

Global Health

A resource guide to understanding cerebral palsy: Commentary on collaboration to support health literacy and shared decision making

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Abstract.

BACKGROUND: Shared decision-making is a newer model of patient-centered healthcare; it is particularly important for people with chronic conditions including cerebral palsy. Health literacy is the ability of an individual to obtain, communicate, process, and understand health information and is a crucial component to shared decision-making. With the abundance of information that can be found on the internet, it can be difficult to navigate and determine which websites contain reliable information.

OBJECTIVE: Provide a commentary article aimed to provide healthcare professionals a current, annotated list of reliable online resources in regards to cerebral palsy throughout the lifespan with the goal of supporting health literacy and therefore improving shared decision-making and reducing disparity.

CONCLUSION: Access to accurate and reliable information is an important aspect of health literacy, which in turn will optimize outcomes and build the foundation for shared decision-making between the provider and the patient. Educational materials should be easy to navigate and utilize. This article serves as a guide for reliable CP resources.

Keywords: Shared decision making, health literacy, cerebral palsy, resources

1. Introduction

Understanding and managing healthcare and the healthcare system can be daunting for all of us. Attitudes of both providers and patients toward healthcare have experienced significant changes over the past few decades, shifting away from a focus on addressing

problems as they arise, to more of a partnership and a shared decision-making process to maximize function and well-being, and reduce potential morbidities [1].

Shared decision-making is particularly important for people with chronic conditions including cerebral palsy (CP), as this population has unique challenges and complex needs across the lifespan that impact health and function. CP refers to a group of static or non-progressive injuries to the immature brain that cause disorders of development, movement, and posture leading to activity limitations. The 2007 definition of CP emphasizes that the motor impairments often will be accompanied by disturbances of sensation, perception,

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cognition, communication and behavior, vision, hearing, the gastrointestinal tract, epilepsy, and secondary musculoskeletal problems. This expanded definition aims to include ramifications of co-conditions and how these impact activity, affect function, and influence health [3].

As healthcare moves toward a more patient-centered approach with an emphasis on collaboration in decision-making between providers and patients, the issue of health literacy has come to the forefront.

Access to information has changed dramatically with the advent of technology over the years. Currently, there are over 4 billion active internet users worldwide, equating to about 57% of the global population, and there are about 3.9 billion mobile internet users worldwide [4]. More people than ever before have access to health-related information through the internet. A plethora of CP educational resources are available digitally (websites, social media, blogs, articles, podcasts, webinars); however, this can also be problematic. The information and sources from a general search may be out of date and be more opinion versus evidence based.

It can be overwhelming to sort through such a large number of resources to determine if the information provided is current, legitimate and reliable. For instance, a number of CP-related websites that show up frequently on internet searches are constructed by personal injury legal teams and serve as a referral entry for their business. We aim to provide healthcare providers a current, annotated list of reliable online resources for stakeholders and parents with the goal of supporting health literacy and therefore improving shared decision-making and reducing disparity.

Situation-specific and age-appropriate educational content play a role in health literacy in the context of chronic conditions like CP. It is important to take into consideration that certain topics play a more prominent role at different time points in a person's life.

To highlight this, we will give three examples of time periods that have different concerns: 1. Initial diagnosis and early intervention, 2. The childhood years when treatment options, communication and school considerations become a priority, and 3. Transition to adulthood and beyond including building independence, self-sufficiency, adult medical care and relationships.

With these three time points in mind, this article will provide and describe reliable online resources that professionals can use during their clinical encounters to assist their patients and families and develop health literacy throughout their lives (Table 1). The authors of this article curated the resources provided by a search

and collectively discussed them prior to inclusion. During the discussion, the decision was made to exclude websites created by specific healthcare institutions, sites with legal affiliations, published books and individual bloggers. Since the resources provided may have considerable overlap in knowledge and critical time periods, each resource will be described in detail the first time it is mentioned and subsequent references to this source will serve to highlight the resource's age-specific content. This may not be an all-inclusive list; however, it is a starting point in discussion with families and individuals with CP.

2. Background

2.1. What is health literacy?

The Patient Protection and Affordable Care Act of 2010, Title V, defines health literacy "as the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions" [5]. The U.S. Department of Health and Human Services (HHS) updated the definition to emphasize the ability to *use* health information rather than just understand it, with a focus on the ability to make well-informed decisions rather than simply appropriate ones [6].

Health literacy extends beyond patients and their families. It is necessary for anyone who interacts with the medical community. Health literacy involves an individual's cognitive ability to comprehend and process medical information that is presented, as well as the social ability to articulate what is understood and personal preferences. It is also important to have the skills and motivation to be able to seek out and critically judge available health information in order to promote and maintain good health [7].

Health literacy forms the foundation on which shared decision-making is built upon. In order for effective communication to occur, health care providers, patients, and stakeholders must have a similar understanding of the terms being used in the conversation. Without this common ground, the discussion will be limited in regards to furthering understanding of the disease process, prognosis, risk-reduction strategies, treatment options, and goals of treatment [8].

2.2. What role do health disparities play?

It has long been established that health literacy promotes equity in the health care setting. It is important

Table 1
Resource list

Resource name	Intended audience	Access
<i>Websites</i>		
American academy for cerebral palsy and developmental medicine (AAPDM)	Clinicians, stakeholders	www.aacpdm.org Community Forum www.aacpdm.org/meetings/2020/community-forum
Center for Disease Control (CDC)	Families, community	www.cdc.gov/ncbddd/cp/index.html
Cerebral Palsy Foundation (CPF)	Families, stakeholders	www.yourcpf.org Just Say Hi www.yourcpf.org/just-say-hi-in-schools/
	Adults with cerebral palsy, families, providers	CP Resource www.cpresource.org Childhood www.cpresource.org/topic/school-education Adults www.cpresource.org/topic/adolescence-adults Virtual Town Halls www.cpresource.org/topic/treatment-options/new-horizons-virtual-townhall-series
Cerebral palsy research network (CPRN)	Clinicians, stakeholders, families	www.cprn.org Cerebral palsy tool kit www.cpnwofoundation.org/wp/wp-content/uploads/2015/11/Toolkit-Preview.pdf www.chasa.org/medical/cerebral-palsy/
Children's hemiplegia and stroke association (CHASA)	Families	
Child neurology foundation (CNF)	Families	www.childneurologyfoundation.org/transitions/
ClinicalTrials.gov	Families, adults with cerebral palsy, researchers	www.clinicaltrials.gov/ct2/results?recrs=ab&cond=Cerebral+Palsy&term=&cntry=US&state=&city=&dist=
International alliance for pediatric stroke (IAPS)	Families	https://iapediatricstroke.org/
National institute of neurological disorders and stroke (NINDS)	Clinicians, families, community	www.ninds.nih.gov/Disorders/All-Disorders/Cerebral-Palsy-Information-Page
<i>Sports</i>		
Cerebral palsy international sports and recreation association (CPISRA)	Children and adults with cerebral palsy	www.cpisra.org
Move united	Children and adults with cerebral palsy	www.moveunitedsport.org
National center on health, physical activity and disability (NCHPAD)	Adults with cerebral palsy, community stakeholders, educators	www.nchpad.org
<i>Mobile apps</i>		
CP channel (CPR)	Teens and adults with cerebral palsy, families, stakeholders	Free mobile app Download for free on any iOS or Android device
<i>Podcasts</i>		
Let's talk CP (CPS)	Families, caregivers	www.cpresource.org/topic/cerebral-palsy-facts/lets-talk-cp-were-together Available on iTunes, iHeart Radio, Spotify, and Pandora
Cerebral palsy health	Families, caregivers	www.cpresource.org/topic/cerebral-palsy-facts/cerebral-palsy-health-jennifer-lyman
DMCN – PC crece	Families, clinicians	https://youtu.be/LvyvadD01X4
DMCN – Terapia Y Ejercicio Fisico	Families	https://youtu.be/vzVrkI8Rkac

Table 1, continued

Resource name	Intended audience	Access
<i>International Resources</i>		
CanChild (Canada)	Clinicians, families, adults with cerebral palsy, stakeholders	www.canchild.ca/en/diagnoses/cerebral-palsy
Cerebral palsy alliance	Children and adults with cerebral palsy, families, stakeholders	www.cerebralpalsy.org.au/our-research/about-cerebral-palsy
Federacion aspace (Spain)	Families	www.aspace.org/
<i>Additional resources on development and developmental disabilities</i>		
Easter seals	Families	www.easterseals.com/
Individuals with disabilities education act (IDEA)	Families	https://sites.ed.gov/idea/?src=policy-page
March of dimes	Families	www.marchofdimes.org/index.aspx
Pathways.org	Families	www.pathways.org
SWIFT schools	Families	www.swiftschools.org/
United cerebral palsy (UCP)	Families	www.ucp.org/

to note that a lack of health literacy might explain some of the variation in health disparities that would otherwise be linked to other socioeconomic factors, such as education or income for example [9,10]. Health disparities are differences in health that occur due to social, economic, or environmental disadvantages. Groups that are more likely to fall victim to discrimination or segregation often face increased difficulties in preserving and improving their health [11].

Indeed, a lack of health literacy has been found to be associated with many of the drivers of health disparities including the incidence and prevalence of CP. However, continued research is needed in this area to further assess linkages and risk factors [12].

Professionals have a responsibility to understand available resources and to direct those affected by CP and their caregivers, if appropriate, to reliable educational resources that serve the purpose of building the bridge to health literacy and shared decision-making.

In the instance of a lifelong condition such as CP, disparities may occur in the form of diagnosis timing, prognosis and severity, access to therapies, home affordances, access to specialty providers, recreational activities, parental ability to take time off work for appointments, and ability to acquire certain medical equipment.

Healthcare professionals need to be cognizant of the level of understanding in each patient, family unit, and stakeholder and take into account alternative perspectives, cultural considerations, and any health disparities that may be present. It is the duty of medical professionals to continually re-evaluate and try to understand the unique beliefs and attitudes of patients and caregivers toward certain topics, as these beliefs may not be the same as their own.

3. The first step in CP health literacy: Early diagnosis

For children with developmental disabilities, there is an increasing realization that diagnosis and intervention should start as early as possible. This may be even more important for those with CP, as the etiology is multifactorial and there may be specific neurocritical interventions that enhance neuroplasticity and outcomes.

An international consensus for the diagnosis of CP was recently reached, making early diagnosis at less than 12 months of age not only achievable, but also desirable [13]. This represents a significant change regarding the timeframe of when CP has historically been diagnosed and presents a new opportunity for family and caregiver education and early information dissemination.

Diagnosing CP as early as possible has profound consequences, positively impacting many aspects of patient care. One of these benefits is the ability to increase caregiver empowerment and involvement early in the process of care [14]. Each case is unique, however, and it is important to understand that each family may require different time periods to process the information surrounding a CP diagnosis. As such, the information provided to the patients and families should be easily accessible at their own pace.

Current best practice in the initial discussion of a CP diagnosis includes providing patients and family members with helpful information as well as providing the family with a plan [15,16]. Reliable resources should be provided during this initial conversation on the diagnosis to enhance the patient's and family's understanding of the condition. Often, the primary concern at the point of diagnosis centers on understanding the disease and early treatment options. Increased knowledge arising

from up-to-date and reliable educational materials has the potential to help raise patient confidence, reduce fear and confusion, and support the therapeutic bond with clinicians and providers [17].

3.1. Early CP diagnosis information resources (Table 1)

3.1.1. The cerebral palsy foundation (CPF)

CPF is the largest CP-specific nonprofit foundation in the United States, and it supports education and provides information for families with children and adults with CP, as well as stakeholders. The CPF was created in 1948 and was originally called the United Cerebral Palsy Research and Educational Foundation. Their current mission is to be a catalyst for creating positive change for people with CP and to define, address, and help accelerate advances for moments of impact – the times at which interventions and insights, if properly implemented, have the power to change lives [18]. Available information platforms include the following:

CP Channel

A free downloadable mobile app for iOS and Android devices, CP Channel puts hundreds of expert videos and more at the fingertips of anyone with a mobile device. Many of these videos focus on the topic of early CP diagnosis and related intervention information.

CPResource.org

Developed in 2020 by leading experts and families, CPResource.org features reliable, up-to-date information and resources through the lifespan including fact sheets, expert videos, and family stories about early CP diagnosis, early intervention information, research, education, educational town halls, adaptive product information, curated content for all ages, and much more. CPResource.org is designed around the International Classification of Functioning, Disability, and Health (ICF) system addressing human functioning, and provides a standard language and framework that describes how people with a health condition function in their daily lives. Links to CP clinical trials and research can also be found on this site.

3.1.2. Centers for disease control and prevention (CDC)

The CDC features general information about a variety of developmental disabilities, including CP. The CDC also provides links to early intervention programs by state, statistics, and family stories [19].

3.1.3. CP tool kit

The CP Tool Kit is accessed through the Cerebral Palsy Research Network (CPRN) and was created to help families sort through the initial emotions in response to a child or loved one receiving a diagnosis of CP and to answer questions and concerns related to CP [20]. The CP Tool Kit is also available in Spanish, and is available for free via download at www.cprn.org and for purchase in print for \$12.69 on Amazon as of January 2021.

3.1.4. International alliance for pediatric stroke (IAPS)

The IAPS unites pediatric stroke communities worldwide to share vetted medical information, bringing education, awareness, and research together to help these children and their families. The IAPS website includes information, resources, fact sheets, videos, stories, and more. A newly-launched (2021) Support Network connects families of children who have had strokes with peers who can help navigate the journey after stroke [21].

3.1.5. Children's hemiplegia and stroke association (CHASA)

This grassroots non-profit organization is dedicated to improving the quality of life for those who developed hemiplegia during childhood. They provide specific information on the hemiplegic subtype of CP [22].

3.1.6. National institute of neurological disorders and stroke (NINDS)

NINDS is a division within the National Institutes of Health (NIH) that seeks fundamental knowledge about the brain and nervous system to reduce the burden of neurological disease. They provide a limited overview of the definition of CP, treatment options, resources, and research projects [23]. It is also available in Spanish.

4. Growing into the childhood years

Childhood is the time for finding one's place in the world and establishing a sense of self. Children of all abilities want to fit in and make friends. Having a chronic diagnosis can make building these relationships and developing independence more difficult. Children with chronic conditions like CP need to find a way to understand their own diagnosis and learn to advocate for themselves with their peers, teachers, and medical professionals as they mature.

Additionally, all children should have opportunities to find ways to explore their interests, participate, and interact with the world, be it through sports, recreation, or other extracurricular pursuits. Becoming active not only improves motor function and physical health, but it also encourages participation in community programs, school sports, and other events that help an individual with disabilities expand physical and cognitive skills. Research has shown improvement in children's speech, self-esteem, and emotional well-being through becoming more active [24]. Becoming engaged in their own health early on sets the child up to continue to actively be involved in their medical care through their lives while promoting self-advocacy and a higher quality of life.

As a child with CP grows, the focus shifts from trying to understand the diagnosis to looking for ways to maximize outcomes and address any potential limitations that may come up through physical limitations, growth spurts, social considerations, and school-related issues. There is no standard therapy or treatment that works for every individual with CP. Once the diagnosis is made and the type of CP is determined, a team of healthcare professionals will work with a child, their family, and caregivers to develop a plan to maximize the child's participation and quality of life.

Families and caregivers have not easily been able to find or access best evidence and treatment standards of care for CP in one place. It is challenging for families and caregivers to understand the treatment options and what might be available to them.

In addition to treatment options, a level of complexity is added when the wide practice variations between practitioners are taken into consideration. Moreover, specific treatments may only be available in certain parts of a country or only certain countries. Thus, not everyone has access to the same treatment options. Caregivers often find themselves in the position of not fully understanding the best evidence for treatment. Access to reliable information, knowledgeable providers, and shared decision-making is critical to successfully address questions and issues.

4.1. Resources for the childhood years (Table 1)

4.1.1. CPRN

CPRN is a 28-multisite group of doctors, therapists, epidemiologists, and patient advocates collaborating to empower, improve treatments, and improve outcomes for people with CP through research, education, and community programming. They facilitate cooperative

research and use rigorous data collection practices to plan and execute a learning health network, clinical trials, and quality improvement protocols. CPRN's recent merger with CPNow has created a platform for educational materials such as the CP Tool Kit (see above) and resources for well-being [20].

4.1.2. CPResource.org (CPF)

This website includes a variety of information and resources for school-age children with CP and their families, including information about education considerations, treatment options, growth, nutrition, sleep, activity, and movement. Information can also be found on their in-school initiative on school inclusion through the "Just Say Hi" initiative.

4.1.3. ClinicalTrials.gov

This database of privately and publicly funded clinical studies conducted around the world includes studies about CP. The majority of CP clinical studies are targeted towards school-age children with a smaller number of trials focused on younger children and adults.

4.1.4. The American Academy for Cerebral Palsy and Developmental Medicine (AACPDMD)

This academy of health professionals is dedicated to providing multidisciplinary scientific education and promoting excellence in research and services for the benefit of people with and at risk for CP and other childhood-onset disabilities. The AACPDMD website can be searched by families and caregivers in order to find clinicians with a focus on CP. The website also features a variety of fact sheets providers can share with their patients and families on topics including executive function, adaptive physical activity, fatigue, sialorrhea, walking over the lifespan, and other topics [25].

Community Council

Made up of a variety of families, individuals with CP, and stakeholders, the Community Council conducts a no-cost family forum during the AACPDMD annual meeting and serves as a resource for families and caregivers.

4.1.5. Individuals with Disabilities Education Act (IDEA)

The IDEA is a law that makes available a free, appropriate public education to eligible children with disabilities throughout the US and ensures special education and related services to those children. The IDEA governs how states and public agencies provide early intervention, special education, and related services to more

than 7.5 million eligible infants, toddlers, children, and youth with disabilities. This website has a wide variety of information and resources for families.

4.1.6. *SWIFT Schools*

SWIFT is a national technical assistance center that builds whole system – state, district, school, and community – capacity to provide academic and behavioral support to improve outcomes for all students.

4.2. *International resources*

4.2.1. *CanChild (Canada)*

As an academic network of international scientists who conduct applied clinical and health services research, CanChild's research efforts focus on children and youth with disabilities including CP and their families. As a world leader in the field, CanChild strives to generate innovative knowledge and translate research in an accessible way that is relevant and meaningful to those who need it most: families and service providers [26].

4.2.2. *Cerebral palsy alliance (Australia)*

Cerebral Palsy Alliance provides family-centered therapies, life skills programs, equipment and support for people with CP and other neurological and physical disabilities and their families in Australia. Additionally, Cerebral Palsy Alliance has dedicated millions of dollars to the study and implementation of CP prevention and advancement of treatments for those living with CP including a consolidated international roadmap for research [27].

4.2.3. *Federacion aspace (Spain)*

This movement of people with CP, families, professionals, and other entities in Spain is dedicated to providing adequate services and support in each life stage of people with CP, regardless of the degree of autonomy. This is a caregiver resource that explains what CP is, gives guidelines for daily living with a child with CP, addresses family dynamics, and other resources [28].

4.3. *Sports and recreation*

4.3.1. *Cerebral palsy international sports and recreation association (CPISRA)*

The only global adaptive sport and recreation organization solely focused on people with CP and related conditions, CPISRA provides and promotes opportunities for recreational sport and activity, develops

grassroots adaptive sports and provides platforms for regional and international competitive and elite sport. CPISRA is also passionate about promoting sport for recreation, well-being, and enjoyment for individuals with CP [29].

4.3.2. *Move united*

Move United provides national leadership and opportunities for individuals with disabilities to develop independence, confidence, and fitness through participation in community sports, competition, recreation, high performance sport and educational programs. Move United annually serves 100,000 youth and adults with disabilities through a nationwide network of over 170 community-based chapters in more than 40 states in the US [30].

4.3.3. *National center on health, physical activity and disability (NCHPAD)*

The NCHPAD is a public health practice and resource center focused on health promotion for people with disabilities through increased participation in all types of physical and social activities, including fitness and aquatic activities, recreational and sports programs, adaptive equipment usage, and more [31].

4.3.4. *Adapted sports journal digest (within AACPDM)*

This digest provides brief, easy-to-read reviews of the most recent research pertaining to adaptive sports, recreation, and physical activity for individuals with disabilities across the lifespan [25].

4.4. *Podcasts and more about CP*

4.4.1. *Let's talk CP (CPF)*

Connecting the CP community one podcast at a time, this CPF podcast series brings education, conversation, support and much more on a variety of topics to the CP community by interviewing clinicians, researchers, families and people with CP [18].

4.4.2. *Cerebral palsy health*

This podcast highlights conversations with experts about issues related to CP that affect health, fitness, function and participation [18].

4.4.3. *Terapia Y ejercicio fisico and PC crece – developmental medicine and child neurology*

Topics of this podcast include the importance of exercise and physical activity, developmental trajectories of children with CP, and aging of children with CP.

4.5. *New horizons cerebral palsy virtual town halls*

These multi-disciplinary virtual panel discussions feature leading clinicians, researchers and therapists from across the US and highlight the latest updates in care of children with CP.

5. Transition to adulthood and beyond

In the past, CP informational resources focused primarily on children and their parents. Since most people with CP have a near-normal lifespan, adult resources are equally important, as is further research on the aging consequences of CP [32]. Recent trends in clinical care and research emphasize a longitudinal model of care which takes into consideration the priorities of adults affected by CP [33,34].

The journey of preparing children with CP for the transition to adulthood generally starts around age fourteen to ensure they have ample time to gain the confidence and skills needed. Maximizing independence, to the highest degree possible, becomes the major focus of this time period. Children with CP should be encouraged to take ownership of their medical needs as early as possible with increased emphasis during the teen years.

During this time, a variety of important issues should be addressed including sexuality, reproductive health, social relationships, well-being, and mental health. Teens with CP should be supplied with critical information necessary for future planning, post-secondary education, job training, employment, and independent living.

5.1. *Resources for transitioning to adulthood (Table 1)*

5.1.1. *AACPDM*

Fact sheets for adults with cerebral palsy on fitness and primary care are available [25].

5.1.2. *CP channel (CPF)*

CP Channel provides an accessible tool that can be used to teach teens basic knowledge concerning CP. It can also be used as a useful starting point for discussion of practical matters related to the transition to adult providers [18].

5.1.3. *CPResource.org*

This website features a section on adolescence and adulthood. Users can explore information from experts and stories from people with CP who have experienced adolescence and adulthood [18].

5.1.4. *MyCerebralPalsy.org (CPRN)*

MyCerebralPalsy.org is a resource for the CP community to participate in research and discuss research priorities. MyCerebralPalsy.org connects to the CPRN Community Registry.

5.1.5. *Child neurology foundation (CNF)*

CNF has available resources tailored to families with neurological conditions including CP and features helpful information about the transition years.

6. Conclusion

Access to accurate and reliable information is an important step to optimize outcomes across the lifespan, improve health literacy, and build the foundation for collaboration between provider and patient during the decision-making process. *S* takeholders with an investment in CP also need access to the same resources to find the common ground in shared decision-making. These sources of educational information about CP should be easy to navigate and reflect the various issues faced in the different stages of a person's life with CP, from early diagnosis through adulthood.

With this in mind, this article serves as a guide for reliable CP stakeholder resources describing the foundational merits of each resource and providing easy access to trusted information for providers, families, and caregivers. From the physician point of view, the more well-versed in healthcare knowledge the patient or caregiver is, the more engaged they are likely to be in goal-setting and shared decision-making.

We encourage you to read available CP educational information and to critically evaluate all of the sources that your patients and families bring to your attention. In an age of misinformation, providers have the duty to independently verify the information as well as question the information within the source. An honest discussion with families or individuals can follow your appraisal of these new potential resources. A partnership in navigating resources will improve trust, and most importantly, empower both the families of a child with CP and the individual with CP over their lifetime.

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