PATIENT SATISFACTION FOR THE ADULTS WITH DOWN SYNDROME SPECIALTY CLINIC

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Abstract

The Adults with Down Syndrome Specialty Clinic (ADSSC) was established in 2008 to better meet the unique needs of adults with Down syndrome due to many concerns regarding the health care that patients with Down syndrome receive. The purpose of this study was to assess the quality of care that the patients and families receive at this clinic and determine any additional resources that need to be incorporated into the patients' care. A satisfaction survey was developed and mailed to all of the patients (N=75) and 24 responses were obtained. The Likert scale questions were analyzed using weighted calculations and the written narrative responses were reviewed. There were six categories that were analyzed which include: ease of getting care, waiting, provider, nursing staff, all other staff, and facility. Overall, the patients were satisfied with the care that they are receiving at the ADSSC. However, two main concerns for the patients were better location of the facility and better parking. Many of these adults face difficulty finding services that can meet their individual needs. As a result of this study we hope to provide more access to resources as well as high quality healthcare to this population.

Introduction

There has been a growing concern of parents who have children with Down syndrome that their children do not receive adequate medical care once they reach adulthood. These patients were sometimes diagnosed prematurely with Alzheimer's disease. Other diseases that this population is predisposed to develop were either under-diagnosed or missed. Thus, facilities that specialized in the health care of adults with Down syndrome were established to provide specialized care to these individuals. Only two healthcare clinics with this specialty currently exist in the Midwest, one in Chicago and the other is in Kansas City at the University of Kansas Medical Center, Department of Family Medicine (Leshin, 2010).

Due to many concerns regarding the health care that patients with Down syndrome are receiving, Moya Peterson, PhD, ARNP developed the Adults with Down Syndrome Specialty Clinic (ADSSC) in 2008 to enhance their access to health care. This clinic operationalizes a unique health care model. The health care provider is a family nurse practitioner (Dr. Peterson) and other members of the interdisciplinary team include a registered dietician and a mental health nurse practitioner. Referrals are recommended as needed to specialized providers who are familiar with this population including a neurologist who works with dementia in Down syndrome and a cardiologist who works with adults with congenital heart defects. The most recent addition to the clinic is legal assistance (especially for guardianship issues) provided through the cooperation of the University of Kansas Law School.

A main concern for the providers of the ADSSC was whether the patients and families were satisfied with the health care that they are receiving and what can be done to improve their experiences. Thus, this study was conducted to assess the needs and level of satisfaction with care by the patients and families. Long-term goals of this facility include incorporating the medical home model that is solely focused on the advocacy for adults with Down syndrome and in the future, establish a "one stop shop" where adults with Down syndrome can receive all of their health care as well as social supports in one location.

Literature Review

Down syndrome occurs in about one in every one thousand births (Smith, 2001). Due to technological advances and improved health care strategies, individuals with Down syndrome are experiencing longer lives. The average life expectancy for adults with Down syndrome is the mid-fifties (Smith, 2001) with 40% surviving to age 60 and 13% surviving to age 68 (Rapp, 2005).

Health Concerns

There are several health concerns for adults with Down syndrome and often there is a lack of healthcare providers who are able and willing to assess these patients due to their complex health histories and lack of understanding of their adult healthcare needs. There is very little research on the health of individuals with Down syndrome as they age. Primary care physicians who care for many of these individuals are unaware of certain health conditions that adults with Down syndrome are more susceptible to such as pulmonary hypertension, hypothyroidism, osteoporosis, Alzheimer's disease, seizures, sleep apnea, gastroesophogeal reflux disease, celiac disease and cataracts (Rapp, 2005).

Adults with Down syndrome have multiple physical impairments. This includes a higher prevalence of heart defects, muscle weakness and hypotonia, and low cardiovascular fitness. These impairments may contribute to a lower level of fitness and a diminished ability to complete daily activities. The high levels of inactivity are worrisome due to its association with obesity, type 2 diabetes, osteoporosis, and cardiovascular disease (Shields, Taylor, & Fernhall, 2010). Obesity is a common problem within this population. One study of individuals with Down syndrome found that 81% of the participants were overweight or obese (Carr, 2007).

When a patient declines, it is important to look at all possible causes and treat the cause if possible. Depression has been determined to be the predominant cause of changes in functioning for this population. In one study of 53 adults with Down syndrome, the patients were able to demonstrate improvement once treatment was initiated however about 11 of the individuals' condition progressively deteriorated and Alzheimer's disease was diagnosed. Four elements are focused on when a patient is diagnosed with Alzheimer's disease, which include: safety, stability (environment), social (emotions), and symptoms (Chicoine, McGuire, & Rubin, 1999). Safety is increasingly difficult to maintain as the patient declines and is often the chief reason that a patient will need to live in a long-term care or another type of group living facility. The patient should be as involved with his or her care as possible to maintain optimal functioning. Thorough assessments are essential to avoid a misdiagnosis of Alzheimer's disease.

Alzheimer's disease is more common in Down syndrome than in any other intellectual disability group and occurs at an earlier age in this population (Iacono, Torr, & Wong, 2010). Research has shown that the progression of Alzheimer's disease will happen earlier and more quickly with a presenting symptom of an abrupt decline in functioning for this population (Nevel, 2010). Adults are more likely to decline in function once the daily structure and support of cognitive and psychological aspects of educational programs are completed at age 21 years. Today, there are relatively few opportunities for social interaction and a lack of employment regardless of the significant contributions of inclusion for persons with disabilities.

The "Health Care Guidelines for Individuals with Down Syndrome" is a widely accepted guideline for screening patients with Down syndrome for specific illnesses to which this population is predisposed (Smith, 2001). Often, an illness can be overlooked due to the limited communication skills of the patient and a provider may believe that the symptoms are due to Down syndrome instead of an illness that could be treated.

Social Activities

These adults have an active lifestyle and enjoy partaking in numerous activities. Within a study of 110 adults with Down syndrome sixty-five percent reported that work was the main activity outside of the home with a majority (65%) working in sheltered workshops and 23% employed at private enterprises. Ninety percent of adults reported watching television and listening to music at least daily. Just under half (45%) reported participating in sports with swimming being the most popular however only one third was regularly engaged in these activities (Carr, 2007).

These participants reported that friendship activities were infrequent but when occurring were with another individual with intellectual disabilities. Thirty-six percent of this sample group stated that they would like to marry, however none of the participants had actually done so. Over half of people with Down syndrome were said to make friends easily and eighty percent had at least one friend (Carr, 2007). In general, adults with Down syndrome have good health however weight issues are on the increase as in the population as a whole without Down syndrome.

The concept of "self-talk", in which one talks out loud to oneself in order to direct behavior or problem solve, is frequently observed in adults with Down syndrome. Unfortunately, self-talk is often misconstrued as psychosis and the patients are given anti-psychotic medications. The Adult Down Syndrome Center at the Lutheran General Hospital determined that 81% of these patients participate in conversations with themselves or imaginary friends (McGuire, Chicoine, & Greenbaum, 1997). This mechanism is very common among these patients and is very helpful to them as tools for coping. The elderly and children without Down syndrome also partake in self-talk which can be due to social isolation or in children, a part of the process of developing higher thinking skills. Therefore, it is important to determine the root cause for self-talk and to initiate treatment only if needed.

Parents will continue to have an authoritative role in the lives of adults with Down syndrome and remain involved with the key decisions for employment and social activities. Over two-thirds of 30 to 35 year olds in one study remained in the care of their parents. Parents of this population act as a 'layer of influence' around the lives of their adult child either by acting as facilitators, such as actively pursuing resources for the adult, or as gate-keepers, in which the parents will re-evaluate the expectations and goals of the adult as he or she develops (Docherty & Reid, 2009).

McGuire (2005) has developed a list of characteristics for adults with Down syndrome based on the hundreds of assessments that he has made during his practice at the Adult Down Syndrome Center at the General Lutheran Hospital. People with Down syndrome like to show affection and enjoy living in the moment. Adults with Down syndrome also tend to be very clean and tidy, similar to an obsessive-compulsive disorder, and are very particular about timeliness. Members of this population also prefer to take their time and may talk to his or herself to help cope with a problem or express his or her emotions. It is important to allow these individuals to have plenty of time to complete their tasks because they are very precise and want to focus on completing their job correctly. This population loves to dance and attend gatherings to socialize with others, which would involve a lot of hugging. They are sensitive to anger and want to resolve conflicts among individuals (McGuire, 2005).

An emphasis on the need for a healthy lifestyle for adults with Down syndrome is essential for greater wellbeing. Surprisingly, this population has not gained increased independence as they age due to two factors: parents' stress and the cognitive ability of the adult (Carr, 2007). Overall, adults in their middle years have vibrant lifestyles. Their health is reasonably good, many are employed, and they continue to be physically active. However, these individuals have limited levels of independence and social interaction.

Purpose

Our goal at the ADSSC was to ensure that the patients and families are provided with quality health care, have a voice in the plan of care and have access to the many services that they need. We then wanted to determine if we were meeting that goal in the first years after the establishment of the clinic. An evaluation on patient/family satisfaction was performed to gain insight on how we are currently providing care and services and how we might improve the care that patients and families receive at the ADSSC. We also wanted to know of any additional resources that need to be incorporated into the patient's care. The four goals of this study included:

1. Strengthen patient/family/professional partnerships through education, mentoring, technology, and financial investment to support family involvement at all levels of decision making
2. Enhance access and services received in the ADSSC
3. Address progression to adulthood by incorporating into practices and policies transition support for youth with disabilities

4. Build system capacity and sustainability

Methodology

Design and Measures

This study utilized an evaluation survey using quantitative and qualitative open-ended items via survey mailings. A survey was developed for the patients and families of the ADSSC to determine their level of satisfaction and to identify any needs that this population may have. The survey consisted of five open-ended questions and a twenty-one item questionnaire using Likert scales. The participants self-reported their own thoughts and feelings regarding this facility.

Ethical Considerations

The survey was reviewed by Institutional Review Board and it was determined not to be human subjects research because it is program evaluation research. A cover letter describing the study with the request to remain anonymous on the survey was included with the mailing. Adults with Down syndrome who were able to fill out the survey were free to do so or the family members could respond from their perspective of the care that they received from the facility.

Sample and Setting

Out of the 75 mailed surveys, twenty-four participants responded to the mailed survey for a 32% response rate. This is an average response rate since the typical response rate is 30% to 35% response rate for mailed surveys (White, 1999).

Within this sample, 20 were Caucasian, two were Hispanic, one was African American, and one was Asian. The age range was 18 years old to 56 years old while the mean age was 34.2 years old. All of the participants resided in either Kansas (69.2%) or Missouri (29.3%).

Data Analysis

The Likert scale data were analyzed using weighed calculations (the mean score of all responses) on a five point scale and the written comments were transcribed verbatim. After a content analysis, three themes were prominent which are: facility, provider care, and services. In general, the participants would like to see more services provided within the ADSSC. The facility had the most suggestions for improvements especially in regards to location, parking and cleanliness. The participants were the most satisfied with the provider care and made several comments pertaining to the level of the care that they received at the facility.

Results

Overall, the patients are satisfied with the care that they received at the ADSSC. The participants of the study generally felt that Dr. Moya Peterson, ARNP provided thorough care and was very compassionate with her patients. On a 1-5 point scale, this healthcare provider was rated as a 4.96 on listening and taking enough time with the patients. She also received a 4.92 on explaining treatments/procedures and providing appropriate advice and treatment. One participant stated:

> The physician [health care provider] who cared for my Adult child was very helpful in our situation, and gave me the information I needed to go back to our regular physicians in our hometown, and I insisted on some changes in my adult child's medications and treatment that in turn helped with a two plus year ongoing serious health issue, which is now better controlled.

Another participant commented, "They seem to take a personal interest in the individual and are very timely in their response to the family and their needs". Nursing staff friendliness and helpfulness was rated as a 4.83 while all other staff friendliness and helpfulness was rated as a 4.77.

Two main concerns for the patients were better location of the facility and better parking. The ease of finding where to go was rated as a 3.87 and the neatness and cleanliness of the building was rated as a 4.19. The convenience of the facility's location was rated as a 3.63 (see Table 1 for a summary of the survey results).

The additional needed resources that were identified by the participants were therapists, especially a speech therapist and an occupational therapist. Also specialties such as cardiology, endocrinology, and audiology were also recommended to include as consultations for the patients. Other suggestions for additional services to offer at the ADSSC were a job coach and a social skills curriculum as well as a behavioral therapist to assist in the management of inappropriate behaviors.

Ninety-six percent of those who responded to the survey were 'very likely' to refer others to the ADSSC. There were several positive comments made in response to the open-ended questions. A participant stated, "I appreciate the caring atmosphere you provide patients and parents". Another participant responded that he/she liked best about the facility, "The fact that there is a 'Down Syndrome Clinic' is very encouraging. These medical problems for these children are not seriously addressed by many doctors".

Discussion

Many of these adults face difficulty finding services that can meet their individual needs. We would like to provide more access to resources and high quality of healthcare to this population.

There were several suggestions for services to provide at the ADSSC all of which would be very useful at this facility. Referrals are another option to provide patients and families with specialized care however one of the goals of this facility is to provide as many resources as possible for this population all housed in one location. Budgeting restraints may deter offering all of the suggested services however the most needed services will hopefully be established at this facility.

The lowest scores of the survey involved the facility's location and parking. Unfortunately, these items can not be managed by the care provider or the clinic. It is noted that in the near future the Department of Family Medicine, which is the home for the ADSSC, will be moving to a brand new state of the art facility. This new facility will also have improved parking availability. However, the fact of the location of the KU Medical Center with in the urban area of Kansas City will not be changed.

The care providers received the highest scores of the survey which is very promising. Care providers are the heart and soul of this clinic. The empathy and passion that providers and staff demonstrate to the patients and their families cannot be taught so it is crucial that all the members of the health care team be internally motivated and possess a compassionate and caring spirit for these patients and families.

Limitations

This study entailed only 24 responses which is a small sample size from which to draw conclusions. The participants were also obtained via mail which can prevent some participants from contributing. A majority of the sample (41.7%) responded that their last appointment was more than 12 months ago. The length of time since interacting with the facility can bias the accuracy of the responses that were given.

Conclusion

This satisfaction study on the ADSSC was very useful in determining the satisfaction level and changes that were recommended at the facility. Although not all of the suggestions can be implemented, the information is constructive for future practices. Families with adults with Down syndrome are experts in this syndrome because it is necessary. For this reason, their input is essential to this clinic. The providers at this facility would not be able to render the best care without providing the resources that the families need.

The unique needs of the adults with Down syndrome are still not well understood since there is little research on the health of this population as they age. It is critical to have health care providers that specialize in the needs of this population. Often, this population can be misdiagnosed simply due to misinterpretations. To alleviate these problems, a multidisciplinary team should be utilized for the welfare of the patient. Specialists in specific fields such as audiology, nutrition, and social work would be very valuable for adults with Down syndrome to assist with their healthcare needs.

The ADSSC was established to provide specialized care to this population in the Midwest. It is important that our patients and families are satisfied with the care they have received. It is also important that the clinic, with its unique care model, continue to evolve, and offer additional services that the patients and families need. This is a first step in the evolution and development of this important facet for the health care of adults with Down syndrome.

Table 1 Summary of the Patient Satisfaction Survey

Category	**Mean**
Ease of getting care:	
Ability to get in to be seen	4.77
Hours Center is open	4.45
Convenience of Center's location	3.67
Prompt return on calls	4.36
Waiting:	
Time in waiting room	4.35
Time in exam room	4.39
Waiting for tests to be performed	4.19
Waiting for test results	4.14
Provider:	
Listens to you and your adult	4.96
Takes enough time with you and your adult	4.96
Explains what you want and need to know	4.92
Gives you appropriate advice and treatment	4.92
Nursing Staff:	
Friendly and helpful to you	4.83
Answers your questions	4.91
All Other Staff:	
Friendly and helpful to you	4.77
Answers your questions	4.80
Facility:	
Neat and clean building	4.18
Ease of finding where to go	3.91
Comfort and Safety while waiting	4.24
Privacy	4.29

Note. All values represent the mean score on a 1-5 Likert scale.

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