

# The Information Practices of Canadian Family Caregivers of People with Down Syndrome

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## Abstract

This literature review was conducted as part of a research study, the purpose of which was to understand how Canadian family (unpaid) caregivers of people with Down syndrome (DS) find, understand, use, share, and manage information to meet their needs and the complex needs of those in their care. Unpaid caregivers are vital to society but are undervalued. The need for caregiving is growing as people with Down syndrome are living longer and are likely to experience dementia as they age; the responsibility for caregiving is being increasingly transferred to families. Information is crucial for empowering and enabling caregivers. In conducting this review, I found that caregiving information work is stressful, mostly done by women, requires robust networks, and links to troubling social and economic trends.

*Keywords:* information, caregiving, family caregiver, Down syndrome

Caregivers are vital to society. One in four Canadians aged 15 and older (7.8 million people) provide care for family members or friends with a long-term condition (Statistics Canada, 2022, para.4). A caregiver, as defined by Caregivers Nova Scotia (2023), is “a person who gives unpaid care to someone who has a physical or mental health condition, or who is chronically ill or frail” (para. 5). The term family caregiving, or family-centred care (Marshall et al., 2015) is common because family members are increasingly assuming the role of care provider, but this care can also be provided by friends, neighbours, chosen family, etc. (Dalmer, 2018). Family caregivers contribute a staggering amount of unpaid labour to society, about 5.7

billion hours of care each year (Bielski, 2023). The estimated imputed economic cost to replace family caregivers with the paid workforce totals \$25 billion (Canadian Caregiver Coalition, 2013, p.2). However, 95% of Canadian carers believe their important role is not widely recognized by society (Embracing Carers, 2020, p.22) and more than one in three caregivers are distressed (Canadian Institute for Health Information, 2020).

### **Care Work Entwined with Information Work**

Dr. Nicole Dalmer (2018) describes unpaid caregiving as an “invisible” form of work (i.e., care work) (p.1). Adding the term “work” here seeks to make “visible the often invisible” (Dalmer & McKenzie, 2019, p.386), which can be “a powerful act, particularly within current climates of austerity, in which responsibilities for care work...are increasingly shifted onto families” (Dalmer & McKenzie, 2019, p. 389). Information practices are also a form of work. For caregivers, care work and information work are intertwined and interdependent. As Dalmer (2018) writes, “information work (the seeking, use, evaluating or sharing of information) is crucial to the work of caring for oneself and for others” (p.2) and information is “fundamental to good care, enabling and empowering carers to make better choices and take control.” (p.2). Studies show that caregivers have complex and ever-changing information needs, and that those needs are consistently unmet (Dalmer & McKenzie, 2016). At any given time, caregivers need information about, but not limited to, healthcare, law and finances, emotional and spiritual support, respite, community services, school services, extracurricular activities, employment opportunities, transportation, nutrition, assistive tools and technology, advocacy and so on. It is important here to distinguish unpaid caregiving from paid, wherein someone who is usually licensed and possesses formal training receives a salary or wage in return for providing care (Caregivers Nova Scotia, 2023). I focused on unpaid caregivers within this study because this is where the burden increasingly falls, and therefore this group stands to benefit most from these studies. This is not to minimize the experiences of paid care providers. However, paid care providers are more likely to have formal support through their employer, and their lives are not intertwined with those in their care to the same extent as family caregivers.

## Caregiving for People with Down syndrome (DS)

There are an estimated 45,000 Canadians with Down syndrome (Down Syndrome Association of Toronto, 2022, para.5). As people with DS have reduced independence in performing daily activities, they require a high level of assistance from their caregivers (AlShatti et al., 2021). And their need for caregivers is growing. In just three decades, the average life expectancy for a person with DS has increased from 25 to 60, while more than 75% of people with Down syndrome aged 65 and older are living with Alzheimer's disease (Canadian Down Syndrome Society (CDSS), 2020, p.29). People with DS and their caregivers have not often been the focus of research. Still fewer studies have focused on the information practices of these caregivers. According to the National Institute of Health, Down syndrome is the least funded genetic condition (Global Down Syndrome Foundation, 2018, para.7).

I have a personal connection to DS caregiving because I am a secondary caregiver for an adult with DS. I will eventually be the primary caregiver. I have some experience navigating this landscape and understand how complex and frustrating it can be. I also understand the isolation and anxiety that can accompany care work. I understand how important accessible, easy to understand information is to strengthen a caregiver/care recipient relationship and one's emotional health within it.

### Study Summary

This literature review was conducted as part of a research study entitled "Informing is caring: The information practices of Canadian family caregivers of people with Down syndrome." The research questions guiding this study were:

- Where do caregivers of people with Down syndrome find, use, share, and manage information? What tools do they use to find, use, share, manage, and understand information? What factors (within and beyond their control) influence how they engage with supportive information?
- What barriers do caregivers of people with Down syndrome encounter within their information practices and what strategies do they use to overcome those barriers?

- Do the information resources meet the needs of the caregivers and if not, how could those gaps be filled?

This was a qualitative phenomenological study, which focused on describing the lived experiences of participants (Leedy & Ormrod, 2019; Creswell & Poth, 2018). Virtual, semi-structured interviews were conducted with six adult caregivers of someone with Down syndrome across Canada to collect qualitative data. The data was analyzed using reflexive thematic analysis. The key findings of the study are that caregivers of people with Down syndrome (DS) need clear, personalized, centralized, consistent information; they need to know where to find this information; and they need more sensitive and empathetic information from medical and government professionals.

### **Literature Review Introduction**

The topic of caregiving is well-documented in research, particularly unpaid caregiving, or care at home. Most caregiving literature focuses on aging or chronic illnesses, such as cancer. An early notable scholar in this area is Anselm Strauss who also co-developed grounded theory (a research method widely used in academia). Corbin and Strauss (1985) describe the concept of “illness related work,” as “regimen work, crisis prevention and management, symptom management, and diagnostic-related work.” (p. 226). Conditions like Down syndrome also go hand-in-hand with caregiving. Although the behavioral and functional abilities of people with DS change as they move from childhood into adolescence and adulthood, most remain in need of at least some degree of support throughout their lives (Namkung et al., 2015). Unpaid caring for someone with an intellectual disability is usually a lifelong commitment for these carers, particularly parents and siblings. Despite this, few studies focus on the specific needs of caregivers of those with Down syndrome and even fewer capture their perspectives using qualitative approaches (Hart & Neil, 2021, p.61). Most research on people with DS groups them into broader categories that they share characteristics with, including people with disabilities (cognitive and physical), autism, and psychiatric disorders (schizophrenia, bipolar disorder). Those with DS are often used as the “control” or “contrast” group for those studying other disability conditions (Hodapp, 2007, p.279). Although these conditions can appear together and share characteristics, they are not the same. As with any condition, capacities vary between individuals.

People with DS have their own needs and abilities, which means the caregivers do as well. As Hart and Neil (2021) state, these individuals, and their caregivers both have unique needs for support, including informational support.

In my lifetime, there has been a massive shift in our understanding and acceptance of people with intellectual disabilities. Until the early 1980s, the main perspective of researchers and the public was “overwhelmingly negative” (Hodapp, 2007, p.279) with the implication that having a disabled child was “bad” (p.279). Advances in medicine and early childhood intervention mean that we know more about disorders like DS than ever before. There is more social inclusion in Canada today, thanks to our expanded understanding of the condition, the work of advocacy groups, and landmark legislation, such as the 1991 National Strategy for the Integration of Persons with Disabilities, and the UN Convention on the Rights of Persons with Disabilities, which Canada signed onto in 2007 (Inclusion Canada, 2019, p.2). People with DS and similar conditions are more visible in our communities and not locked away in institutions (although it is worth noting that institutionalization has not been eradicated). These changes are reflected in the language used in research studies, with a shift from harmful terms like “mental retardation” to “special needs” or “disabled,” and dated phrasing, like “the Down syndrome child” (which defines the person by the condition) changing to “child with Down syndrome”. Though we have come a long way, there is still a lot of work to be done on these fronts, and more research is part of that work.

Most research into the information practices of caregivers concerns health information, health literacy, and caregiver interactions with health professionals. A lot of it is written from the perspective of the medical community, including doctors or pediatricians, and is published in medical or pediatric journals. Much of what is written about DS caregiver information practices concerns pre-natal, early intervention, or post-diagnosis information needs. It is not surprising that demand for information by caregivers is high at these stages. However, almost all the research I consulted points to a need for ongoing support for caregivers, as “caregivers’ educational needs vary throughout the course of their caregiving experience” (Washington et al., 2011, p.41). Pre-natal information is a contentious topic when it comes to intellectual disabilities

because of the modern prevalence of fetal genetic screening. There is much debate about this for various reasons; this is beyond the scope of this paper. For those that want to learn more, I will point to the excellent resources provided on the Canadian Down Syndrome Society website: <https://cdss.ca/resources/prenatal/>.

### **Literature Review Methods**

To begin with gaining a broad sense of the literature, I conducted basic searches through Google Scholar using the search terms “down syndrome, caregiver, information practices”. This resulted in a large number of broad resources, some of which were useful. Most of the useful resources that appeared at this stage were reports from community organizations related to Down syndrome or caregiving, or internet articles regarding trends in these topics (e.g., “Canadian Caregiver Strategy” from the Canadian Caregiver Coalition, the “Canada Carer Well-Being Index” from Embracing Carers, and “Today and Tomorrow: A Guide to Aging with Down syndrome” from the Canadian Down Syndrome Society). The websites for Canadian caregiving organizations were very useful to my study. The glossary (see Appendix A) and “caregiving language” page on the Caregivers Nova Scotia website were tremendously valuable, particularly for the distinction between care providers (those who provide paid care) and caregivers (those who provide unpaid care). I found their definition of “caregiver” concise and appreciated that these terms were developed in consultation with caregivers.

A subject specialist librarian at my institution guided me through some advanced searches in Google Scholar, and the full catalogue of EBSCO databases. Upon her recommendation, I used the following search strings in Google Scholar and EBSCO: caregiver, “down syndrome”, intitle: information; information (intitle) AND caregiv\* OR “parent” OR “family” AND “down syndrome” information (intitle) AND care AND down syndrome NOT prenatal. Finally, I utilized the reference lists from significant articles to find further related sources. To analyze each source for inclusion in this review, I read each thoroughly and highlighted any discussion or findings that related to my research questions.

## Literature Review Analysis and Commentary

My synthesis of the studies relating to the information practices of caregivers of people with Down syndrome revealed four key themes: caregiver burden, outdated gender roles, the importance of networks, and links to troubling social and economic trends.

### Caregiver burden

All the caregiving literature I consulted presented evidence of caregiver burden. Caregiving is often cited as a stressful experience that results in poor mental and physical health. Issues commonly connected to caregiving responsibilities include depression and anxiety, high stress levels (Lee et al., 2021; Buteau-Poulin et al., 2020; Phillips et al., 2017), decreased social and professional life, and feelings of isolation, guilt, and entrapment (Gallagher et al., 2008). Many studies point to the consistently unmet needs of caregivers (Dalmer & McKenzie, 2016; Siklos & Kerns, 2006; Washington et al., 2011). The caregiver experience is often described as complex, intense (Barros et al. 2017), and ever-changing, as are their information needs. Caregivers need a wide range of information at various levels of specificity. Washington et al. (2011) found that key caregiver information needs are medical information (etiology, diagnosis, prognosis, treatment options), information about the availability of services for caregivers and care recipients, and information about financial support programs. Several topics of information are captured here. This information must be “easily comprehended... avoiding technical language.” (Washington et al., 2011, p. 40).

To add to the complexity, caregivers must act as “information proxies” for the people in their care, practice constant vigilance and be prepared for unanticipated changes (Dalmer & McKenzie, 2016, p. 2). Chronic conditions are by nature unpredictable. As Corbin & Strauss (1985) describe, these conditions have a “trajectory” (p. 235) characterized by “phases” (p. 235) and “with each phase, different tasks are required for trajectory management and different resources are necessary to perform those tasks” (p. 228). A set of organizational tactics are required for these caregivers to control their lives. Information work, including “networking, scouting out, coaching and training, providing and clarifying instructions, distinguishing between needs and wants,

searching for people, places, and necessary things” is a crucial tactic (Corbin & Strauss, 1985, p. 244).

### **Outdated gender roles**

According to the literature, a significant proportion of caregivers are female, “emphasizing the historical and cultural tradition of the woman in taking the main responsibility for care” (Barros et al., 2017, p. 3630). Despite societal changes that have expanded women’s opportunities, they still take on the majority of “hidden work” in our society including serving as household information keepers and coordinators (Dalmer & McKenzie, 2016). Women are seen as naturally caring and tend to take on nurturing roles within their families. This work is usually invisible, “seldom acknowledged” (Harris, 2009, p.80), and usually takes place at home, where “information management, self-care, and health maintenance remain largely invisible and underarticulated” (Harris, 2009, p. 80). Many studies into caregivers of people with Down syndrome focus specifically on mothers (Hodapp, 2007; Singer 2006; Bailey et al. 1992 Nes et al. 2014; Phillips et al., 2017). Hodapp (2007) refers to this as “longstanding interest in mothers of children with disabilities” and states that “mothers have been the subject of most studies of the families of children and adults with Down syndrome” (p. 281). Thus, caregiving research demonstrates that outdated gender roles and expectations continue to persist in our society, which influences caregiver health and, in turn, their information practices. Not surprisingly, there is a lot of feminist scholarship around the topic of caregiving and its associated activities (including information practices). This is mostly focused on reframing care as work. Hooyman & Gonyea (1999) describe care as “a central feminist issue” (p.150) and this perspective “recognizes that women have historically been oppressed within the home and the labour market” (p. 150-151).

### **The importance of networks**

Consistently, strong networks are cited as an invaluable tool for family caregivers of people with DS. These social supports provide psychological benefits and are an important source of information sharing. All studies reflect that caregivers who maintain these networks can cope much better with their responsibilities. Many caregivers have limited social lives due to the all-encompassing nature of their care work. They sacrifice their own needs to ensure a healthy life for their children (Al Shatti et al., 2021), have



more restrictions on their time (Barros et al., 2017), and may isolate themselves from society (Gallagher et al., 2008), whether intentionally or not. These behaviours are understandable, but only aggravate the burden they feel. Given the constraints that caregivers of disabled people experience, they have an even greater need for information and networking than the average person (Buteau-Poulin et al., 2020). Social activities such as talking to other caregivers of disabled people, sharing information with other families, and advocacy opportunities, such as joining a local group concerned with DS (Eaves et al., 1996; Hart & Neil, 2021) directly contribute to reduced caregiver stress.

In addition to strong social networks, it is important for caregivers of disabled people to have a supportive health information network, including care organizations and healthcare professionals (Dalmer & McKenzie, 2016). Melvin et al. (2018) describe this as “a two-way partnership” (p. 426) of sharing and receiving information. Health professionals have a responsibility to provide clear, current information to these families and yet most caregiving studies show that this is lacking. Marshall et al. (2015) found “a lack of sensitivity, knowledge, and care co-ordination among providers” and state that families are “frequently alone” (p. 370) in care coordination. Eaves et al. (1996) found caregivers of people with DS have a “very high desire for better informed professionals”, while only 30% of parents in their study felt they had excellent resources (p. 68). Studies consistently show that caregivers need information that is specialized, patient-centred, and flexible to accommodate each family’s unique needs (Skelton et al., 2021; Siklos & Kerns, 2006; AlShatti et al., 2021; Marshall et al., 2015).

Ultimately, the literature cites strong and supportive networks as crucial to the empowerment of caregivers. Access to good information is enabling, allows carers to confidently self-advocate and self-help, and leads to informed decision-making (Dalmer, 2018; Siklos & Kerns, 2006; Melvin et al.; 2018; Washington et al., 2011).

### **Links to troubling social and economic trends**

The scholarship indicates an increased need for caregiving in our society in general. There are clear links between dementia and Down syndrome, with more than 75% of people with DS aged 65 and older living with Alzheimer’s disease (CDSS,

2020). This means that their need for adequate and consistent caregiving is increasing. According to Statistics Canada, the number of Canadian caregivers increased by 5 million between 1997 and 2012 (Sinha, 2013). Our population is ageing, and our resources are increasingly strained; our current age is a “climate of austerity” (Dalmer & McKenzie, 2019, p. 389). Many studies highlight the need for families to navigate confusing, decentralized services with high personnel turnover (Marshall et al., 2015), and service systems that are “crisis-driven” (Siklos & Kerns, 2006, p. 922). This translates to increased frustration and stress for those families.

Scholars consistently call for caregiving to be reframed because it requires a great deal of effort, time, and resources in information seeking (Dalmer & McKenzie, 2016; Harris, 2009). This work is unpaid and takes place mostly within the home, while our traditional, capitalist view posits that valuable work is paid and public. This contrast, and the increased strain on medical resources, unfortunately links caregiving to economic instability. Many researchers have found that family caregivers must leave their jobs to manage their responsibilities. This results in caregivers experiencing “reduced cultural and economic resources” (Barros et al., 2017, p. 3631). They are living on tighter budgets, meaning they are more dependent on funding, and this financial insecurity leads to greater emotional stress (Buteau-Poulin et al., 2020; Washington et al., 2011). Ironically, caregivers can end up dependent on the dysfunctional systems that forced them into unpaid work in the first place. Additionally, some studies have shown that resources are more prevalent and accessible in large centres, and lacking in rural areas (Hart & Neil, 2021). Marshall et al. (2015) found that families experience gaps in much-needed services like insurance, childcare, and respite due to these economic factors and recommend addressing these underserved through changes in public policy, to ensure that “fewer families fall through the cracks” (p. 371). This climate is characterized not only by a scarcity of money, but a scarcity of expertise and of innovation, which means caregivers of people with DS struggle to get the personalized, adaptable information that they need.

### **Literature Review Conclusion**

This literature review serves to support the larger research project “Informing is Caring: The Information Practices of Canadian family caregivers of people with Down

syndrome.” In highlighting the key themes from what is known about the information practices of caregivers of people with Down syndrome, it can support or be the catalyst for other related research.

In conducting this literature review, I found that caregivers require a range of information on an ongoing basis, through every stage of their caregiving journey. Their information needs are constantly evolving. Most family caregivers experience high levels of stress and burden, their unpaid work is not valued, and demand for their work is only increasing as our population ages. Dalmer and McKenzie (2019) call for us to decrease the dichotomisation of everyday and workplace information practices in order to “bring into view the often invisible forms of work required to make everyday life possible” (p. 386).

In summary, this literature review demonstrates that caregivers for people with DS need to have access to clear, consistent, individualized medical information, advocacy information, and opportunities to exchange information with other DS families. They need to feel empowered to make informed decisions on behalf of their care recipient for the good health of their entire household. In order to feel empowered, they need to be able to quickly and easily find, understand, and exchange information related to their caregiving work, which (in short) is information that answers their caregiving questions.

Library and Information Science (LIS) professionals are expected to “provide consultation, mediation, instruction, and guidance...for all user populations” (American Library Association (ALA), 2022, p.7) and for “understanding and assessing the information needs of a community, and...the ways the library can assist and collaborate in meeting those needs.” (ALA, 2022, p. 7). It is particularly important for them to understand the information practices of marginalized people. This links to the American Library Association (ALA) (2022) core professional competencies of user service (p. 7) and social justice (p. 8). People with intellectual disabilities (such as DS) and unpaid caregivers are marginalized groups. They experience large gaps in resources (financial, educational, geographic, etc.) that negatively impact their information practices. My broader study, supported by this literature review, revealed caregivers do not feel they receive adequate information from their medical teams or government representatives.

This means they are increasingly turning to community resources, including libraries. Libraries are well positioned as central, timely, and convenient information sources for caregivers of people with DS. LIS professionals can guide these groups to complete their information work more quickly and easily than they could on their own. This guidance can help them feel seen and heard, providing them with visibility, acknowledgement, and in turn, empowerment. This literature review contributes to the ongoing need for more research supporting LIS professionals with proper approaches to use with caregivers and people with Down syndrome, increasing the quality of service and in turn the quality of their information experience.

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