

Looking in From the Outside: Perspectives of Caring for an Individual Diagnosed with Agenesis of the Corpus Callosum

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Abstract: Agenesis of the corpus callosum (AgCC) is a rare condition in which the neural connection between the left and right hemispheres of the brain is missing. This descriptive phenomenological study included the voices of 82 individuals, spanning three countries, who were identified as family members and caregivers of individuals diagnosed with AgCC, and three adults diagnosed with AgCC living independently. Analysis of the data revealed there was a lack of information about the disorder to support families and health professionals. Results of the study provide insight into the financial struggles, relationship issues, and the hopes for the future through the lived experiences of the participants. There is an undeniable impact upon families of individuals born with disabilities. As the number of individuals with AgCC continues to escalate due to improved medical techniques, proactive problem-solving for children and adults with AgCC must be considered.

Keywords: Disabilities, agenesis of the corpus callosum, family support, care experiences, social problems.

Agenesis of the corpus callosum (ACC or AgCC) is described as a birth disorder in which the structure connecting the two hemispheres of the brain, the corpus callosum (CC), is partially or completely absent (NINDS, 2011). In the human brain, the CC is the largest neural pathway within the central nervous system, comprising approximately 200 million axons (Aboitiz & Montiel, 2003). Without a CC, the two hemispheres of the brain cannot cooperate; each side of the body seems to work independently rather than as a whole. The prognosis for children with AgCC can vary (University of Maine, 2008) and related problems are only a prediction. Levels of intellectual and developmental disability vary greatly in AgCC children (Cavalari & Donovan, 2015; Demopoulos et al., 2015; Paul, Erickson, Hartman, & Brown, 2016) ranging from minor to quite severe problems such as poor muscle coordination, vision loss, a lack of pain perception, sensitivity to touch, insomnia, elimination issues (University of Maine, 2008), sensory dysfunction (Demopoulos et al., 2015), sleep problems (Ingram & Churchill, 2016), communication, learning and behavioural disorders (Paul et al., 2016; Rehmel, Brown, & Paul, 2016) coupled with other forms of disruptions, which impact both the children and their families. By utilizing a descriptive, qualitative approach, the goal of this article is to provide the reader with a glimpse into successes and the challenges of those living with AgCC through the lens of those caring for them.

Review of Literature

According to the World Health Organization [WHO] (2002), a disability is a complex issue often affecting the medical and social needs of the individual. Specifically, *disability* has been defined as “a complex phenomenon, reflecting an interaction between features of a person’s body and features of society in which he or she lives” (WHO, 2011, para. 2). For families impacted with callosal disorders, the prevalence rate may occur in as many as one in every 4,000 individuals (University of Maine, 2008). However, according to The National Organization of Disorders of the Corpus Callosum [NODCC] (2009), “Estimates of the frequency vary greatly” (p. 2). Some researchers suggest AgCC occurs as frequently as one

in every 7,000 births with others proposing the disorder is as rare as five in a million (NODCC, 2009). In 75% of diagnosed AgCC cases, no underlying basis for the lack of a callosal formation has been identified (Moutard, Kieffer, Feingold, Kieffer, Lewin, Adamsbaum... Ponsot, 2003).

The NODCC (2009) noted that disorders of the CC are conditions one must “learn to live with” rather than “hope to recover from and are associated with long-term challenges” (para. 15). Also, outcomes for children depend on how they are “treated with medicines, counseled with coping strategies, educated in both academic and social skills, and guided through a two decade long journey from infancy to adulthood” (NODCC, 2009, para. 3). Much of this guidance will take place from family members or others caring for the individual with a disability.

Research has shown that families living with an individual with a disability have increased stress levels, illness, and marital strain (Cavalari & Donovan, 2015; Rowbotham, Carroll, & Cuskelly, 2011; Hock, et al. 2012). And, having a child with a disability will have an impact, whether positive or negative on the structure of the family system as well as family members’ roles and relationships (Aksoy & Yildirim, 2008). Siblings and extended family members may share the same emotions that parents feel (i.e. grief, anger, and guilt) and some of these feelings may arise from fear and misunderstanding (Petalas, Hastings, Nash, Dowe, & Reilly, 2009). Yet, for those living with or caring for an individual with an AgCC disability, a dearth of research exists. According to the ACC Network, research on the impact of callosal disorders is still in its infancy (University of Maine, 2008). No empirical studies were located specifically examining impact of the AgCC disability upon contemporary families. Information about cognitive, social and emotional consequences of AgCC is limited, leaving families with trial-and-error methods for helping their children with AgCC (Caltech, 2012, para. 2). Jones (2007) noted: “If we cannot hear the voices of those who have been

marginalized, then we are not compelled to act on what they say... eliminating their perspective from the discourse” (p. 33).

Theoretical Underpinnings

In this study, we utilized the social-relational model of disability proposed by Thomas (1999). Based upon the model, Liddiard (2014) noted that disability is considered to have “political, material, economic, structural, emotional, intimate, and personal dimensions” (p. 116). A purely social model would not have supported personal narratives of the lived experiences of those impaired (Liddiard, 2014) and a purely medical model would be limited to the portrayal of a disability solely on the basis of impairment or medical condition. In Thomas’ (1999) social-relational model, the impact of impairment and social barriers are intertwined, emphasizing the lived experience of individuals with a disability. In this paper, the voices of caregivers for individuals with AgCC, specifically family members, are brought into the discussion, bridging the general research on families living with disabilities to the specific issues related to AgCC that illuminate the perceived disabilism described by participants.

Methods

This descriptive phenomenological study was conducted using open-ended questions on an Internet survey. The study focused on understanding and interpreting narrative texts generated through survey documents. The study provides a narrative account of the lives, perceptions, and daily activities of caregivers of individuals diagnosed with AgCC. The primary researcher in this study was also a participant-observer. As the mother of a child with AgCC, the researcher was, as Anderson (2006) defined, a “complete member in the social world [of AgCC] under study” (p. 379) with optimism to “change the world and make it a better place” (Denzin, 2000, p. 256). To maintain objectivity, researchers’ biases and personal experiences with the disorder were bracketed (Groenewald, 2004). Additionally, other

researchers provided the “outsider” perspectives, ensuring that the voices of the participants were carefully considered.

The primary goal of this research was to explore the perceptions of those caring for individuals diagnosed with AgCC and to add to the literature to contribute a better understanding of AgCC and its impact upon family life. The specific research question was: *How does caring for an individual with the neurologic disorder AgCC impact the life of caregivers?*

Participants

A purposive sampling approach was used to recruit participants caring for an individual diagnosed with AgCC. Due to the desired population being both rare and difficult to locate, the research flyer and online survey link were posted to a listserv located at the University of Maine and three Facebook group pages created for parents, families, and friends of children with AgCC. Before beginning the research, the research was approved by the University Institutional Review Board and informed consent was obtained from all participants.

Instrument

The research tool included an online, structured interview containing six multiple-choice demographic questions (e.g. age, gender) and four open-response questions. The open-response questions were created to elicit information around experiences of living with an individual with AgCC including: the general impact of the disorder on the family, the effect of the diagnosis, and the financial and social consequences of the disorder. Lastly, participants were asked if they had any additional information they wished to share.

Demographic Data

Seventy-five women (93%) and six men (6%), across three countries (Australia, Canada, and U.S.) participated in the study. One participant’s gender was not identified. The population consisted of seventy-four parents (90%), two caregivers (2%), one sibling (1%),

and two grandmothers (2%). In addition, three adults, living independently, diagnosed with AgCC contributed to the results. The mean age range of participants in the study was 30-39 (41%). Participants (who were caregivers of a child with AgCC plus three independent adults) reported that individuals diagnosed with AgCC comprised forty-seven males and thirty-five females. Many (40%) of the individuals identified with AgCC were three years of age or younger.

Data Analysis

Although this research involved structured interview questions, the aim was not to obtain quantitative results, but to examine participants' responses as part of a narrative, conveying insights from those caring for an individual with AgCC. Independently, the researchers coded open-ended written items, creating an audit trail through a constant comparative analysis to identify specific themes and categories (Ryan & Bernard, 2000). This process involved reducing data into "manageable units, synthesizing, searching for patterns, discovering what is important" (Bogdan & Biklen, 1992, p. 157). Strategies included using research memos, audit trails, and a trustworthy research team to build integrity (Merriam, 2009). Triangulation included the interpretations and conclusions of the findings which were discussed with two other peers not involved in the study. Although member checking was not possible due to anonymity, exact quotations from participants conveyed experiences in their own words. Lived experiences of participants allowed the data to speak for itself.

Findings

When participants were asked "*How does caring for an individual with the neurologic disorder AgCC impact the life of a family?*" the reaction of those closest to the individuals (parents, siblings, grandparents) fluctuated from despair to hope. Upon diagnosis, families either unified to meet challenges; or, unable to handle the stress, unravelled. Regardless of outcomes, responses revealed changes in family dynamics. Collected narratives, integrating voices from families, provided insight into the daily lives of those living with AgCC.

Analysis of data revealed six primary themes: *Timing of the diagnosis, a lack of information, interpersonal relationships, a change in future planning, financial impact, and social implications*. Each of these themes will be reported next.

Timing of the Diagnosis

The first theme was *timing of the diagnosis* of AgCC with subthemes: prenatal, childhood, or adulthood. According to family narratives, the AgCC disorder may be diagnosed anytime between prenatal and adulthood. Screening may include a detailed ultrasound, fetal anatomy survey, amniocentesis, fetal magnetic resonance imaging (Reddy, Filly, & Copel, 2008) or Computerized Axial Tomography [CAT scan] (NODCC, 2009).

Prenatal

The families expressed anxiety, devastation, and uncertainty with the initial diagnosis, worrying about the future began before the birth of the child: “When we first learned of the diagnosis (5 months prenatal), our family was devastated.” The diagnosis led to worry, fuelled by the uncertainties that accompanied it. “The initial dx [diagnosis] of AgCC in utero filled us with a lot of worry and what if’s.” Rather than providing a clear sense of understanding, the prenatal diagnosis increased parents’ anxiety. “I was told of my daughter’s diagnosis this past May. She was born this past June... it’s devastating; I don’t know what to expect in the future. I continue to stay prayerful, faithful, and hopeful that my daughter will be okay.” This parent’s worries were echoed by another parent: “When I was pregnant, and for the first year, her diagnosis impacted me in terms of worry and anxiety- it was always in the back of my mind.”

Childhood

According to the California Institute of Technology [Caltech] (2012), the possibility of prenatal detection is relatively new. This may account for individual diagnoses of AgCC occurring later. The physical and cognitive impairments likely were not obvious during birth but emerged during childhood as evident as one parent reported:

It wasn't until he was 9 weeks old that we had the diagnosis of AgCC. It was definitely the most difficult week of our lives. The doctor had painted a very bleak picture of the prognosis and it was heartbreaking and worrisome to know that there were so many potential difficulties he could have.

Adulthood

Outcomes of the disorder may be extensive or even delayed; some individuals were not diagnosed until adulthood. For example, one participant with the disorder noted, "I wasn't diagnosed until the age of 37. I always knew there was something different about me. Having this diagnosis has explained a lot to me."

A Lack of Information

The second theme revealed a lack of information on AgCC. Outside of pathology reports, even the medical profession had a narrow scope of the disorder. Dobyms (1996) noted, "The heterogeneity of agenesis of the corpus callosum (AgCC) is so great that it will take decades rather than years to sort it out" (p. 7). Also, one participant remarked, "It is a journey that has very little research and support. It seems like we live on an island that is lost on a map... At times, the navigation seems overwhelming." Similarly, another participant expressed, "We were not given any information as to where we could access support and were initially told to consider termination (as a prenatal diagnosis)".

As individuals with AgCC are enrolled in schools, parents might become advocates for their children. One parent remarked: "Because ACC is so rare, we find ourselves having to educate the school (i.e. his teachers and learning support teacher) about the differences." Participants underscored the need for further disability studies regarding callosum disorders and additional training for educational, medical, and social service professionals.

Interpersonal Relationships

The third theme relayed information about interpersonal relationships surrounding individuals diagnosed with AgCC. Family members shared how the diagnosis impacted not

only the individual, but also the core family unit (husbands, wives, siblings) and extended family (grandparents, cousins). The focus of the family moved to individuals with AgCC as other family members received less attention: “Family exists, and rotates around our daughter... it’s pretty well an existence as a family in name and in no other way.”

Parents

Parents described being “more tired than friends with typical children” while “never get[ting] a break or time together.” The stress on marriage facilitated one family to draw closer: “This has impacted the family in a positive way... it has brought us as a family closer together. We all want the best for our son and we are ready and willing to help in any way we can.” For others, the disorder was too much and the marital relationship crumbled:

It is very difficult to maintain a cohesive family when there are the added pressures of having a child born with a rare medical condition. My 28-year marriage ended 9 years ago and my ex-husband is still in denial about having a daughter with special needs.

Raising a child with a disability can be complicated and may turn parents against each other. The first excerpt presents a husband’s experience of raising a daughter with AgCC. In a different case, a wife shares feelings of the impact of AgCC on her marriage.

Excerpt 1: Husband

We knew even before birth that there was a problem with my daughter. I think in time it had a part in our breakup and ultimately our divorce. I love my daughter and I believe my ex-wife does also, but we didn't agree on how to deal with it all on a day to day basis. I try to take her places - Zoo, Museums, park, shopping and my ex keeps her as a shut in.

Excerpt 2: Wife

My daughter’s condition has impacted my husbands and my relationship, on the basis that we process and deal with things differently but when I am concerned about

possible symptoms such as seizures, he is dismissive (he likes to believe everything is fine; I am the opposite and on the alert 24/7 so it makes an unhappy household at times.

In any family when parents disagree over how to raise a child, tensions rise. When parents of a child with AgCC disagree over child-rearing issues, consequences can resonate throughout the family.

Siblings

Family members raised concerns about the impact the disorder had upon siblings. Parents acknowledged being preoccupied, having a lack of time for other children. One parent explained, “His little sister, 5 years old, gets the short end of the stick, in that her brother gets the lion’s share of attention.” Roles also changed for siblings as they became caregivers, “We have 3 boys that are younger than our ACC child and they are growing up being helpers for their older brother.”

Participant excerpts illustrated that caring for an individual with a disability may affect non-disabled siblings in a variety of ways. One parent acknowledged, “We have another son also and it definitely impacts him... He has no friends.” Other participants admitted that oftentimes, siblings felt embarrassed by their brother or sister: “Social and language deficits are embarrassing for his 10 year old sister who notices the difference between him and others who are his age or less than his age.” One respondent disclosed, “Our younger children are known at school for having an older brother that “cannot talk or see very well.”

Extended Family

The birth of a child with AgCC can also produce tensions among extended family members. One family member conveyed: “Friends and family will exclude you because you restrict things they want to go do; I think that some stay away because they don’t know how to deal with it.” Another responded, “My husband’s parents do not have anything to do with

our family... It has caused a huge impact on our family... Nobody ever offers to help out and holidays [are] not spent with any family.” Additionally, parents reported that behaviour related to the disability caused undue stress on the family: “Meltdowns [are] a regular event that strain all relationship[s] including husband, siblings, grandparents and friends.”

Other families conveyed the disability brought intimacy to their home. One participant noted, “Close and extended family, as well as friends and acquaintances have learned tolerance and not to judge people with disabilities.” Another replied,

I didn't choose this condition for my daughter; it chose us, but we learn everyday a bit more about patience, not to judge and understanding. As these are the qualities we ask families and friends to live by when interacting with us.

Extended familial support was important in terms of physical and emotional support as a set of grandparents stated, “Fortunately we, the grandparents, live close [and] can help whenever needed.”

A Change in Future Planning

Theme four illustrated how the diagnosis influenced choices families make about the future. Parents originally wanting more children acknowledged they, “decided to only have one child” or now may “choose to have just one more, instead of two.”

Because AgCC is a spectrum disorder, child care, respite care, and residential options are also considerations many families with AgCC must make. A parent of a child diagnosed with AgCC reported:, “It's more difficult to go out socially because finding someone to babysit a 6 year old who is nonverbal, still in diapers, and unable to feed herself is difficult.” Another parent echoed this frustration:” I have tried 2 residential places but neither worked out... It's really sad because we cannot participate in life like we would like to.”

Parents were concerned about caregivers for their children in the future. Adult siblings may face additional responsibilities due to their unique relationship with their brother or sister with a disability depicted in the following statement: “Her older brother (only sibling)

and his serious girlfriend, with whom she gets along very well, will one day have to take responsibility for her well-being, as she will never be completely independent, and it may change their relationship.” Also, parents who had originally thought of being “empty-nesters” now turned to planning “retirement for three.”

The Financial Impact

The fifth theme illuminated the impact of a disability upon family finances. Subthemes included *out-of-pocket costs of medical care, insurance, outside resources, and childcare expenses.*

Out-of-pocket costs of medical care. Several of the participants responded that having adequate financial support was a concern. Some family members documented the need for employment to cover the additional expenditures of therapies and insurance associated with raising a disabled child, especially those who do not qualify for U.S. government assistance such as Social Security Disability (SSD) or Supplemental Security Income (SSI). Family members stated, “[We] spent an entire year's teaching salary on OT, ABA, and speech therapies out-of-pocket” and “We spend a lot of money on things that make life work better, shoes, pants with no snaps, sensory equipment like pool, and trampoline, speech, camp, and iPads.” Another stated, “We do NOT get to see doctors we wish we could without paying out of pocket.”

Insurance. Several of the participants reported that their health insurance coverage was limited, especially in regards to therapies and additional resources. One participant stated, “No insurance covers all of her therapies.” Another struggled with “supplements that insurance will not cover” and a “special diet that is not covered.” One participant stated the high price of having to pay for additional insurance: “extra insurance costs \$700/year.” A participant mentioned that although her son’s health insurance covered doctor visits, the “hospital did not accept our insurance.” Some family members lost their employment or

primary insurance coverage due to the diagnosis, “We lost our primary income because I had the better health insurance.” Another stated “military insurance dropped him.”

Outside resources. Although many of the caregivers struggled with insurance or therapy costs, some participants reported they were able to find assistance from government subsidies. One family stated, “[We are] helped greatly by our state. Our son is enrolled in Family Support and they help with recreational and adaptive medical that is not covered by my employer’s insurance. He is also covered by Medicaid which helps a lot.” Another family member noted, “Therapies have been covered under Early Intervention Services from the state.” Two other participants noted the individuals in their household with AgCC qualified for “SSI and Medicaid”, “and Section 8 housing” (government subsidies in the USA).

Child care expenses. Quality affordable childcare is difficult to find for families caring with individuals with disabilities. Family members reported needing special care nurses for babysitting because of special medical needs and having to schedule around childcare in order to “have someone available to be with them.” Another participant noted having a babysitter “5 days a week with him after school from 2-5:30 to talk to him, play with him, and read with him for vocabulary development.”

Respite programs may provide temporary break for families or caregivers in a variety of settings. In this study, some families that were provided state services also had additional respite benefits. For example, one participant remarked that “VA pays for 40 hrs. per month for respite.” Another family member stated although respite care was provided, it was “over 3 hours away.”

Social implications. The last theme emerging from the data was the social impact of the diagnosis. Two sub-themes emerged *friendships* and *social settings*.

Friendships. Families of children with disabilities have the same aspirations as other parents. They want their children to have friends and positive relationships; however, they often face social isolation and loneliness. One family’s candid statement described feelings

of separation: “It’s like looking inside this globe with people laughing and having fun, dancing and having lots of friends, having freedom. We are looking [in] from the outside.” The impact of isolation occurred in the U.S. and abroad: “We are socially isolated, as we spent 20 years not knowing or hearing of anyone in the country (Australia) with ACC... It’s hard to make friends when you have [a] disability and little money.” Other participants stated that making friends, as adults caring for individuals with ACC was difficult: “I can never understand why no one in my family has any friends but it has to go back to having a son with ACC.” A third stated,

We have NO close friends. We do not go out with other couples. We are not invited to parties or any type of get-togethers. Celebrating anniversaries, birthdays and holidays can be very difficult. Most of the time, we don't even bother.... We feel alone. Additionally, due to a lack of appropriate age-appropriate social and communication skills, making friends and participating in social activities were reportedly limited for individuals with AgCC. One family member stated, “She doesn't have sleepovers like her peers; we don't get invited to friends' houses as she is the cause of most disruptions including repetitive[ly] asking the same questions causing many friends to not invite us anymore.” Another family member wrote, “They spend a lot of time trying to fit in but they are still socially isolated.” One parent remarked that the lack of social understanding inhibited their child’s understanding of personal space, “He has difficulty reading social cues, pronounced emotional sensitivity, and is very pro-social, often invading other's space.”

Family members reported that individuals with AgCC generally want to be social and develop friendships, “She loves to make friends wherever she goes and accepts every one for who they are without judgment.” However, this also created stress among family members due to worries about the AgCC individual’s welfare because they may have difficulty differentiating between safe and unsafe persons. One family member wrote, “An issue is that

he will talk to anyone, anywhere. We were always watching him like a hawk because he would just take a stranger's hand and walk off with them at a park.”

Social Settings. Results indicated that the general public’s reactions to the child with AgCC behaviour, physical appearance, or mental ability had a negative impact upon families. Parents reported wanting to protect the dignity of their child’s self-worth and self-esteem:

The social impact is huge. Everyone you meet thinks your kid is unfriendly, spoiled, not disciplined... You get countless advice and comments. The AgCC child has a very hard time keeping friends. They can't keep up. The self-esteem issue is a big one.

Another stated, “In public, we have to [deal] with the stares, laughing and making fun of my son which hurts me deep in my soul.” Going out in public also involved taking risks because of possible behaviour outbursts or a lack of communication or comprehension skills.

For families raising individuals with AgCC, activities required scheduling around the needs of the child; often, families chose not to participate in social events. For example, one parent stated, “We are very careful about schedule, where and when we go places and have a limited social life. We don't do parties, Wal-Mart, sporting events or holiday gatherings.”

Another reported feelings of isolation:

Due to some behaviour and impulsivity issues, we miss out on a lot of opportunities to go places we would normally go. We limit our excursions based on what we think our ACC'er can handle. Many things that we think would be enjoyable are often just "too much" for our little guy to handle. We've had to readjust our way of thinking on a lot of things.

Families also recognized difficulties in transitioning from home to the job market. “People are not willing to allow him a chance with a job because of comprehension and needing extra time to learn.” Even individuals with AgCC who reached adulthood recognized that social connections were different for them as one adult reflected: “I have a hard time in social

settings. I can't quite put my finger on it. What seems very clear to me sometimes gets misconstrued in the delivery.”

Discussion

How does caring for an individual with the neurologic disorder AgCC impact the life of caregivers? The answer to this research question is as complex and unique in how the diagnosis of AgCC affected families in different ways. However, across each of the categories emerging from the research, commonalities did exist. For example, although the timing of the initial diagnosis varied, the pendulum of emotions was evident in each stage. And, although some abnormalities may be evident during routine birth screenings, oftentimes, they are not apparent until childhood. And, even with newer medical technologies and capability to network, participants in this study reported a lack of information and support. This may due to the variability of the disorder and that interventions and therapies are unique to the individual. Additionally, because many of those diagnosed are still in childhood, little is known about the impact upon the family as they approach adulthood. And, milder cases of AgCC may go undiagnosed altogether or misdiagnosed.

Secondly, many of the individuals in this study who were provided government assistance also qualified for low income benefits. It is important to note that in many cases, in order to qualify for government subsidies, families' incomes must fall below specific ranges, which prevented many families in this study from receiving funding. Support for individuals with AgCC and their caretakers must come through programs which restructure benefit systems to provide increased insurance benefits and employment support; these systems will provide a safety net for other families in the future. The study highlights that families need an array of individualized support services and childcare opportunities for both self and family. It is important to note that as of October 2015, The U.S. Federal Government Centres for Medicare and Medicaid Services (CMS, 2015) and the National Centre for Health Statistics (NCHS) will identify disorders of the corpus callosum in the International

Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM) (CDC, 2015). By coding AgCC as a medical condition, over time, the hope is that the patient's care will be improved through better documentation and acuity of care and expand public health research (e.g. clinical trials epidemiological studies) and knowledge of this low-incidence disorder. Also, having a coded diagnosis will allow for improved reimbursement of care for patients using the Health Insurance Portability Accountability Act (HIPAA) including both the Medicaid or Medicare systems (CMS, 2015).

Thirdly, although the intent of this study was to explore perceptions of those caring for individuals diagnosed with AgCC, three adults with AgCC, living independently completed the survey. For many adults with the disorder, completing an online survey would be difficult if not impossible without assistance. However, statements from these participants are meaningful and informative as research shows that there are few individuals with AgCC able to live independently (Caltech, 2012). These adults illustrated how they unknowingly lived with the AgCC disorder and struggled to make friends and find employment and the sense of relief when diagnosed that enabled them to understand their past. Similar to stories told by older adults in this study, Joseph Gaibraith (2014) wrote in his blog *A Boy with a Whole in His Head*, "Having both ACC and ASD, I am always struggling to put all the pieces together in my life... I always feel like *the odd piece left out*" (para. 10-11).

Finally, this research found delays in social skills wide-spread in individuals with AgCC. This is not surprising as studies have shown AgCC individuals to have deficits in social cues, judgments, and self-perception (Brown & Paul, 2000; Rehmel, et al., 2016). It is of interest to compare the above findings with social impairments found in other low-incidence disabilities such as autism-related spectrum disorders (ASD; See Jurevičienė & Šostakienė, 2014). According to Frith (2004), individuals with ASD have diminished abilities to understand complex emotions, facial gestures, or feelings of others. Furthermore, ASD individuals may have a reduced awareness of their own feelings. These findings suggest that

individuals with AgCC may fit the profile of ASD in relation to the deficits in social norms. And, in a more recent study, it was found that one-third of individuals diagnosed with AgCC met diagnostic criteria for autism (Paul, Corsello, Kennedy, & Adolphs, 2014). According to Frazier, Keshavan, Minshew, and Hardan (2012), there are recognized size reductions of the corpus callosum (CC) in individuals diagnosed with autism. However, recent research has not been able to confirm this link in that “the causal relationship between callosal agenesis and autism remains unclear” (Paul et al., 2014, p. 15). Yet, Boothe, Wallace, and Happe (2011) suggested that proven interventions commonly given to individuals with ASD may also benefit those with AgCC.

Implications for Practice

As the number of individuals with AgCC continues to escalate due to improved medical techniques, proactive problem-solving for children and adults with AgCC must be considered. Research indicated that when families are adequately supported, they are better able to cope with many of the issues raised in dealing with a disabled child (Burke, 2008; Coons, Watson, Yantzi, & Schinke, 2016). This study supported Reinke and Solheim’s (2015) finding that social media like Facebook is a valuable tool for families to find information and online social support especially in isolated geographical areas.

A critical challenge will be to educate caregivers, health, and educational professionals on the disorder in order to influence the level of care and support individuals with AgCC and their families receive. This will mean moving beyond just a medical disability and toward a team approach by bringing others into the conversation. Healthcare providers may find social media an avenue to move beyond clinical healthcare to provide research based information on the AgCC disorder to families and caregivers.

Since 40% of individuals identified with AgCC were under three years of age, additional research should be undertaken to identify perspectives of diagnosed adults and coping mechanisms and strategies they have used to reach adulthood. Future research may

consider a longitudinal study to look at how caregivers' perspectives change as the child gets older. Also, future research may need to examine behavioural interventions and instructional practices crucial for supporting individuals diagnosed with AgCC as they reach school-age.

Limitations

One of the major limitations of this study was the nature of the data collection. Since the actual number of individuals with AgCC is unknown, the social networking sites consisted of only a representation of the population being studied making it difficult to generalize findings to all individuals with AgCC disorders. It is possible that for every participant that responded, there are likely many others that are silent, unaware, or do not have access to social media to gain support or information about AgCC. Also, the study focused on primary caregivers, specifically family members of the individuals with AgCC and not the individuals with the disorder. Adults with AgCC who participated were higher functioning and may not reflect the broader community of individuals with AgCC.

Conclusion

This study confirmed that there is an undeniable impact upon families of individuals born with disabilities. However, participants in this study were not in denial but rather relaying both stressors and positive aspects of raising an individual with AgCC. This disorder impacted the families in significant ways (emotionally, financially, socially); however, sentiments of love (n=23), hope (n=17), and understanding (n=31) were repeated. If given the choice, most parents would not choose this disability for their child; but, if they had to do it over again, would choose to have their child. As one parent so thoughtfully wrote:

Although it can be hard to care for our son, the greatest impact of having him in our home is learning that progress is measured in little steps and life is not a race. Intelligence is not just found in those who speak and read well but also in those who are disabled. I love to watch our son play. There is no one like him in the whole world. He examines items that most children are not interested in and he finds the lines,

angles and joints in everyday objects. And for whatever reason they give him joy. He is learning things and even though he cannot yet express to me what he is learning, I see him learn and I am proud of him. I know he is intelligent and I am grateful he is in our home.

According to Lalvani and Polvere (2013), these situated narratives can be helpful in understanding the meanings of disability and cultural definitions of normative family life. Recognizing concerns may be the first step towards building the knowledge base for individuals with low-incidence disabilities such as AgCC so their families can receive the needed support to lead the healthy and fulfilling lives they deserve.

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