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Care for Children with Special Health Care Needs in a Managed Care System: A Patient Satisfaction Survey

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In 1994 the government of Puerto Rico adopted a capitated managed health care system for the medically indigent. The new law has been implemented in most municipalities. A survey of children with special health care needs treated at a tertiary pediatric center under the capitated managed care system and the prior non-capitated system was analyzed using the Consumer Assessments of Health Plan Survey (CHAPS) instrument. One third of the patients who were under the new capitated managed care system were not satisfied with the medial care they were receiving. The parents of children with multidisciplinary conditions found it much more difficult to access care at the tertiary center. It took parents two years to learn to navigate within the capitated managed care system. Studies to measure outcome and health quality of children with special health care needs in capitated managed health care programs must be developed to learn how the potential benefits of managed care can be maximized and the potential harms minimized. The purpose of this study was to analyze the accessibility and satisfaction of caretakers of children with special health care needs under a capitated managed health care system

Key words: Children, Special health care needs, Managed care system

Managed care has initiated the movement of a stationary pendulum with regards to the practice of medicine. This change has taken place rapidly with little attention to the impact on access of health care services and the quality of services rendered in the pediatric population. How children do in this new system, particularly special needs children, is highly speculative. The small amount of published information on the subject of the pediatric population confirms that the children in these arrangements are less likely to be seen by a specialist, and that families and providers are less satisfied under managed care (1).

Children with special health care needs present a great challenge for the managed care model and differ from adults in a managed care environment. Current managed care programs have been predominantly focused on adults not children, even less focused for children with special needs (2). The medical needs of these children are unique in a number of ways. One is the changing dynamics of child development that affects the needs of these children at different developmental stages and alters their expected outcomes (3). Children grow and develop at a fast pace, which increases their risk of being affected intensely by illness and injury. This can be even greater for children with special needs. If the health problems are not identified quickly and efficiently they can affect a child's cognitive, physical, behavioral, and/or emotional development (2). Furthermore, the prevalence and low incidence of childhood disabilities, many rare and uncommon, differ widely from that of adults with disabilities. In adults there are few rare conditions and several common ones (3). Also, the health and development of children with disabilities depend entirely on their families' health and socioeconomic status. Consequently, this subset of the pediatric population faces a great challenge with the growth of managed care in accessing all the necessary services.

In February 1994, the island of Puerto Rico adopted a new managed health care program (Puerto Rico Health

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Care Reform) for the indigent population. Its primary goals were to implement and promote a single health care system that is accessible to the people of Puerto Rico, provide health insurance for the medically indigent and to transfer funding for the medically indigent from the government run hospitals and clinics to contracted private insurers (4). In the new system, private insurers provide a wide range of services on a capitated payment plan through a referral system under a managed care model assuming the financial risk. The services provided at a pre-established cost per beneficiary include specified screening tests, maternal child services, medications, mental health services, dentists, specialist with required referral from a primary care physician, emergency care, and hospitalization (4). The island is divided into 78 municipalities, roughly equivalent to state counties, each with a different private health insurance provider. Currently, some of the bigger municipalities of the Island are in the process of reforming (Figure 1). The implementation of the health care reform responds, among other situations, to the continuously increasing cost of medical technology and the budgetary insufficiency of the central government.

Managed care attempts to provide quality health services while constraining costs. Achieving these goals for children with chronic illness and disabilities requires special attention to important issues. According to the American Academy Of Pediatrics Committee on Children With Disabilities, "studies indicate that 6% to 35% (depending on what is included among the disabling conditions) of children have disabilities and need special health care services. It is estimated that the 5% of children with special health care needs account for slightly more than 35% of the health care costs of all children and adolescents" (3). Strategies for cost containment are difficult when dealing with sub-specialized and inpatient care, often at tertiary facilities, as well as ongoing complex out-patient management, community-based services, and medical supplies (3). Children with special health care needs encounter a difficult challenge with the growth of managed care due to the Puerto Rico Health Care Reform, particularly in accessing the services they require.

Prior to 1994 and the start of the health reform, Medicaid was organized as a preferred provider organization (PPO) that covered the indigent children with special health care needs. These children were referred to secondary and tertiary pediatric centers where they were cared for by pediatricians and pediatric subspecialists.

Pediatric Center for Habilitation Services of the University Pediatric Hospital

The children at the Pediatric Center for Habilitation Services of the Pediatric Hospital of the University of Puerto Rico School of Medicine encompass a wide variety of diagnoses, many of which require specialized medical services. The admission to the Center is based on diagnosis and patients range from premature newborns to young adults (21 years of age). A sample of conditions treated at the Center is listed in Table 1. As defined by

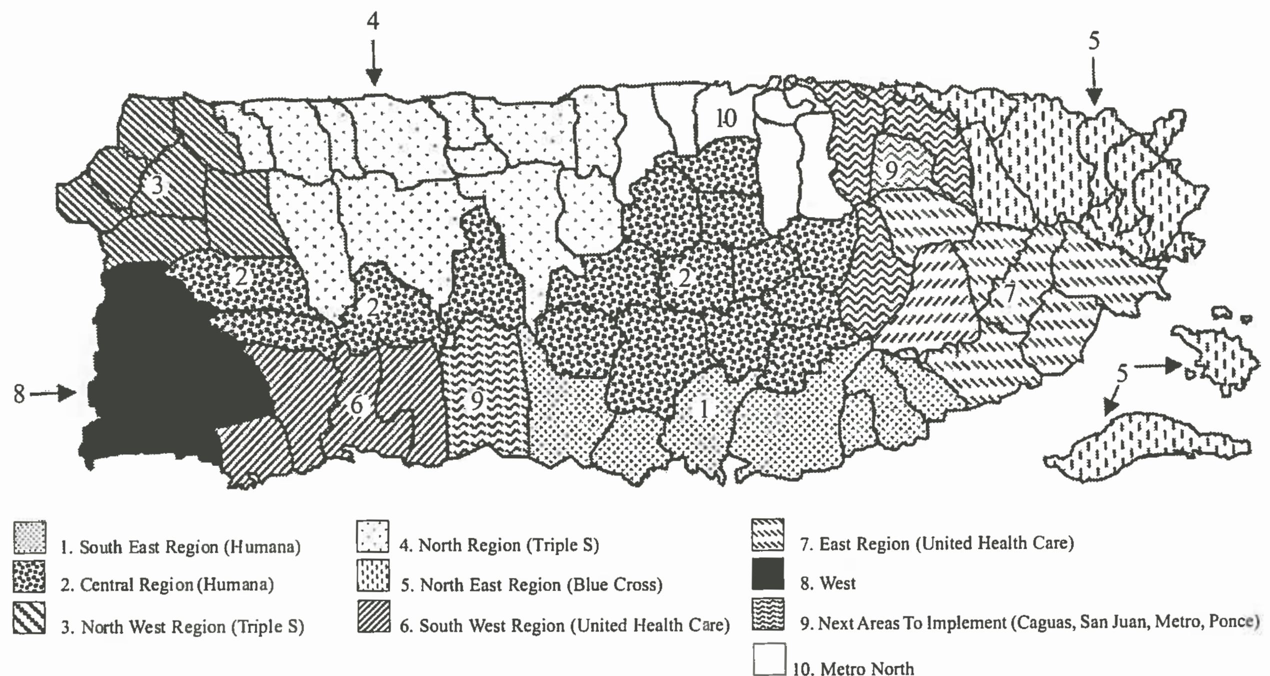

Figure 1. Map of Region and Insurance Providers Under the Puerto Rico Health Reform

Table 1. Conditions Treated at the Pediatric Center for Habilitation Services of the Pediatric Hospital of Puerto Rico.

1. Myelodysplasia
2. Hydrocephalus
3. Craniosynostosis
4. Cerebral palsy
5. Degenerative CNS conditions
6. Hydrocephalus
7. Neurological post-surgical or traumatic sequelae
8. Cataracts
9. Palpebral ptosis
10. Enucleation
11. Refraction problems 20/100
12. Congenital torticollis
13. Scoliosis
14. Legg-Calvé-Perthes disease
15. Arthogryposis
16. Talipes equino varus
17. Cleft lip/palate
18. Metabolic diseases
19. Pierre Robin, Crouzon syndrome and others

Gruskin, the term children with special health care needs "describes a unique group of children who require ongoing medical input to maintain their health status because they have chronic health conditions, are technologically dependent, and experience functional limitations in their age-appropriate normal daily lifestyle" (5).

The Center is coordinated through a pediatrician who evaluates the child and decides if the condition requires the services provided by a specialist of the Center. The specialists providing services at the Center include: neurosurgeons, neurologists, ophthalmologists, orthopaedic surgeons, general surgeons, pediatricians, plastic surgeons, physiatrists, and geneticists. In addition, all pediatric ancillary services are available.

Materials and Methods

The Orthopaedic Department of the University of Puerto Rico, School of Medicine, and with assistance from the Department of Biostatistics and Epidemiology of the University of Puerto Rico, Medical Sciences Campus, Graduate School of Public Health, developed a survey that collected data about the present satisfaction of the parents of patients evaluated at the Pediatric Center for Habilitation Services, with their respective health insurance plan. Besides that, the survey would obtain information of the accessibility of medical services for their children at the Center.

Since the Center has been facing many new challenges with the implementation of the health reform in Puerto Rico, the objectives of the survey were the following: (1.) to obtain sociodemographical data, (2.) to determine the degree of difficulty encountered by the patients and families in receiving specialized medical services through the referral system implemented by the health reform, (3.) to compare the satisfaction of the patients who are participating in the health reform to those who are participants of non-managed care programs such as Medicaid or private preferred provider organization programs, and (4.) to measure the perceived satisfaction of the parent or guardian with the primary health care providers, specialist, and ancillary services.

The instrument used for the survey was from the Consumer Assessments of Health Plan Survey (CAHPS) which is a collaborative effort between the Agency for Health Care Policy Research (AHCPR), Harvard Medical School, RAND, Research Triangle Institute, and Westat obtained through Penn State University (6). This instrument was adjusted to the population studied to meet the objectives of the project. The variables measured were general information of the patients and care takers, information about the patients current health plan, general information about the patients primary physicians and specialists, and health maintenance provided in the Pediatric Center for Habilitation services over the past year. The population consisted of commonwealth Puerto Ricans using health plans under an implemented health reform by the central government based on a capitated managed care system, Medicaid, and private preferred provider organizations.

From March 8, 1999 through March 26, 1999 a sample of 449 parents, guardians, or relatives of the patients seen at the Pediatric Center for Habilitation of the University Pediatric Hospital of Puerto Rico completed a self-administered questionnaire on a voluntary basis. Seventeen patients who missed appointments during the aforementioned period received the questionnaire by mail in a pre-addressed, stamped envelope with the same instructions given to those interviewed at the Center. Patients were categorized either with multi-disciplinary conditions (e.g., myelodysplasia, cerebral palsy, and hydrocephalus) or single discipline conditions (e.g., strabismus and scoliosis). The total sample consisted of 466 answered questionnaires of patients with appointments to the Center from March 8, 1999 through March 26, 1999. Informed consent was given for each questionnaire. EPI-Info. 6.04 version and SAS System for Windows v.6.12 statistical programs were used for analysis.

Results

Four hundred fourteen persons (89%) answering the questionnaire were the parents of the patient seen at the Center (n=466). Of the remaining respondents (11%) were the grandparents, uncles or aunts, brothers or sisters, or legal guardians. The age of the care-takers fluctuated between 25 and 34 years (34%), followed by 35-44 years of age (30%), and 15-24 years of age (23%). Ninety-seven percent of the participants were females and 3% males. The sample consisted of people from all regions of the island of Puerto Rico, including 49% from the metropolitan area of San Juan, 26% from the north, northwest, and northeastern part, 13% from the central part, 4% from the southeast and southwest part, 6% from the eastern part, and 2% from the western part of the island. Diagnosis most commonly found were strabismus (23%), followed by myelodysplasia (20%), and hydrocephalus (15%) (Figure 2).

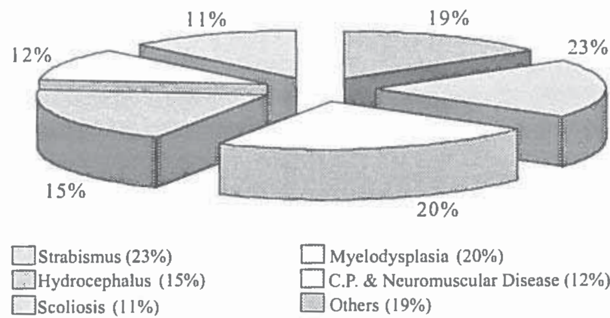

Figure 2. Common diagnosis found at the Pediatric Center for Habilitation Servicesn(n=466)

Those covered by the Puerto Rico Health Care Reform totaled 287 (61.5%). Patients under a private insurance PPO or Medicaid was 168 (36.1%), and 11 (2.4%) did not mention their health care provider. Of those patients under the categories of private insurance PPO and Medicaid, 120 were covered by Medicaid (71.4%) and 48 by private insurance PPO plans (28.5%). Insurance plans of patients under the Puerto Rico Health Care Reform commonly found were the following capitated independent physician associations (IPA) Triple S 45.9%, Blue Cross 24% and Humana 19.5%.

Of the patients under the implemented Puerto Rico Health Care Reform, 42.8% have been part of the health care reform for less than 12 months, 22.9% from 12 months to 24 months, and 32.4% from 2 to 5 years. Of the patients participating for 2-5 years in the new system, 86.1% were satisfied as compared to 67.1% of those active for less than one year. This difference was marginally significant (p=0.056).

The health reform was perceived as improving access of health services provided by the Center 69.3% of the time, while 24.7% stated it had not. Patients under the health care reform had an average of 9.76 visits to the pediatric Center over the past year. Before the implementation of the health reform, 52.2% of the patients had appointments at the Center in the range from 0 to 10 (n=232). When questioned about problems with referrals to a specialist over the past year, 44.9% stated they did have a problem. Problems varied from primary physicians not granting referrals to limiting the number of referrals given by the health plan. Also, 33% missed an appointment due to problems with referrals and 23% had problem with coverage of ancillary services (Figure 3). Ancillary services were defined as physical therapy, occupational therapy, and speech therapy.

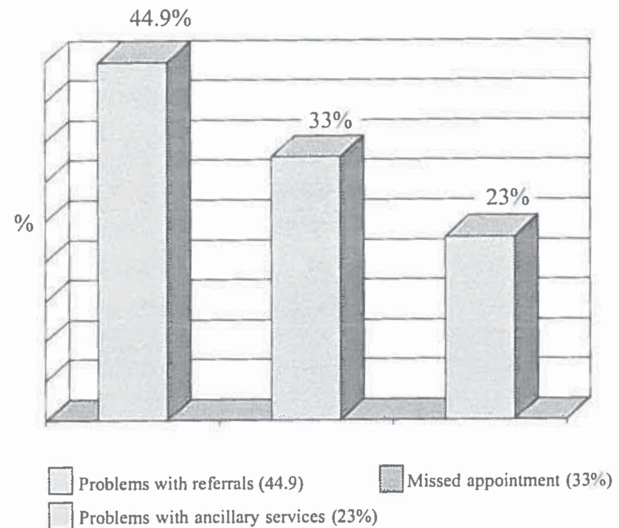

Figure 3. Problems with the referral system for patients under the Health Reform (n=287)

Perception of quality of care offered by physicians was measured using a Likert scale, 0 being the worst value and 10 the best. Patients graded their primary care physician between 0-5 16% of the time, while 84% graded them between 6-10 (n=416). In addition, 9% graded their specialist between 0-5 and 91% between 6-10 (n=410). Ancillary services were graded 21% between 0-5 and 79% between 6-10 (n=208). Technological support was graded 33% between 0-5 and 79% between 6-10 (n=377) (Figure 4).

Fifty-five percent of the people surveyed perceived their health insurance, be it health reform or other, improved services at the pediatric Center (n=466). It was found that those who had perceived deteriorated services, 61% were under the health reform. Those caretakers whose children were classified as multi-disciplinary 58.6% were satisfied

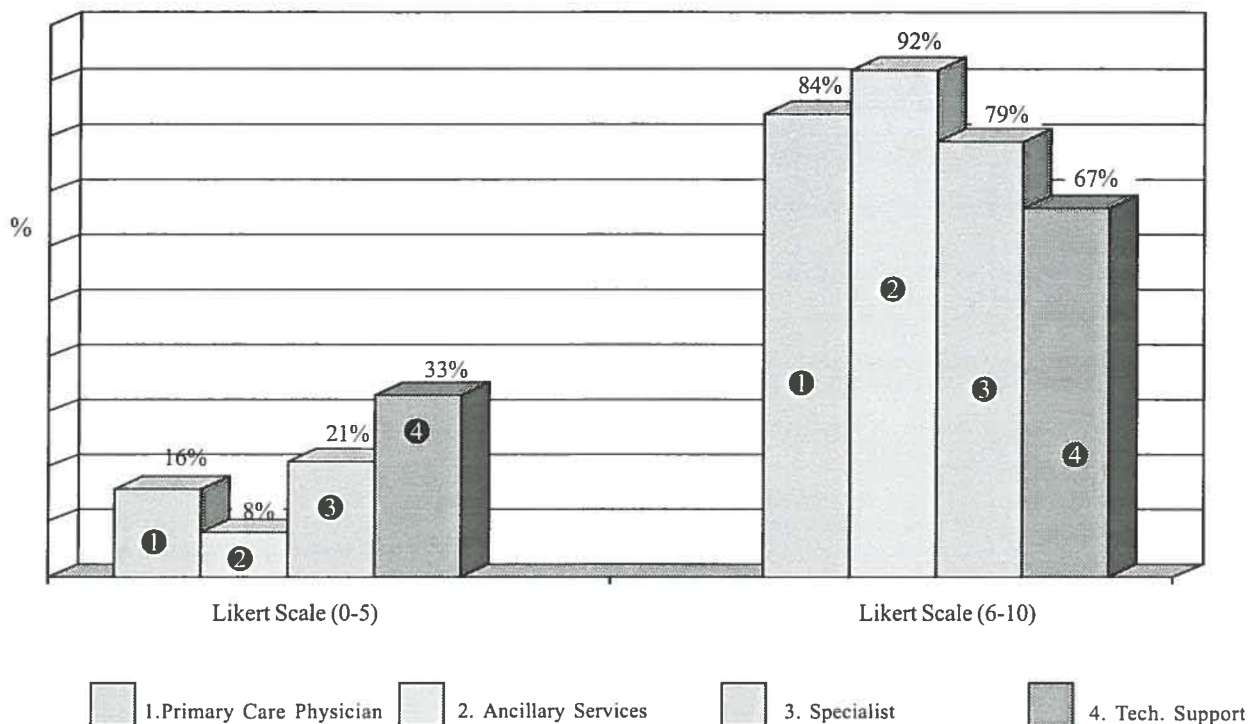

Figure 4. Evaluation of primary care physician , ancillary services and technological support

with the health plan. On the other hand, 70.1% of caretakers whose children were classified as having single discipline conditions were satisfied with the health plan. This difference was statistically significant (p=0.043).

Discussion

The ability to access medical care and being able to measure quality of care are essential elements in today's ever-changing field of health insurance. Children with special needs are enrolling in managed care programs in increasing numbers. Managed care may improve service coordination with use of primary care physicians. On the other hand, it may also threaten health outcomes for these children by potentially decreasing access to the range of needed services, decreasing progress in developing community-based service systems, and failing to assure quality of care. The survey presented in this study summarizes the experience of a multi-disciplinary pediatric center in Puerto Rico with a "special needs" population. Under a new evolving capitated managed care program by the central government of the island, with five years of experience, and with some fee-for-service and private health care providers used at the Center, information was collected concerning satisfaction with care and access to care.

Newacheck et al outlined seven key domains needed to monitor and evaluate managed care in the pediatric population with chronic illness and disabilities. Those include: (1) access to care, (2) utilization of services, (3) quality of care, (4) satisfaction with care, (5) expenditures for care, (6) health outcomes, and family impact (7). Satisfaction of care, utilization of services, and access to care were the key areas of focus in this survey.

One third of the patients who were under the new managed care plan implemented by the government of Puerto Rico were not satisfied with the health care they were receiving. They perceived deterioration in services when compared to their prior medical insurance. This was seen through problems with refused referrals, missed appointments to the Center due to incomplete referrals given by the primary physician, and problems with accessing ancillary services. The children with multi-disciplinary conditions had more difficulty in communicating their needs to the primary physician reflected in a frequent refusal or incomplete referrals to the Pediatric Center.

Parents who have been in the Puerto Rico Health Care

Reform for 2 –5 years were more satisfied with the services than those parents in the system for less than one year. The time it takes for parents to learn to navigate within the system is approximately two years. Caretakers' perception of quality of care delivered by primary physicians in the Puerto Rico Health Care Reform and specialist at the Pediatric Center was graded as good to excellent by 84 % of the respondents.

A limiting factor in the study could be the possibility that the instrument used did not measure all the relevant variables. In addition, the sample was not random, it was of voluntary participants. Likewise, it may not reflect a global experience of patient population seen at the Center.

Conclusion

We concluded that one third of the patients under a capitated managed care system perceived a deterioration in the quality and access to health care when compared to a non-capitated preferred provider system. The parents of children with multi-disciplinary conditions found it much more difficult to gain access to sub-specialty care at a tertiary Pediatric Center. Parents of children with special health care needs take two years to learn to navigate within the capitated managed care system. Studies to measure outcome and health quality of children with special needs in capitated managed care programs should be developed to ascertain how the potential benefits of managed care can be maximized and the potential harms minimized.

Resumen

En el 1994, el gobierno de Puerto Rico adoptó una reforma de salud, con un sistema de salud capitado, para pacientes médico-indigentes. La reforma de salud ha sido implementada en la mayoría de los municipios. Se llevó a cabo una encuesta de niños con necesidades de salud especiales en una clínica de salud terciaria, bajo el sistema nuevo de la reforma de salud y bajo el previo sistema no-capitado. Para este análisis se utilizó el "Consumer Assesments of Health Plan Survey", o C.H.A.P.S. por sus siglas en inglés. Una tercera parte de los pacientes que estaban bajo la nueva reforma de salud no estaban satifechos con el cuidado médico que recibían. Los padres de los niños con condiciones multidisciplinarias encontraron que el acceso al centro terciario era mucho más difícil. Le tomó a los padres dos años para aprender a desenvolverse dentro del sistema de la reforma de salud. Se deben desarrollar estudios para medir el resultado y la calidad de salud de estos niños en un sistema de reforma de salud y entonces aprender a maximizar los beneficios y minimizar los riesgos de este sistema.

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