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RESEARCH ARTICLE

Multidisciplinary Care for Children with Down syndrome in the Netherlands: A Modular Perspective

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Abstract

Down syndrome is a complex congenital condition and the most prevalent genetic cause of intellectual disability in humans. Although people with Down syndrome share a typical appearance, intellectual disability, and delayed motor development, each individual with Down syndrome is unique. In addition, many individuals with Down syndrome experience various comorbidities, therefore, people with Down syndrome have complex healthcare needs. The prevalence and severity of these comorbidities varies. This makes individuals with Down syndrome a very diverse and heterogeneous patient group from an early age, despite their common genetic background (trisomy 21). Providing adequate healthcare and interventions in the early life of individuals with Down syndrome improves physical and mental development. In the Netherlands, 22 pediatric outpatient clinics organize multidisciplinary team appointments (so-called "Downteams") to address the complex healthcare needs of children with Down syndrome. In this study, we present the healthcare provided by these multidisciplinary teams in a modular way and show that this modular approach results in improved healthcare provision for children with Down syndrome.

Introduction

Down syndrome (DS) is the most common chromosomal condition associated with intellectual disability, several typical physical conditions, cognitive impairments, and behavioral patterns. Down syndrome was named after J. Langdon Down, who described the clinical features of people with the syndrome[1]. Common physical characteristics are a flat nasal bridge and small body length, among others[2]. People with DS have delayed motor development, increased chance on congenital heart diseases, hearing and vision disorders, respiratory problems, immune deficits, skin problems, and overweight, among others[2-3]. These problems are more common among people with DS as compared to the general population. The prevalence and severity of these problems vary. This makes people with DS a very diverse and heterogeneous patient group from an early age, despite their common genetic background (trisomy 21). Providing adequate healthcare and interventions in the early life of individuals with DS improves physical and mental development [2-3].

The different health professions most frequently involved in pediatric healthcare services for individuals with DS are pediatrics (celiac disease, growth, hypothyroidism, leukemia), cardiology (congenital heart defects), optometrist and ophthalmologist (visual acuity and squint), ENT physician (chronic ear infections, hearing defect, and sleep apnea), orthopedics (hip dysplasia and dislocation), speech therapy (speech delay and disturbed oral motor function), dietetics (obesity and malnutrition), and physiotherapy (motor retardation and screening of development)[2-4]. Although each separate clinical problem is often well known, it is the personal tailoring of the screening, prevention, and treatment in a patient with DS which makes the organization and delivery of chronic DS healthcare complex. In the Netherlands, pediatric outpatient clinics organized multidisciplinary team appointments (so-called "Downteams") that consist of several subspecialists (medical, paramedical, and non-medical) who provide multidisciplinary care for children with DS. Currently, there are 22 Downteams in the Netherlands[5] and the set-up and working methods differ from team to team. Best practices for the organization of these teams have not been identified yet, even though there is a multidisciplinary guideline for the provision of (para)medical care available that is developed by the Dutch Pediatric Association[6]. The professionals in these Downteams increasingly look for ways to (re)organize current DS healthcare provision, at the same time, they explore options for adaptation to individual patient's needs and preferences.

We turn to modularity, an approach from the operations management discipline, to describe the chronic healthcare provision for children with DS. Modularity involves the decomposition of a complex service into modules and components[7] that can be mixed and matched to individual needs, so that each patient receives an individualized service package. Modules are independent parts of a service with a specific function that can be offered individually, or in combination[8]. Within these modules, standardized components can

be distinguished. These are the smallest elements in which a service can be meaningfully divided[9]. The decomposition of a complex service into modules and components is captured in the modular service architecture[7]. Given the potential of modularity to provide cost-effective, yet customized services, an increasing amount of studies have successfully applied the concept of modularity in healthcare[4,9,10]. By conducting this modular decomposition exercise, 1) insight can be provided in the underlying organizational structure of healthcare provision, and 2) it provides opportunities to offer patients individualized healthcare based on standardized components and modules that can be selected related to patients' needs and requirements. The goal of this study is, therefore, to provide insight into the set-up and working methods of the multidisciplinary care provision for children with DS in the Netherlands. The aim is to apply a modular perspective to offer transparency for professionals on the available healthcare elements [components and modules] in care provision for children with DS in the Netherlands.

Methods

We carried out a qualitative, exploratory case study in chronic healthcare provision for children with DS in the Netherlands. When we conducted our study, 22 Downteams were present in the Netherlands. We carefully selected four Downteams out of the 22 that were representative of all the Downteams in the Netherlands. The four Downteams included are geographically dispersed, demonstrate variety in their set-up, and are well-known in the field. In our opinion, those four teams provide a comprehensive view of chronic DS healthcare in the Netherlands. All healthcare professionals involved in all four Downteams were approached to participate in our study; all of them decided to participate in our study, showcasing the perceived importance of our study on the organization of care for children with DS. Ethical approval was obtained from the Ethics Review Board of Tilburg University [EC-2017.60t]. Written informed consent was obtained prior to participation from all participants. We conducted a total of 51 semi-structured interviews with healthcare professionals involved in the four Downteams. Table 1 provides an overview of the healthcare professionals interviewed for each Downteam and highlights the diversity of involved medical, paramedical, and non-medical professionals.

In addition, we conducted 12 observations at Downteams and collected a large amount of secondary data (e.g., protocols, guidelines, history forms).

Table 1. Respondents for each Downteam

Downteam A	Downteam B	Downteam C	Downteam D
ENT-doctor (2x)	ENT-doctor	Audiology assistant	Child psychologist
Dietician	Dietician	Contact parent	ENT-doctor
Doctor for the mentally handicapped (2x)	Doctor for the mentally handicapped	ENT-doctor	Doctor for the mentally handicapped
Ophthalmologist	Medical social worker	Dietician	Occupational therapist
Pediatrician (2x)	Ophthalmologist	Doctor for the mentally handicapped	Ophthalmologist
Physiotherapist (2x)	Orthoptist	Orthoptist	Pediatrician
Secretary	Pediatrician (2x)	Ophthalmologist	Physiotherapist
Social worker	Physiotherapist	Pediatrician	Preverbal speech therapist
Speech therapist (2x)	Secretary	Physiotherapist	Secretary
	Specialized nurse	Secretary	Speech therapist
	Speech therapist	Social worker	
	Rehabilitation doctor	Speech therapist	
	Youth healthcare physician		

A thematic analysis of the content[11] was carried out. We started with the identification of possible modules, using the definition of a module[8] as our guiding principle: "*independent parts of a service with a specific function that can be offered individually, or in combination*". Then, we identified possible components using the definition of a component[9] as our guiding principle: "*The smallest elements in which a service can be meaningfully divided*". The multidisciplinary guideline for the provision of (para) medical care available that is developed by the Dutch Pediatric Association[6] was constantly used to validate our findings. In doing so, we were able to identify the healthcare parts [modules] and elements [components] of each distinct healthcare professional in each Downteam. For example, we assigned the distinct parts of the consultations from each individual healthcare professional as modules (e.g., Physical examination) and identified components as elements of healthcare provision that belong to a certain module (e.g., Movement skills as part of the module Physical examination), as per our definition of modules and components. This modular perspective on this type of healthcare provision simplifies information processing and provides a means for interpreting contexts that are not modular by nature[12]. Since the healthcare professionals involved in chronic healthcare provision for children with DS in the Netherlands did not express themselves in modular terms or considered their care provision as being

modular, we described the practices executed by these healthcare professionals in modular terms. The modular terms used in this study are our well-considered interpretations of the working methods and practices in the provision of chronic healthcare for children with DS. By doing so, we pursued a modular perspective on this type of healthcare. In other words, we interpreted the chronic healthcare provision for children with DS in the Netherlands in modular terms. This modular interpretation of study contexts has been successfully applied before in the existing healthcare modularity literature[4,9,10].

Results

When a patient visits the Downteam, s/he subsequently meets all the various (para) medical specialists involved in the Downteam, within one given part of the day. Downteams offer a range of consultations from various professionals to each patient. However, no standardized approach is applied because the number of professionals, profession of the professionals, and duration of the consultations differ for each Downteam. For example, most Downteams provide no possibilities to change the number of professionals that the patient should visit: "*With our team, you can either participate in all consultations, or in none of them*" (Pediatrician, Downteam A). In one of the Downteams, the secretary argued that the carers of children with DS can indicate, in advance, which professionals they would like to visit at the Downteam: "*We send an invitation letter to the patients which they can return with their preferences with regard to whom they want to visit during the Downteam*" (Secretary, Downteam D). The interviewees mentioned that they were not aware of the differences in set-up and working methods between Downteams, as they assumed that each Downteam was organized in the same manner: "*I assume that, since everyone follows the Dutch guideline on Down syndrome care provision, all the multidisciplinary teams are more or less organized in the same manner*" (Physiotherapist, Downteam B). When we returned to the Downteams with our results, they were quite shocked that there was such a big difference in the way the Downteams were organized in the Netherlands: "*This is surprising. This lack of standardization of healthcare cannot be beneficial for our patients*" (Contact parents, Downteam C).

Based on the information from the interviews, we were able to describe the practices executed by the healthcare professionals involved in the Downteam in modular terms. Using our modular perspective, we assigned the distinct parts of the consultations from the various individual professionals as modules (e.g., Medical examination, Basic motor skills). The professionals explained that each module is based on the national DS guideline developed by the Dutch Pediatric Association[6]: "*The parts [modules] of my consultation stem from the national Down syndrome guideline. I base my consultation on that guideline. I do not always use all parts, but make a selection on what to offer for the patient in front of me*" (Speech therapist, Downteam A). We identified the components

of the care currently provided by the professionals as elements of healthcare provision belonging to a certain module (e.g., Length & weight as an element of the module Medical examination, Muscle strength as an element of the module Basic motor skills). These components are based on guidelines, protocols, and screening forms, among others, used in healthcare provision: "*The parts [modules] of my consultation consist of smaller elements [components]. These elements form the backbone of my profession. Without them, I cannot offer my consultation. I often use a screening form to assess these elements*" (Physiotherapist, Downteam C). Based on the decomposition into modules and components, and the resulting transparency on services offered, the mixing-and-matching of components and modules becomes possible which can result in individualized modular packages for each child with DS. One of the pediatricians emphasized the importance of offering individualized healthcare for each child: "*With the insights into what I offer a patient during my consultation and what my fellow colleagues offer during their consultations, we are better able to provide care that fits best with the needs and wishes of patients and we prevent overlap in treatment or even missed treatments*". The quote by the pediatrician also illustrates that the modular perspective provided insight in overlapping or missing treatments. We observed that, for example, the component 'measuring length and weight' was offered multiple times by various professionals. From an efficiency point of view, this is not ideal, but also from the patients' point of view this can be frustrating because it can give the impression that care provision is not coordinated. We also observed that sometimes professionals assumed that their colleagues in the Downteam dealt with a particular health-related issue of a patient, whereas this turned out to be not the case: "*I assumed that the physiotherapist already checked the backbone of the child, but when we met after the consultation, it turned out he thought that I would check the backbone*" (Pediatrician, case B). Our modular composition can help to prevent overlaps and gaps in DS healthcare provision.

Discussion

The multidisciplinary approach for organizing chronic DS healthcare provision is not unique in the Netherlands, given same approaches in the US[13], Israel[14], and Taiwan[15]. However, we uncovered the potential of this multidisciplinary approach from a modular perspective. Although multidisciplinary care can be considered more complex as opposed to monodisciplinary care, modularity proved to be useful to reduce this kind of complexity, while still offering customized healthcare for each individual child with DS. Previous research on healthcare modularity has mainly focused on less complex types of healthcare, in terms of professionals involved[9]. Our study adds to this stream of research by showing the application of modularity in a complex, multidisciplinary care context.

By reducing complexity and consequently realizing customization, modularity can provide the flexibility to support the provision of person-centered care, which is being advocated by influential policy-making bodies like the World Healthcare Organization[16], but also on a national level by, for example, the Dutch patient association for individuals with DS[17]. Although the modular decomposition of chronic DS healthcare provision required an incredible amount of work, the resulting insights proved to be very insightful for healthcare professionals. The empirical findings showed that professionals were hardly aware of the working methods of the (other) involved healthcare professionals in the same Downteam, but also across Downteams in the Netherlands. This, sometimes, led to gaps and overlaps in healthcare provision. The duplication of care, that was made explicit by our modular perspective, does certainly not enhance efficiency in healthcare provision. In addition, missing treatments were also illustrated by our modular perspective which can cause health risks. The revealed modular composition of chronic DS healthcare offered greater transparency to professionals by providing a clear and representative overview of the available components and modules in care provision and can help in preventing missing treatments or overlap in treatments. By selecting a combination of components and modules, every child can be offered an individualized modular package that fulfills the needs and preferences of children with DS. In this way, modularity can create a customized healthcare service from a standardized set of components and modules in chronic DS healthcare provision in line with findings of previous research in conceptual studies[18], and other types of healthcare like elderly care[9] and mental healthcare[10], among others.

Conclusions

The multidisciplinary team appointments (Downteams) as organized by pediatric outpatient clinics in the Netherlands can identify and address many healthcare needs of children. However, given the involvement of multiple healthcare professionals, there was a lack of transparency on who delivers what in chronic DS healthcare provision. Our modular perspective allowed us to decompose the healthcare provided by Downteams in modules and components. The decomposition of chronic DS healthcare led to mutual insight into each other's work practices, both within and across Downteams. This triggered plans to evaluate and consider restructuring their Downteam, as best practices from other Downteams as well as overlaps and gaps regarding the delivered components and modules within their own Downteam became apparent to every healthcare professional. It is therefore that the modular perspective is considered useful in chronic DS healthcare provision in the Netherlands.

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Conflict of Interest Statement
The author has no conflicts of interest to declare.

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