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Abstract

Background: Assessing the quality of care has become increasingly important to health care providers, regulators and purchasers of care.

Aims: This study assessed the quality of care provided to children with cerebral palsy attending Alexandria University Children's Hospital, Egypt.

Methods: Paediatric neurology residents (n = 15) who provided care to children with cerebral palsy at the hospital completed a structured checklist assessing their compliance with generic care standards. The medical records of 84 children with cerebral palsy who received care at the hospital were reviewed using the same checklist. Another checklist was completed by the head of the paediatric neurology unit, medical director of the hospital, head of physical medicine and head nurse to assess adherence to process and service improvement standards. Face-to-face interviews were conducted with the caregivers/parents of the children using a client satisfaction questionnaire.

Results: Based on what was reported by health care providers, most did not adhere to the recommended practices in the care of children with cerebral palsy. Review of the medical records also showed a lack of compliance with standards. The mean total satisfaction percentage score of parents/caregivers was 55.43% (SD 18.16). Satisfaction was particularly low for waiting time, waiting area and availability of required facilities for their child's care.

Conclusions: There is a wide gap between the actual care provided to children with cerebral palsy and the recommended standards. Moreover, the documentation system in the hospital is poor. A quality improvement plan is needed for the provision of care to children with cerebral palsy.

Keywords: Cerebral palsy, Child care, Standard of care, Hospitals, Egypt

Citation: Khalil M; Elweshahy H; Abdelghani H; Omar T; Ahmed S. Quality of care provided to children with cerebral palsy, Alexandria, Egypt. East Mediterr Health J. 2018;24(6):522–531. https://doi.org/10.26719/2018.24.6.522

Received: 03/11/16; accepted: 30/03/17

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Introduction

Cerebral palsy is the most common cause of motor disability in childhood (1,2). It accounts for 60% of severe motor disabilities in school-aged children (3). The prevalence of cerebral palsy is around 1.5–3 per 1 000 live births in both developed and developing countries (4–6). Differences in prevalence may be due to differences in the characteristics of the populations studied or may also be the result of variations in identifying cerebral palsy cases because of inconsistency in the definition and classification of the condition. A study in Egypt reported a prevalence of 2.04 per 1 000 live births among children in Al-Karga District, New Valley Governorate (7). Another study in Al-Quseir City, Red Sea Governorate reported a prevalence in children of 3.06 per 1 000 live births (8).

Assessment of children with cerebral palsy is best performed by a multidisciplinary team. Management aims at minimizing disability, improving quality of life and encouraging

participation in society (9).

The demands of caring for a child with cerebral palsy are considerable, and parents have to deal with the continuously changing needs of their child. Disabilities associated with cerebral palsy affect children's independence and hence the lives of their caregivers. Caring for a child with cerebral palsy can negatively affect parent's physical and psychological health, social relationships, and financial situation. However, the quality and type of care given to children with cerebral palsy are likely to affect the resultant disability, and the quality of their lives and that of their families (10,11).

Measuring the quality of care has become increasingly important to health care providers, administrators, managers and policy-makers. Data from assessment of quality of care should be applied to improve the delivery of care and patient outcome (12,13). Explicit methods of measuring quality of care should be based on reliable, valid and standardized tools. Quality measures are usually categorized into structure, process and outcome measures. Structure and process measures are based mainly on the availability of standards of care and/or quality indicators (13).

The present study was conducted to assess the quality of care provided to children with cerebral palsy attending the Alexandria University Children's Hospital, Egypt.

Methods

Study design and setting

This was a cross-sectional study conducted at Alexandria University Children's Hospital, Egypt within its affiliated Paediatric Neurology Outpatient Clinic and Physical Medicine and Rehabilitation Clinic. The hospital provides care for children with cerebral palsy, including management of acute conditions, inpatient services, rehabilitation and follow-up care. The field work was carried out between 1 February and 30 April 2014.

Participants

The study included the following participants.

Fifteen paediatric neurology residents working at Alexandria University Children's Hospital for more than 1 year and directly involved in the care of children with cerebral palsy.

The Head of the Paediatric Neurology Unit, Medical Director of the Hospital, Head of Physical Medicine and Head Nurse of the Paediatric Neurology Department at Alexandria University Children's Hospital.

Parents/caregivers of all children with cerebral palsy attending Alexandria University Children's Hospital during the period 1 February to 30 April 2014 (88 children).

Data collection

Health Care Improvement Scotland developed standards for care of children and young people who are experiencing difficulties that could be related to their mental health, known as integrated care pathways (ICPs) for mental health (14). The standards have 3 elements: process standards, generic care standards and service improvement standards (21 standards).

Process standards (9 standards) outline the infrastructure that must be in place in order to provide high quality care, the key tasks to be undertaken and who is responsible. Generic care standards (10 standards) describe the interactions and interventions that must be offered to anyone who accesses specialized child and adolescent mental health services. Service improvement standards (2 standards) ensure that ICPs are being implemented and actively used for data capture and variance analysis, leading to service improvements. Each standard includes a number of criteria to be fulfilled (14).

We developed a structured checklist of statements included in the process and service improvement standards in the ICPs that were relevant to the service provided to children with cerebral palsy in Egypt and best fit the culture, resources, and economic and administrative situation in Egypt. The checklist consisted of 19 statements with 3 possible answers (not met, partially met or fully met). It was completed by the Head of Paediatric Neurology Unit, Medical Director of the Hospital, Head of Physical Medicine and the Head Nurse of the Paediatric Neurology Department to assess the degree of adherence to process and service improvement standards.

A second checklist was designed based on the criteria of generic care standards in the ICPs. It included 33 statements divided into 4 domains, which related to standards of: care assessment (16 items), care planning (8 items), care delivery (5 items) and outcome (4 items). Each statement had 2 options, usually done or rarely done. This checklist was completed by the 15

paediatric neurology residents; none declined to participate.

The medical records of all children with cerebral palsy who regularly attended the paediatric neurology outpatient clinic (n = 84) were reviewed to assess their completeness according to the generic care standard using the same checklist filled by the paediatric neurology residents. Each item was marked as recorded or not recorded in the medical records.

Face-to-face interviews were held with the parents/caregivers of 88 children with cerebral palsy (the 84 whose records were reviewed and 4 other children who had no medical records at the clinic as they had just started coming to the clinic). None declined to participate. Education, marital status and working status of the caregivers were recorded. They were asked a general question about their overall satisfaction with the services provided at the hospital for their children. In addition, a structured client satisfaction questionnaire, consisting of 8 items, was used to assess their degree of satisfaction with specific aspects of the services: waiting time, waiting area, availability of facilities, number of days the services are available, cost of services, time allowed to discuss problems with care providers and the adequacy of the explanation received.

Data analysis

Data were coded and entered in Microsoft Excel. Descriptive statistical were mainly used. Numbers and percentages were used for conformity with generic care standards as reported by the residents and as documented in the medical records reviewed.

Range, mean and standard deviation (SD) for the total score for conformity to generic care standards was calculated twice – as reported by the residents and as documented in the medical records reviewed. Items that were not done or not recorded were scored zero and those that were always done or recorded were scored 1.

Parents' satisfaction was analysed using number and percentage as well as by calculating the total raw and percentage score for every parent (by giving a score of 0 for unsatisfied, 1 for uncertain and 2 for satisfied), and then calculating the mean satisfaction percentage score. The question about their overall satisfaction with the services provided at the hospital for their children was not included in the calculation of the total satisfaction score. Analysis of variance and Student t-test were used to examine the relationship between the mean satisfaction percentage score and caregiver characteristics, after testing for normality (Shapiro–Wilk test) and homogeneity of variances. A P-value ≤ 5 was considered statistically significant.

Ethical considerations

Approval for this study was obtained from the Research Ethics Committee of the Alexandria Faculty of Medicine. Verbal and written consent was obtained from all participants in the study after explaining the aim and procedures of the study. Complete confidentiality was ensured: the data were collected only by the researchers and no one else had access to them.

Results

Conformity to process and service improvement standards

Table 1 shows the conformity to process and service improvement standards as rated by the Head of the Paediatric Neurology Unit, Medical Director of the Hospital, Head of Physical Medicine and the Head Nurse in the neurology department. The majority of process and service improvement standards were not fully met (either totally unmet or only partially met) except for 3 standards: presence of a local plan with details of how the organization will deliver care for the children with cerebral palsy who are accessing services for the first time or who are currently accessing services; availability of a secure system that allows the recording of and access to information in the child's care record; and demonstrated relationship between local governance arrangements and ICP for children with cerebral palsy in hospital.

Standards that were totally unmet at the hospital included: lack of a system to monitor care providers of children with cerebral palsy and demonstrate that their training and supervision needs are acted upon and actively promoted; lack of an annual survey of children with cerebral palsy and their parents/carers about care they have received.

Conformity to generic care standards as reported by health care providers

Table 2 shows the reported adherence to the generic care standards of the 15 health care providers (residents) who were directly involved in the care of children with cerebral palsy at Alexandria University Children's Hospital.

Care assessment standards. During the initial assessment, developmental history is taken by most of the providers (80%), and 73% take a history of past and current interventions. Two thirds of the care providers reported that they usually assess the child for the presence of other associated co-morbidities. A schedule of routine visits for the child was reported by 73% of the providers. The majority of the providers reported that information on how the diagnosis of

cerebral palsy was reached was not recorded and there was no cooperation with other agencies in the process of care. Only 33% of the care providers said they explained the diagnosis of cerebral palsy to the parents and none of them provided educational, social and lifestyle information and guidance to the parents.

Care planning standards. Two thirds of the providers reported that they recorded the timing of the child's reviews and 53% of them reported that the child's care plan was planned and agreed with parents/caregivers. Only 33% reported that the child care plan was based on multidisciplinary assessment, and its specific goals were identified. None of the providers recorded the child's care plan or his/her treatments and interventions in the child health record.

Care delivery standards. Regarding care delivery, particularly for children admitted as inpatients, 33% documented the reasons for admission in the child's follow-up record and 13% recorded the aim of the admission. Only 7% of the health care providers recorded the plan for discharge and length of inpatient stay.

Care outcome standards. Less than a half of the providers (47%) said they identified and recorded what had improved or what had got worse in the child's condition, and what aspects of the plan had been changed. All the care providers rarely recorded whether the planned outcomes were achieved or not.

Conformity to generic care standards as found in health care records

Our review of the health care records of 84 children with cerebral palsy to assess their conformity to the generic care standards are shown in Table 2 .

Care assessment standards. In nearly all records, the diagnosis of cerebral palsy was documented. The majority of records (87%) included data on associated co-morbidities, and the developmental history of the child was noted in 63% of the records. On the other hand information on how the diagnosis of cerebral palsy was reached and the current and past interventions were documented in only 21% and 19% of the records respectively. Information given to the parents about cerebral palsy, and guidance and advice to them were noted in 20% of the records. The records do not include any system to record parents' disagreement with the child's care plan. No consent form signed by parents for the care and treatment was present.

Care planning standards. The timing of reviews was clear in only 44% of the records, while the specific goals of the care were identified in 98% of records. The child's care plan was documented in 59% of records.

Care delivery standards. The decision-making process, including when to start, review, maintain or end medications, and their side-effects were noted in 2% of the records. Few records contained data about the reasons and aims of inpatient admission (2%) and none had information about the actual length of stay. The plan for discharge was identified in 34% of the records.

Outcome standards. Only 20% of the records contained information about whether the planned outcome have been achieved or not. In addition, 33% and 1%of the records respectively documented what had improved and what had become worse in the child's conditions. The aspects of the child care that had been changed were identified in only 7%of the records.

Conformity scores

Table 3 shows the scores for conformity to the standards in the 4 care areas as reported by the health care providers and found in our review of the children's health records.

As reported by the health care providers, scores for care assessment standards ranged from 2 to 10 with a mean of 6.53 (SD 2.95). For care planning standards, out of 8 points, the mean score was 2.0 (SD 1.36). Scores ranged from 0 to 3 in both care delivery and outcome standards with a mean of 1.27 (SD 0.88) and 1.40 (SD 1.35) respectively.

Based on the review of the children's records, scores for care assessment standards ranged from 2 to 10 with a mean of 4.71 (SD 2.13). For care planning standards, the mean score was 2.52 (SD 1.61). Scores ranged from 0 to 3 for both care delivery and outcome standards with means of 0.45 (SD 0.59) and 0.89 (SD 1.13) respectively.

Satisfaction of parents/caregivers with the care provided

All interviewed caregivers were mothers. Table 4 shows the satisfaction of the mothers with the care provided. Only 37% said they were satisfied with the services provided at the hospital for their children; 2% were unsatisfied and 61% were uncertain. Satisfaction was particularly low for waiting time, waiting area and availability of required facilities for their child's care. About two

thirds of the mothers (64%) were satisfied with the cost of services. Only 28% were satisfied with the amount of explanation received about their child. The total satisfaction percentage score ranged from 0 to 94% with a mean of 55.4% (SD 18.2%) and a median of 55.7%.

Table 5 shows the mean satisfaction percentage score of the mothers in relation to their sociodemographic characteristics (education, marital status and working status). No statistically significant associations between the score and sociodemographic characteristic were found.

Discussion

Children with developmental disabilities are likely to experience unmet service needs, which will affect them and their families (15,16). Integrated care plans across all agencies involved in caring for children with cerebral palsy are essential in providing high quality care. A plan should contain general principles of care agreed by all members in the decision-making team and adapted to fit the local context taking into consideration differences in culture, educational levels of parents/caregivers, availability of trained health care providers and local resources (17).

In our study, from the perspective of head managers in the hospital involved in the care of children with cerebral palsy, the hospital lacked a named strategic lead and a coordinator for implementing a multiagency and multidisciplinary plan. Moreover, a lack of multiagency and multidisciplinary work forces involved in the care pathway development process was also reported.

At the centre of the decision-making team are the parents of the child with cerebral palsy and the child/young person him/herself. No decision about any aspect of care should be made without full involvement of the child/young person and their family in the decision-making process (18). In our study, the respondents reported that children with cerebral palsy and their parents/carer were not involved in the care pathway development process. Moreover, no surveys were conducted of the children and their family members to assess their satisfaction with the care they received and identify their expectations and their concerns.

Based on the skills and competencies required to meet the operational objectives of managing a child with a chronic disability, periodic assessment of training needs of health care providers should be conducted. The training plan should be based on the gap between the current capabilities of the health workers and the required capabilities to achieve the objectives of care (19). Among the standards reported as totally or partially unmet at the hospital was the lack of a system to monitor the training and supervision needs of care providers for children with cerebral

palsy and demonstrate that they are acted upon and actively promoted. In addition, there is no system to ensure that these training and supervision needs and requirements are incorporated into the hospital development plans.

A report by the care quality commission in the United Kingdom in 2012 described the experiences of stakeholders and administrative staff about how services are provided to children with disabilities and their families (20). They reported generally negative experiences, particularly concerning coordination of services, their involvement in decisions and in the delivery of care, and the general quality of care provided. Moreover, they considered that health care action plans were inconsistent, so people using services had different experiences depending on the service they got.

High standards for documentation and management of health care records are consistent with current best practice requirements in any health care organization. A system should be in place to audit health care records and report results. Facility/service managers are responsible for ensuring that requirements of this policy are disseminated and implemented in their hospital, department or service. Moreover they must ensure that health care personnel within their facility or service have timely access to paper-based and electronic health care records. The health care record is a documented account of a patient/client's: history of illness; health care plan/s; health investigations and evaluations; diagnosis; care; treatment; progress; and health outcome for each health service intervention or interaction. It serves as a basis for planning care and for communicating patients' conditions and treatments with other health care providers (21).

The senior managers in our study reported that, although there is a secure system that allows information to be recorded in and accessed from the child's care record, the system lacks child diagnostic and assessment information that allows any changes to be detected. Moreover, our review of the child health records showed that most items on our checklist were not recorded, including medical and developmental histories, how the diagnosis was reached, structured care plan, medication decisions, specific goals of care, admission information and outcome measures. This finding is in contrast to the results of a study in California (22) that reviewed the service system delivered to children and young people with special needs and reported the health records were considered adequate. Nevertheless, they recommended that all families be able to receive a copy of the health record of their children whenever needed.

One of the basic measures of quality improvement in health care is to monitor the process of care and identify any deviation from the recommended care. Reasons for deviations should be specified and discussed, action taken and recorded, and the outcome documented and fed back to front-line staff (14). In our hospital, weakness in the documentation system, lack of

record-keeping standards, and the absence of systems for recording, collating, analysing, reporting and acting upon changes are major barriers to quality improvement in the care of the children with cerebral palsy.

The responses of the 15 health care providers directly involved in the care of children with cerebral palsy showed that the standard of care was poor as indicated by the small number of providers who reported adherence to the recommended generic care standards of care. Specific areas that showed poor adherence were: recording a structured care plan; including the family in the decision-making process; giving enough information to the family about the diagnosis, plan of care and the anticipated outcome; and recording details of admissions to the hospital and the outcome of child care.

Parental involvement in the process of child rehabilitation is very important for both parents and professionals, and raises the level of parental satisfaction with the delivered care (23). Two community-based studies of family-centred services in Australia used the Measure of Processes of Care for Service Providers to assess the perceptions of parents/carers of the services provided (24,25). The families rated “respectful and supportive care” highest and “providing general information” lowest.

Another study in Finland, which assessed the child health care from the perspective of both health care providers and users, indicated that providing written information about the child’s condition, therapies and progression, and information about family group supports and community voluntary organizations that offer services were rated by both families and service providers as being poorly delivered (26). In a study in Switzerland, parents reported the overall level of care as fair to moderate but provision of information was the lowest rated area (27).

Parent/caregiver satisfaction with the care provided to their children is one of the outcome measures commonly used to assess the quality of health care (28). In our study, the mothers’ satisfaction was very low for the waiting time and waiting areas as well as the availability of required facilities for their child’s care. Moreover, they were dissatisfied with the amount of explanation they received about their child. The fact that there was no significant association between the mothers’ characteristics and their satisfaction with the care provided indicates a sub-optimal level of care from the perspective of all caregivers regardless of their background. In a study in Iceland, parents reported the overall therapy services as respectful, supportive and coordinated (29). Nevertheless, they felt that the information they received from professionals was insufficient. Similarly, a study in the Netherlands reported that parents of children with cerebral palsy did not feel adequately informed, especially about services for their children and family (30).

Similar to our study, 2 studies conducted in public hospitals and outpatient health care services reported low levels of patient satisfaction with care received with regard to attitudes towards professionals, quality of the surrounding atmosphere (including waiting areas), waiting time before being seen by a professional and quality of administrative services (31). They compared these services with those provided by the private sector and found better patient satisfaction in the private sector. They attributed this to the lower burden on professionals in the private sector, the availability of more facilities and more organized administrative services.

Conclusions

Our study shows that there is a wide gap between the actual provision of care for children with cerebral palsy and the recommended standards for the process of care of such children. Most mothers were not satisfied with several aspects of care provided to their children. Moreover, the documentation system in the hospital is poor.

A quality improvement plan is needed for care provision of children with cerebral palsy and their families, which includes continuous monitoring to identify variations in care and their causes, and to take action to address any problems. Periodic assessment of training needs of health care providers is important and the findings should be acted upon. Furthermore, a specific documentation system is urgently needed as part of the care pathways for children with cerebral palsy.

The family is the primary support for their child; it is therefore very important for health care providers to work in collaboration with families and to find ways to increase their participation in the care and rehabilitation plan of their child. As effective communication and information is key to quality standards for health and social care, strategies are needed to allow professionals enough time to listen carefully to the families' needs and to respond to their enquiries.

Acknowledgements

We thank Sara Fekry Maklad for her help in the collection of data from the children and their families.

Funding: None.

Competing interests: None declared.

Qualité des soins apportés aux enfants atteints de paralysie cérébrale, Alexandrie (Égypte)

Résumé

Contexte : Évaluer la qualité des soins est devenu de plus en plus important pour les prestataires de soins de santé, les autorités de réglementation et les acheteurs de soins.

Objectifs : La présente étude a évalué la qualité des soins fournis aux enfants atteints de paralysie cérébrale pris en charge à l'hôpital universitaire pour enfants d'Alexandrie (Égypte).

Méthodes : Le personnel médical résident du département de neuropédiatrie (n = 15) responsable de la prise en charge des enfants atteints de paralysie cérébrale a rempli une liste de contrôle structurée visant à mesurer leur observance des normes de soins génériques. Les dossiers médicaux de 84 enfants atteints de paralysie cérébrale traités dans cet hôpital ont été examinés à l'aide de la même liste de contrôle. Une autre liste de contrôle a été remplie par le responsable de l'unité de neuropédiatrie, par le directeur médical de l'hôpital, par le responsable de la médecine physique et l'infirmière en chef afin d'évaluer l'observance des procédures et des normes d'amélioration des services. Des entretiens en face-à-face ont été conduits avec les soignants et les parents des enfants à l'aide d'un questionnaire de satisfaction clients.

Résultats : Sur la base de ce qui a été rapporté par les prestataires de soins de santé, la plupart ne se conformaient pas aux pratiques recommandées pour les soins apportés aux enfants atteints de paralysie cérébrale. L'examen des dossiers médicaux a également démontré le non-respect des normes. Le score de satisfaction total moyen des parents/soignants était de 55,43 % (ET 18,16). La satisfaction était particulièrement basse eu égard au temps d'attente, aux salles d'attente et à la disponibilité d'établissements compétents pour la prise en charge de leurs enfants.

Conclusions : Il existe un écart important entre les soins fournis actuellement aux enfants atteints de paralysie cérébrale et les normes recommandées. De plus, le système de documentation de l'hôpital n'est pas performant. Un plan d'amélioration de la qualité est requis

pour la prestation de soins apportés aux enfants atteints de paralysie cérébrale.

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