic, 31% with the early intervention system, and 29% with hospital based therapy services. Families reported that 74% utilized medical insurance which includes HMO systems to pay for therapy services, 63% utilized some form of public payment to pay for services, and 17% reported personal sources. Families were asked to report all payment systems that were utilized, and often time families reported more than one type of payment source. The families reported physical therapy, occupational therapy and speech and language therapy as the top three services that were received.

Table 3 reveals that the family’s perceptions of the barriers to scheduling therapy evaluations are very different from the perceptions of therapists. The top three barriers reported by families were: the lack of funding for therapy services, inconvenient appointment times, and inconvenient locations for therapy services. In contrast, the top three barriers according to the therapists’ perceptions were scheduling conflicts, transportation problems, and lack of funding. While the families and therapists had similar concerns regarding the impact of funding on a child’s ability to receive therapy evaluations, it is clear that this is a more significant barrier from the families’ perspectives. Although each group recognized the lack of availability of therapists and the lack of convenient appointment times as barriers, the inconvenient locations of therapy services were a more significant barrier from the families’ perspectives than from the therapists’.

To arrange an evaluation for a child with CP, a family must successfully negotiate the availability of a therapy provider, the location where services are provided, and an appointment time, while taking into account all other competing demands for the family’s time and resources. The lack of availability of therapists coupled with inconvenient appointment times make scheduling appointments difficult for families. This difficulty in scheduling and attending appointments can be compounded by the distance to or location of the therapy provider. Therapists perceived transportation concerns to be a significant barrier for families wishing to obtain therapy services for children with CP.

A therapy evaluation often occurs when a child is referred to determine the need for therapy services. Once it is determined that a child could benefit from OT and PT services, it is common for children with CP to receive therapy services one or more times a week for extended periods of time. The need for ongoing therapy services creates a burden for many families. As seen in Table 4, funding to pay for ongoing therapy services is the number one concern for families, followed by finding an appointment time for therapy services that will fit into the family’s schedule. The availability of a therapist and the location where services are to be provided are also key concerns for the family.

While families identify issues related to transportation and childcare for siblings to be barriers, they consider them to less important. Personal/cultural mismatch and goals mismatch were concerns for many families. This may be partly due to the diversity of the population that resides in the south metropolitan region of Chicago. Therapists on the other hand consider these issues to be less important.

The therapists perceived that the inconvenient appointment times, transportation concerns, and lack of funding were the most significant barriers that families
face when scheduling and attending ongoing therapy appointments. Although all variables are not statistically significant, the difference in the families’ and therapists perceptions about the availability of convenient appointment times and convenient service locations demonstrates varying perspectives.

Sixty participants at the educational forum took a pretest and post test to assess their knowledge of CP. The scores on pre and post test didn’t show significant changes in the participant’s knowledge of CP. This result could be attributed to several factors, the small number of questions on the tests and the simplistic nature of the questions. The open ended questions yielded more information; the most frequently reported barriers were reported lack of knowledge about community resources, feelings of isolation from others who had a family member with CP, and lack of opportunity to exchange information with others.

Although the pretest and post test did not demonstrate significant differences, the participants rated the forum with highly satisfaction. The participants reported that they appreciated the opportunities to network with other families and professionals at the forum. They valued the information exchange and opportunity to hear stories from other families about their experiences and from adults with CP who shared their stories. They appreciate the networking and requested that the investigators consider holding additional forums and information exchange opportunities in the future.

Four main themes became apparent during the focus group sessions: funding, access, opportunities, and services. In the area of funding, the families were very concerned that there would be insufficient funding resources to provide for care over the lifetime of their child. They expressed concern that medical insurance coverage may run out and that limited family financial resources would force them to make critical decisions between paying for therapy services and meeting other more basic family needs.

Difficulties in accessing therapy services were a common experience for families. The concerns related to access included insufficient public transportation, insufficient funding for therapy services, difficulty in finding convenient appointment times, and difficulty in locating therapists who were experienced in providing services to children with CP.

The lack of opportunities and services for individuals with CP over age 21 was a major concern for all the families who participated in the focus groups. They were acutely aware of the limited potential for meaningful employment, independent living, and therapy services once the children turned 21 and were no longer eligible for the public educational system where prevocational education, supported employment, and therapy services are often available. In addition, families found it difficult to find a therapist who had expertise and knowledge of CP to provide treatment to adolescents and young adults. Often it was less difficult for families to find a therapist who would provide therapy services for younger children, particularly those children under age 5.

3. Discussion

It is clear from the data, that families face many significant barriers when accessing occupational and physical therapy services for their children with CP. Lack of funding for therapy services is the largest barrier reported by families. Many children with CP will require therapy services throughout their life. Due to other medical expenses, children with CP may reach their life-time health insurance limit in the first several years of their lives, placing enormous burdens on their families who must search for funding for therapy services.

In many cases knowledgeable therapists, those who have specific training in working with children with CP, do not have the time to provide therapy services to children in the early intervention or school system and meet the demand for additional therapy services that comes from community outpatient or hospitals. The lack of availability of a therapist, inconvenient appointment times, and inconvenient locations of therapy services were other barriers noted by families who participated in this study. Although many of the children received therapy services through the public educational system or through publicly funded early intervention services in the home, the availability of a knowledgeable therapist was of concern. According to the families, many therapists appear to lack specific training in providing services to children with CP. Families often reported these therapists were employed in a hospital or community clinic setting rather than the public education system. Typically, therapy services offered by community-based and hospital providers are only available during traditional business hours. Scheduling appointments on an ongoing basis often proves difficult for families trying to balance work, school, and other family obligations.

Most families reported that they utilized their own transportation to attend therapy appointments, and for
Table 3  
Barriers to scheduling evaluations

<table>
<thead>
<tr>
<th>Therapist</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scheduling Conflicts (53%)</td>
<td>Lack of Funding (38%)</td>
</tr>
<tr>
<td>Transportation (40%)</td>
<td>Appointment Time Availability (31%)</td>
</tr>
<tr>
<td>Lack of Funding (35%)</td>
<td>Location of Therapy Services (31%)</td>
</tr>
<tr>
<td>Availability of Therapist (30%)</td>
<td>Availability of Therapist (29%)</td>
</tr>
<tr>
<td>Childcare for Siblings (19%)</td>
<td>Transportation (18%)</td>
</tr>
<tr>
<td>Location of Therapy Services (10%)*</td>
<td>Childcare for Siblings (18%)</td>
</tr>
</tbody>
</table>

*a* Sig at <0.05.

Table 4  
Barriers to scheduling on-going therapy appointments

<table>
<thead>
<tr>
<th>Therapist</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appointment Time Availability (57%)*</td>
<td>Lack of funding (51%)</td>
</tr>
<tr>
<td>Transportation (40%)</td>
<td>Appointment Time Availability (42%)*</td>
</tr>
<tr>
<td>Lack of Funding (35%)</td>
<td>Availability of Therapist (36%)</td>
</tr>
<tr>
<td>Childcare for Siblings (19%)</td>
<td>Location of Appointment (36%)*</td>
</tr>
<tr>
<td>Availability of Therapist (18%)</td>
<td>Transportation (24%)</td>
</tr>
<tr>
<td>Location of Appointment (9%)*</td>
<td>Childcare for Siblings (18%)</td>
</tr>
<tr>
<td>Personal/Cultural Mismatch (7%)</td>
<td>Personal/Cultural Mismatch (13%)</td>
</tr>
<tr>
<td>Goals Mismatch (6%)</td>
<td>Goals Mismatch (13%)</td>
</tr>
</tbody>
</table>

*a* Sig at <0.05.

Some therapists found this was a significant barrier. In the south metropolitan region of Chicago, public transportation is limited and may not provide access to clinic locations or match the scheduled time for therapy. For those families that have more than one child, traveling to and from therapy appointments can be challenging. If their child with cerebral palsy is not ambulatory, the added responsibility of managing additional children can be overwhelming. Some families expressed the need for childcare assistance for siblings so that they could consistently attend therapy appointments.

Effective communication between families and service providers is essential for the design of successful therapy outcomes. Once the therapy evaluation has been conducted, establishing appropriate treatment goals that meet the needs of the child and family requires collaboration. The therapist and family need to share information, as well as determine the needs and priorities for the therapy plan. Additionally, this process must be built on mutual trust and respect. Families expressed concerns about not feeling a level of comfort that would allow the collaborative process to occur. In many cases, their perception was that this barrier was due to a personal or cultural mismatch. It is possible that families have difficulty collaborating with therapy service providers to establish meaningful, culturally-relevant therapy goals if the providers are from different racial, ethnic, or socioeconomic groups and are not culturally competent.

The participating occupational and physical therapists recognized that children with CP and their families faced several barriers when they attempted to access therapy services for their children. Therapists were most acutely aware of the problem families faced when scheduling therapy sessions for their children. Families often preferred therapy to be scheduled early in the day or in the late afternoon. Therapists also recognized that funding therapy services was challenging for many families. This awareness may come from the interface that therapists have with funders through medical necessity review processes, eligibility reviews for therapy services in the public school, and early intervention systems.

Finally, families and therapists differ in their assessments of the barriers to therapy services. Therapists perceived transportation as a significant hurdle for families, but it was less of a concern for the families who participated in the project. It is possible that therapists assume the difficulties families face in scheduling appointments are due to transportation concerns – i.e., that many families who reside in the south metro region do not own cars, and that public transportation is limited. However, families were more likely than therapists to perceive barriers to collaboration due to personal or cultural differences.

3.1. Limitations

There were some limitations noted by the investigators. There is no data base or registry for individuals with CP so it was challenging to identify participants...
for the family survey. The investigators recognized that the method of survey distribution that was chosen may have not been comprehensive; however it was felt that the method of distributing family survey via therapy service providers would likely included a large number of families in the region. It is difficult to access families who are not receiving any medical or therapy services. Locating children who had not yet received a diagnosis or families who hadn’t accessed therapy services proved to be much more challenging. In approaching health care providers in the region, that could have possibly identified these underserved children, it quickly became apparent that many of the providers either didn’t have any patients with the diagnosis or hadn’t made the diagnosis in any of their patients. In a meeting with our advisory group, it was suggested that we offer an educational forum that could increase community awareness about CP, thus help us identify additional participants. They also suggested adding focus groups to the study, with the intent of identifying underserved children and families in their local communities. All these efforts were utilized to increase the data gathered.

3.2. Recommendations

This study shed light on several aspects of providing therapy services to children with CP. To be effective, therapists must recognize that their perceptions of the barriers families face when accessing therapy services may be different from perceptions of the families themselves. Therapists should consider alternative delivery models such as early morning, evening, and weekend appointments. Therapists should also consider offering services, even infrequently, in the child’s home or daycare setting as well as providing onsite sibling care in medical and community settings. Therapists also need to be aware of how families’ preferences and expectations are influenced by cultural differences and disparities in their knowledge about CP.

The researchers also found a substantial knowledge gap for families concerning the diagnosis of CP and the availability of appropriate services in the region. Based on what has been learned, it is apparent that ongoing educational and networking opportunities must be abundant and easily accessible, and they must provide relevant evidenced-based information to individuals with CP and their families. These individuals desire the opportunity to build their own knowledge base to empower themselves, rather than to be fully dependent on health care providers. This was particularly true for the families in the study who expressed concerns about the availability of services for their children after they became adults. Most of the families who participated in the study had children who were receiving services in a public school or early intervention system. Many families were concerned about what would happen when their children “aged out” of the current systems at the age of 21 which were providing therapy and other necessary services. Families ask numerous questions about the availability of health services, accessible housing, social and recreational opportunities for individuals with disabilities and public transportation. They are concerned with the availability of services available and how those services are funded.

The findings from this study will also be utilized to help occupational and physical therapists develop and implement alternative models of service delivery that provide greater access to therapy services. Therapists working with individuals with CP and movement disorders should be encouraged to pursue continuing education opportunities that focus specifically on evidence based therapy treatments and service provision.

This knowledge is essential; therapists can help or hinder a family’s successful journey within the therapy experience. Therapists should be active advocates within their professional organizations, with state and federal governments, and within their community to create awareness for the need for services and to improve existing services for children with CP. Therapists should also teach and empower parents and guardians to be advocates for their family members. By recognizing the barriers that families face in accessing therapy services for their children with CP, therapists can become partners in working to resolve some of these issues.

Most importantly the findings of this study were shared directly with community members in the south metro region, the health care community, early intervention providers to help inform policy makers, community planning and transportation initiatives.

4. Conclusion

Clearly inclusive community based research must continue. Funding for these initiatives is essential to develop the evidence that is needed for community based, culturally responsive, and accessible therapy services.

The three primary goals of Project Export were to build interdisciplinary research capacity and infrastructure at Governors State University which is located in the south metro region, improve the education of health
professional students in the areas of health disparities and cultural influences on health care, and to translate research findings into community intervention strategies to improve the health status of the region. This study examined the barriers that children and their family face in the south metro region of Chicago when accessing occupational therapy (OT) and physical therapy (PT) services from the perspectives of families and therapy providers.

This study supports all three goals of Project Export by building interdisciplinary research capacity through the collaboration of an occupational therapy and physical therapy researcher. The findings of the study have been utilized to enhance the learning of the occupational and physical therapy students regarding the importance of research to provide evidence for changes in therapy service provision systems, therapy treatments and importance of collaboration with families that create therapy goals that are cultural responsive and meet the family needs. Most importantly, the third goal is being accomplished by working directly with the community members in the region to provide the research so that it can be translated into information that can be used to improve existing services and create new services that are responsive to the needs of individuals with CP and their families.

References