

**CAREGIVERS' SATISFACTION WITH PHYSIOTHERAPY SERVICES AT A CEREBRAL
PALSY CLINIC IN KAMPALA, UGANDA**

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Abstract

Introduction: The evaluation of satisfaction with health care service provision is important when trying to provide quality care. Satisfaction with service provision has been found to be related to the expectations prior to receiving the service and the actual experience of the service.

Objectives: To explore the expectations and satisfaction that caregivers of children with cerebral palsy have when they attend physiotherapy services.

Methods: A qualitative study using two focus groups. A semi-structured interview guide was used to facilitate the focus group discussions. Data was collected and thematic analysis was undertaken

Participants: Nine caregivers, five mother, three grand mothers and one grandfather, participated in the focus group discussions.

Setting: A cerebral palsy clinic in Kampala, Uganda.

Intervention: No intervention but an interview schedule was used to obtain information.

Results: The caregivers were satisfied with seeing an improvement in the children's abilities, the outcome of the home programme and the assistive devices. Not all the caregivers were satisfied with the knowledge they had gained and the development of their skills. Caregivers were dissatisfied with regards to communication with the physiotherapists.

Conclusion: Physiotherapy plays an important role in the improvement of cerebral palsy children's physical abilities and knowledge given to caregivers but physiotherapists need to improve in their communication skills.

Key words: Caregivers, satisfaction, cerebral palsy, physiotherapy, Uganda

Introduction

The world of health care is changing from a time when the patient knew very little of what to expect and health care workers provided the care they thought suitable, regardless of the cost or the patient's expectations.

Rehabilitation services are recognised internationally as one of the key components of health care (WHO, 1995). However, in Uganda, it is estimated that only 2% of the over one million people with disabilities, utilise rehabilitation services (Ministry of Health, 2003a). To try to improve the utilisation of the rehabilitation services, it is important to determine people's satisfaction with the physiotherapy services.

Monitoring and evaluating quality of health services by assessing patient satisfaction is important (Pruitt, Varni, Seid & Setogichi, 1997). Measuring health care quality from a patient-based marketing perspective, gives the healthcare provider an insight into alternative methods of organising, providing or improving the health care (Fitzpatrick, 1991). Such insight cannot be obtained from administrative reports or by observing care directly (Ware, Synder, Wright & Davis, 1983). Marketing industries that have carried out satisfaction surveys, and implemented their recommendations, report that there is an improvement in the quality of service and increased compliance among their customers. The health care sector reports the same experience.

Though recognised as an extremely important concept, satisfaction is a difficult elusive construct to define or describe. Goldstein, Elliot and Guccione (2000) defined satisfaction as a patient's evaluation of a healthcare service based on the fulfilment of their expectations. Satisfaction in health care is

perceived as a multidimensional concept. A person may be satisfied with one or more aspects of health care and simultaneously dissatisfied with other aspects. Many theoretical concepts have been developed to explain factors that influence satisfaction including expectations, experience and service quality (Conway & Willcocks, 1997; Fiebelkorn, 1985; Woodside, Frey & Daly, 1989). While the results of some studies demonstrate an association between expectation and satisfaction, other studies suggest no relationship exist. Further research on this association is needed (Haas, 1999; Linder-Pelz & Struening, 1985; Staniszewska & Ahmed, 1999).

Health care expectations represent the patient's desires or needs in relation to what they want from the healthcare provider. These expectations constitute the attributes of satisfaction (Gabbot & Hogg, 1994). They can be subdivided into, firstly, functional or process attributes; secondly, technical or outcome attributes; and, thirdly, the structural attributes (Grontoos, 1982; King & Cathers 2001; Unwin & Sheppard, 1995). Parents of children under treatment find process and outcome attributes most important.

The process attributes ranked highest include interpersonal care-giving and communication. Parents look out for respectful and supportive care, including the feeling of being listened to and attaining rapport with the provider. In addition, reliability, reassurance, responsiveness and empathy are among the most important determinants when patients evaluate service quality to determine their satisfaction (Parasuraman, Zeithaml & Berry, 1988). An enabling partnership where the professional involves the parent as a team member in the ultimate decision-making and

accommodates family needs and wishes is important. Parents also consider the competence of the practitioner including both knowledge and skills (Calnan et al., 1994; King, & Cathers, 2001). The amount and the clarity of information supplied by the provider are important.

Outcome attributes that parents expect following physiotherapy treatment include gaining a better understanding of the child's condition and prognosis, and an increased understanding of the child's difficulty with movement. Parents expect to gain the ability to physically handle their child to develop and to be able to implement realistic home activities or programmes (Unwin & Sullivan, 2000). Finally, the parents expect the children to progress physically and cognitively.

The monitoring and evaluation of satisfaction of rehabilitation services is limited, despite widespread evaluation of satisfaction in other health services (Keith, 1998). In Uganda, administrative supervision reports are the major source of data on the service quality (MOH, 2003a). To date, there has not been an evaluation of patients' satisfaction with medical or rehabilitation services in the health institutions (MOH, 2003b). The purpose of the study was to determine the caregivers' initial expectations when they visited the physiotherapy cerebral palsy (CP) clinic at a Hospital, their experiences with the physiotherapy services they received and their satisfaction after receiving these services.

Method

A qualitative study, using two focus group discussions, was conducted to allow the caregivers to describe their expectations, experiences and satisfaction with the physiotherapy service.

Setting

The study was conducted in the Physiotherapy CP clinic at a Hospital in Kampala, Uganda, a national referral and training institute. The hospital has a weekly out patient paediatric neurology clinic, which has identified cerebral palsy as the most common condition that children present with at the clinic with over 37.5% of the children presenting with CP (Tumwine, 1995). The neurology clinic refers most of these children to the physiotherapy CP clinic within the hospital where they are seen by the physiotherapist. The physiotherapists rotate through the clinic every few months so most caregivers would have several physiotherapists treating their children.

Participants

On average, 48 children with CP attend the physiotherapy clinic each month. Parents, grandparents or other close relatives bring them. Purposive sampling was used to select twelve caregivers for the study, six for each of the two focus groups. The inclusion criterion was that the physiotherapist at the CP clinic had seen the child on at least three occasions. However, only nine caregivers arrived for the focus groups including five mothers, three grandmothers and one grandfather. Four of the children had attended the clinic for four years, two for one year and three for a few months. The caregivers came from different parts of the country and were from different educational and social backgrounds.

Interview guide

A semi-structured interview guide was used to determine: firstly, caregivers' expectations of the physiotherapy services; secondly, their experiences of these services; and, thirdly, the satisfaction that they attained. The questions covered the following

seven areas: (1) the caregiver's expectations; (2) the interaction and communication between the caregiver and the physiotherapist; (3) the caregiver's understanding of their child's problems; (4) the caregiver's management of their child; (5) the partnership between the caregivers and the physiotherapist in planning the home programme; (6) the barriers encountered by the caregivers; (7) and the caregiver's overall satisfaction.

Procedure

The two focus groups, conducted in Luganda, the local language, were facilitated by an experienced facilitator who was fluent in the language. The investigator observed, listened, wrote notes and recorded the proceedings. Each interview lasted approximately one and a half hours.

In order to ensure trustworthiness of the findings, the investigator and the facilitator met immediately after each focus group discussion to discuss the process. This purpose was to assess whether the interview guide was fully covered, identify any new issues that came up and to analyse the field notes to ensure accuracy of records. The investigator and the facilitator each translated and transcribed the recorded data and then met a week later to compare and discuss the transcripts to ensure that the transcribed data were an accurate record of what the participants had said.

Data analysis

The transcribed data were compared to the field notes to ensure that translation was accurate. The investigator continued the process of data transcription and categorisation. The data were coded and then grouped together into themes of expectations prior to treatment and experiences with physiotherapy services.

Ethics

Ethical consent was obtained, firstly, from the Senate Research and Study Grant Committee at the University of the Western Cape, South Africa where the principal researcher was a student. Secondly, consent was obtained from the Ethics Committee and the Director of the Hospital Complex in Kampala, Uganda. Finally, after explaining the purpose of the study, informed consent was obtained from the participants. Permission was obtained from each participant to tape-record the discussion. Participants were informed of their right to withdraw at any stage without prejudice.

Results

Expectations prior to treatment Caregivers spoke of their expectations for their children and from the physiotherapy services at the CP clinic

Normal motor and cognitive development

All of the caregivers expected their children to progress through all motor developmental stages.

"I wanted the therapist to work on my child so that she could be able to crawl, sit, stand and walk."

Caregivers had high expectations that their children would grow and develop like other children without disabilities.

"I expected my child to be able to carry out the normal things that other children can do."

Gaining knowledge

The caregivers expected the physiotherapist to explain what CP means and how long it would take for the child to improve.

"I wanted the therapist to explain to me what happened to my child, how long they expect me to

do exercises before the child becomes normal like other children."

Developing skills

Caregivers expected to learn how they could help their children. This included doing exercises so the child would then be able to participate in activities.

"I expected to be shown exercises that would strengthen my child's body so that he could be able to carry out some activities."

Effective treatment

Caregivers expected the treatment to be performed effectively, in a way that demonstrated respect for the child and the caregiver.

"I also expected to receive proper treatment from the clinic."

Experiences of physiotherapy service

Caregivers spoke of their experiences of physiotherapy.

Interpersonal relationship with physiotherapists

All the caregivers reported that the physiotherapists had good interpersonal skills. They described the physiotherapists as courteous, empathetic and compassionate to them and the children. Caregivers who were poor did not feel discriminated against.

*"They received us well, talked to us with great concern ... whether the child was clean or poorly cared for, or minding about the parent's status."
"They handled us well, and took good care of the children. There was no shouting at the parent or child."*

Physiotherapist's skills

Many caregivers were impressed with their physiotherapist's skills.

"I am impressed with the services that I received. The child was well handled."

However, three of the caregivers said that not all physiotherapists were equally skilled and three others felt the treatment was inadequate.

"Sometimes the therapist would want me to strap my child on to the standing frame. However, because of her stiffness and the many jerky movements, it was a real struggle to do so. The moment she cried the therapist removed her in less than ten minutes. Then I would lament on how much the therapist achieved."

Gaining knowledge

The caregivers said some physiotherapists gave clear explanations of the causes of CP and how the brain damage relates to the problems that they see and encounter with their children.

"The physiotherapist explained to me my child's problems. He told me that it does not take one day or week for the child with CP to improve, but it takes long...I learnt that it would take him long to improve."

In spite of trying, some physiotherapists were unable to explain clearly. Others did not explain why the child had a problem with movement, the purpose of the treatment, or how the child would benefit from the treatment. As a result, caregivers' knowledge differed and some were frustrated.

"The physiotherapist never told me why the child could not sit, crawl or even walk; she only told me to continue with exercises, yet I would very much have liked to know."

Caregivers found the abnormal patterns of movement difficult to understand.

"But those jerky movements... that is why I wanted the physiotherapist to tell me, when would those strange movements stop? What should I do to make sure that she does not jerk?"

Developing skills

The majority of the caregivers reported that the physiotherapists did most of the exercises with the children themselves while the caregivers only observed. The physiotherapists then asked them to repeat the same exercises at home. A few caregivers had more time with the physiotherapists. These caregivers said they received adequate teaching, were able to ask more questions and had some of their problems solved. They reported learning some skills.

"I am impressed. I was taught what to do and shown how to use sticks for standing and I tried that as well. I have already constructed parallel bars at home."

The majority of caregivers, however, complained that the physiotherapists had no time for teaching, demonstrations or allowing them to practice with the physiotherapists' guidance and supervision.

"The physiotherapist did not have enough time to teach us skills. We had to follow along what she was doing and made sure that we grasp what to do by watching her working ... She did not have the

time to get back to teach you or demonstrate to you."

Most of caregivers appreciated the home programmes and reported that the exercises and other ideas had contributed immensely to the improvement of the child's movements and activities.

"The home programme has helped my child a lot ... For a long time she could not sit and lay down most of the time ... then gradually I realised the neck was improving, she sat, crawled and she can now stand."

Most caregivers said that the advice that was given on improvised assistive devices was valuable.

"Feeding the child while seated on a chair has made the feeding much easier. The chair limits her from continuously moving the head from one side to the other. The hands stay in one place on the table and she eats well in that position."

Decision-making

The caregivers reported that they were not involved in deciding on the home programme jointly with the physiotherapist. The physiotherapist did not consult them about time they had to implement the programme.

"The physiotherapist at times would not bother to find out whether you had done the home exercises or not ... there was no discussion to follow up whether the home programme was implemented or how much was achieved ..."

Improvement in child's ability

All the caregivers reported some improvement in their children. The improvement included the child's

ability to perform functional activities including controlling their heads, holding objects, feeding themselves, sitting, crawling and walking with support.

"I have really noticed a lot of improvement. He used to sit stooping forwards but he now sits upright. He was pouring a lot of saliva but that has stopped. He cried for a whole year, but even that stopped. He could not stand on his own, but can now do so with some support. I really have strong hope that he will continue to improve."

However, caregivers were still aware of the gap in abilities between their children and children of a similar age.

"She has managed to do major activities ... The only activities remaining for her to learn are standing, walking and speaking ... Therefore, I have noticed a lot of improvement."

Caregivers were happy to see small changes that improved their relationship with their children.

"He turns around to look at any person calling him ... then he smiles. Originally he could not turn around at all ... he now appreciates what is done to him."

Waiting time

Although the physiotherapists always arrived to give the children their treatment, the caregivers were not happy about the long waiting time as they would become tired and hungry.

"The bad thing is that the therapist gives one the appointment to come as early as eight o'clock in the morning. And indeed you arrive that early and you

sit ... the clinic finally starts to operate by eleven o'clock."

Caregivers felt some of the therapists were concerned about the waiting time while others were not.

"I one time came and the therapist kept me waiting unattended for so long and yet the physiotherapist was inside doing her own things ... I felt bad because both the child and I became tired and hungry."

The caregivers complained that the physiotherapist always appeared to be in a hurry. However, they realised that this may have been because there was only one physiotherapist available to see all the children.

Discussion

Normalisation of the child

Most caregivers in this study expected to see their children grow and develop like other "normal" children without disabilities. However, abnormal patterns of movement are a characteristic of CP. Normal movement patterns cannot be achieved. Parental hopes for a normal child are common in any society. Since physiotherapy focuses on facilitating the child's ability to attain independence, it may contribute to the high expectations and unrealistic hopes among some parents. This is true especially where parents have not been well informed about the child's condition.

However, all the caregivers interviewed in this study reported some improvement in their children. Thus in a small way their expectation of improvement in the children's ability had been met and caregivers reported some satisfaction with the services related

to this improvement in their children. Rey, O'Brien & Walter (2002) also argue that parental satisfaction is associated with the outcome of the treatment. Clinical improvement and achievement of the goals of the intervention are important factors in achieving satisfaction.

Gaining knowledge

Caregivers expected the physiotherapist to provide them with a clear explanation about their children's condition including information about the diagnosis, the prognosis, the purpose of the treatment, how it would help the children, and what they needed to do. The caregivers, however, encountered inconsistency in the ability of the different physiotherapists to give a clear explanation. This could be attributed to an inadequate knowledge of CP and/or inadequate preparation for the explanation.

While professionals inevitably use technical language when communicating to their fellow workers, it is important to translate these terms into everyday language so that the clients are not confused in their understanding of facts and events. Effective communication requires an appropriate level, bearing in mind the differing social status and educational backgrounds of the caregivers. The physiotherapists need to make the information specific, and give it in small digestible doses that aid recall and understanding. Drawings or diagrams can be used to help in explaining complex techniques, skills or problems. Apart from aiding explanations, these audio-visual materials provide a concrete basis for conceptual thinking, create interest, develop continuity of thought and make learning more permanent.

Caregivers, who were well informed about the child's condition, were satisfied with the physiotherapists' explanations. They kept their expectations within the child's level of impairment and ability, felt comfortable with the child and were willing to participate in whatever would promote the child's improvement. The caregivers who received incomplete or had had no explanation were dissatisfied and remained frustrated about not understanding the child's problems.

Developing skills

Caregivers expected to be taught how to help their children perform activities. They came to the clinic expecting to be shown how to do exercises that would enable their children to recover or at least to improve. The caregivers liked the way the physiotherapists explained what they were doing as they treated the children. Most caregivers said that the home programmes and the assistive devices had helped the children. However, they were unhappy about the limited teaching they had been given on how to do the activities at home with the child.

This suggests a mixture of satisfaction and dissatisfaction with the development of skills. There was satisfaction with the explanation by the therapist; the way the home programme helped the children; and the assistive devices. However, there was dissatisfaction with the way they were taught the skills. A home programme is an essential part of most patient education. The teaching needs to include a demonstration of each exercise, followed by practice with guidance and feedback from the physiotherapist on how well the parent has performed. Depending on the complexity of the skill, the complete action can be broken down into logical segments, which the parent can practice in parts

(Klaber Moffett, 2002). Additionally, the caregivers found it difficult to implement the home programme because of work overload and insufficient time.

According to Sluijs, Van de Zee & Kok (1993), the physiotherapists who inform, instruct and advise their patients most frequently are those who follow a systematic plan of treatment, and have a good relationship with their patients. The achievement of such a service requires the physiotherapist to spend quality time with the patients. The caregivers at the Hospital complained that their physiotherapists were always in a hurry and there were too many children for one physiotherapist. As a result the physiotherapist spent too little time with each of them. Overworked practitioners are less likely to pay attention to their patients' demands, perceptions or follow a systematic approach to treatment. Besides, 'feeling rushed' has been found to influence parents' perception of the quality of the service provided (Bagwell, 1987). This might explain why some caregivers in Uganda were dissatisfied with the service when they did not develop the knowledge and skills that they had expected. However, although the physiotherapist had limited time or was overworked, the problem could also have been due to their failure to follow a systematic approach to treatment.

Respectful treatment

Caregivers expected the physiotherapist to demonstrate respect for them and their children. Effective communication between the patient and the physiotherapist has been ranked the most important of all expectations by Potter, Gordon & Hamer (2003). The physiotherapist did not ask many of the caregivers about their needs, listen to them, answer their questions or discuss much with them when working in a hurry. Few caregivers were

included in decision-making. They reported that apart from sharing ideas on how to improvise appliances at home, they were not involved in deciding on the home programme, or how often they could perform the exercises. The implementation of a home programme is one area in which the physiotherapist needed to involve the caregivers. Caregivers know their own commitments at home or at work and know best what they can do and what activities to modify to accommodate the home programme. Together, caregivers and physiotherapists could develop programmes based on realistic goals and appropriate activities with a grade of difficulty that the caregiver could implement within the daily tasks, thus avoiding the experience of failure to carry out the home programme, as was reported by most of the caregivers. This indicates that many caregivers were dissatisfied with the communication with the physiotherapist, particularly during the treatment process.

The children were seen once a month irrespective of whether the child was a new or an old patient at the clinic. The caregivers felt that they could gain more benefit from the services if the clinic opened for longer hours and the physiotherapist kept their time of appointments. The caregivers proposed that it would help to improve rapport and communication if there was a permanent physiotherapist at the clinic. Sluijs, et al., (1993) argue that few physiotherapists ask patients to talk about their perceptions, feelings and expectations. They spend most of the consultation time exploring the nature of the illness or injury, deciding on the treatment plan and providing home exercises. Physiotherapists at Mulago Hospital CP clinic need to take time to identify the caregivers' expectations prior to embarking on treatment, if they are to meet the caregivers' expectations satisfactorily. The simplest

method would be to ask the caregivers directly about their expectations during the initial consultation and to determine emerging expectations in subsequent sessions.

Caregivers value spending time with their physiotherapist. Klaber Moffett & Richardson (1997) state that empowerment is recognised as an important component of health care that can be achieved through good communication and provision of appropriate information, given regularly over time. It is also the physiotherapist's responsibility to provide the caregivers with information that will promote active parent involvement, understanding and self-efficacy. However, it appears that the physiotherapists at the CP clinic disregarded or were not aware of these aspects of communication or how much the caregivers expected to learn from them.

Waiting time

Caregivers indicated that the physiotherapist was reliable and had even worked through lunchtime in order to ensure that all the children were treated. However, caregivers were dissatisfied with the waiting time to keep appointments, with the physiotherapists failing to keep to the times for the appointments and opening the clinic late. Long waiting times are known to negatively affect patient satisfaction (El Shabrawy & Mahmoud, 1993) and may be one reason why some caregivers have stopped attending the physiotherapy CP clinic at Mulago Hospital.

Conclusion

The study investigated the caregivers' satisfaction with the physiotherapy service for children with CP at a CP clinic in Kampala. The expectations prior to treatment and the experience of physiotherapy

services were described to identify how they influenced satisfaction. Areas that needed improvement included information from therapists, education of caregivers as well as identifying caregivers' needs. Thus identifying expectations and experiences of physiotherapy services does appear to be a useful tool for evaluating satisfaction.

Implications for practice

Continuing professional education for the physiotherapists through short courses or workshops to build knowledge and skills is needed in order to improve the quality of service. This is likely to increase caregiver satisfaction.

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