

Assessing Oncology Services for Autistic Adults in Hamilton/Burlington

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Contents

Executive Summary	2
Introduction	3
Research Questions.....	3
Methods and Limitations	4
Methods.....	4
Limitations	5
Findings	5
Literature Review and Environmental Scan Findings	5
Unique Healthcare Challenges	5
Accommodating Individual Needs	6
Our Local Context.....	7
Interview Findings	8
Discussion.....	11
Conclusion	13
References	14
Appendix A: Literature Search Terms.....	17
Appendix B: Interview Questions	18

Executive Summary

While developmentally appropriate services are often prioritized for children, there is a significant gap in understanding how the specific needs of autistic adults are addressed within oncology care. The McMaster Research Shop partnered with the Youth Alliance for Intersectional Justice (YAIJ) to explore services available for autistic adults during their cancer journeys. People with autism face unique challenges when interacting with the healthcare system. Cancer care is an important area of concern as research shows that individuals with autism are at higher risk for health problems, including cancer. As the autistic population continues to grow, it is crucial for healthcare systems to adapt and ensure that oncology services are inclusive and responsive to their unique needs.

We conducted a literature review to understand existing research and performed an environmental scan to gather publicly available information about services in the Hamilton/Burlington area. We also interviewed two healthcare workers to learn about their experiences caring for autistic adult patients and what services are available for them.

We did not find specialized services for autistic adults with cancer, although there are other services available that are geared to broader groups (e.g., neurodevelopmental services, support for cancer patients). Our interviewees recommended implementing specialized navigator roles in oncology services in Ontario to better support autistic adults.

Moreover, in their interactions with the healthcare system, autistic adults experience unique challenges such as limited knowledge and understanding of medical information, communication, and sensory sensitivities in healthcare environments. Our interviewees highlighted the need for individual accommodations as well as sensory and emotional support. Healthcare providers may also lack knowledge about caring for autistic adult patients, hold stigma towards them, and experience ethical concerns due to challenges implementing “standard of care” strategies. We did not find specific policies or guidelines for providing cancer care to adults with developmental or intellectual disabilities. In practice, healthcare workers seem to use ad hoc solutions to address the unique needs of each patient.

Overall, our findings point to a gap in developmental oncology services for autistic adults. There is also a need for more healthcare provider training, policies, and guidelines to improve the healthcare experiences of autistic adults.

Introduction

In recent years, the autistic population in Ontario has grown. Administrative health and social services data reveal that between 2010 and 2016, 10,646 men and women in Ontario were diagnosed with autism (Lunsky et al., 2022; Tint et al., 2023). This demographic shift underscores the need to address the unique challenges faced by individuals on the autism spectrum, encompassing both developmental and healthcare-related support. Access to oncology services is a critical area of concern, as individuals with autism spectrum disorder (ASD) are at higher risk for health problems, including mental health issues and chronic conditions such as cancer (Weiss et al., 2018). Despite the emerging needs, very little is known about oncology services provided to autistic adults with developmental and/or intellectual disabilities and their cancer journeys. Autistic individuals often face specific barriers that complicate their interactions with healthcare systems. Moreover, autism research and services have historically had a greater focus on children, resulting in gaps in support and resources for adults (Krahn & Fenton, 2012). As the autistic population continues to grow, it is crucial for healthcare systems to adapt and ensure that oncology services are inclusive and responsive to these unique needs, promoting equitable and effective care for all.

The Youth Alliance for Intersectional Justice (YAIJ) is a Black youth-led collective of Black and racialized neurodiverse youth, adults with and without intellectual disabilities, and allies (Youth Alliance for Intersectional Justice, n.d.). Youth defy intellectual and/or developmental dis/ability labels by engaging in youth-centered, community-based projects and research focused on education, technology, housing, and entrepreneurship. YAIJ approached the McMaster Research Shop with an interest in investigating the oncology services available to autistic adults in the Hamilton/Burlington area and to better understand more broadly the healthcare service challenges and needs in this area.

Research Questions

Primary research question:

What are the developmental oncology services available, if any, to autistic adults with and without intellectual disabilities?

Sub-research questions:

- What are the unique healthcare service challenges and needs of autistic adults?
 - What are the unique needs of autistic cancer patients?
- What policies/legislation/guidelines exist, if any, for the provision of healthcare to adults with developmental and/or intellectual challenges, e.g. autism?
 - What policies/legislation/guidelines exist, if any, specifically for autistic adults?
- What healthcare services and supports are available to autistic adults in the Hamilton/Burlington area, if any?

Methods and Limitations

Methods

This study was divided into two main parts: part one focused on a literature review and environmental scan, while part two centered around key informant interviews.

We conducted a literature review focusing on the unique healthcare needs of autistic adults and autistic cancer patients. We searched APA PsycInfo and CINAHL using search terms in Appendix A and conducted a thematic analysis on our findings. We used the following inclusion and exclusion criteria:

Characteristic	Included	Excluded
Population	Autistic children or adults with or without cancer	Children <15 years
Outcome	Services and supports available to autistic adults; needs, challenges, barriers experienced by population	Mortality, incidence of cancer, association between ASD and cancer
Setting	Canada (UK, Australia, NZ, Austria, Germany, Denmark)	
Year published	2000 onwards	
Study design	Observational and experimental studies, reviews and meta-analyses, case study	Clinical trial Opinion pieces Editorials Commentaries
Language	English	

We also conducted an environmental scan to identify existing policies, legislation, and guidelines related to cancer care or systems navigation for adults with developmental and/or intellectual challenges, with a particular focus on the Hamilton/Burlington area, Ontario, and Canada. We reviewed the websites of relevant organizations such as the Government of Ontario, non-governmental organizations, and advocacy groups. The findings of both the literature review and environmental scan were used to inform our interview questions.

We conducted semi-structured interviews with two healthcare workers in the Hamilton/Burlington area to understand the current services and supports available to autistic adults. Our partner organization, YAIJ, led the recruitment process and provided a list of contacts to the research team. We also used snowball sampling by asking interviewees to refer their own contacts. However, the interviewees were not aware of any other professionals who could provide useful responses to our questions. The interviewees were asked to provide insights on our research questions, drawing on their professional experiences and observations. The full list of interview questions can be found in Appendix B. Their responses were analyzed to identify recurring themes and gaps in

the current healthcare system that may impact the quality of care provided to autistic adults, particularly in the context of oncology.

Limitations

Our study has several limitations that may impact the comprehensiveness and generalizability of our findings. First, our literature review was limited to only two databases, which could have narrowed the research scope and potentially missed relevant studies. This is significant given the challenge of finding sources specifically focused on autistic adults. Much of the existing literature focuses on adults with intellectual disabilities, a group that may include individuals with autism but does not fully represent the broader autistic adult population. As a result, our literature review may not fully capture the unique needs and experiences of autistic adults.

Additionally, the interview component of our study only involved two participants. Recruitment difficulties, and a focus on healthcare provider perspectives, meant that not all relevant perspectives were included, potentially leading to an incomplete understanding of current views on oncology services for autistic adults. For example, due to an explicit focus on healthcare provider perspective, we did not seek input from advocacy groups or individuals from other social service providers who may work with autistic adults and have experience helping them to navigate healthcare systems. As a result, while our study provides valuable preliminary insights, our findings should be interpreted with caution, and we recommend further research involving broader and more diverse sources.

Findings

Literature Review and Environmental Scan Findings

Unique Healthcare Challenges

Our literature review identified healthcare challenges and barriers that are experienced by **autistic adults**:

- They may have limited knowledge and understanding of medical information, including diagnoses, treatment options, and prevention (Abells et al., 2016; Dell et al., 2008; Heller & Sorensen, 2013; Stirling et al., 2021; Taggart et al., 2011; Tuffrey-Wijne et al., 2010). This lack of understanding can lead to confusion, fear, and anxiety (Dell et al., 2008; Heller & Sorensen, 2013). They may also be fearful, stressed, and anxious about changes in routine or going to an unfamiliar environment such as a hospital (Dell et al., 2008; Millard & de Knecht, 2019; Weiss et al., 2018). Some individuals may show denial or avoidance behaviours (Millard & de Knecht, 2019; Tuffrey-Wijne et al., 2010).

- Challenges with communication was also a major theme in the literature. Autistic patients may have difficulty communicating with healthcare providers (Dell et al., 2008; Heller & Sorensen, 2013; Stirling et al., 2021) and healthcare providers may lack training on how to facilitate effective communication (Malik-Soni et al., 2022; Vuattoux et al., 2021). Autistic patients may have limited verbal ability or communication skills (Dell et al., 2008; McEnhill, 2008; Millard & de Knecht, 2019), making it difficult to express their needs and ask questions (Tuffrey-Wijne et al., 2010). Some individuals depend on their caregivers for communicating (McEnhill, 2008), which can lead to information being misrepresented (Tuffrey-Wijne et al., 2010).
- Other barriers to accessing healthcare services include sensory sensitivities in healthcare settings (Abells et al., 2016; Dell et al., 2008; McEnhill, 2008; Taggart et al., 2011; Vuattoux et al., 2021), clinical processes (Stirling et al., 2021), physical barriers (Abells et al., 2016; Dell et al., 2008; Stirling et al., 2021; Taggart et al., 2011), logistical accessibility (Abells et al., 2016), and geographical or social isolation (Abells et al., 2016).
- Notably, Weiss et al. (2018) mention that autistic adults are more likely to visit a pediatrician, suggesting that their transition from pediatric to adult healthcare may be more challenging compared to the general population.

The literature also identifies challenges from the perspective of **healthcare providers**:

- They may lack knowledge about caring for autistic adult patients (Abells et al., 2016; Stirling et al., 2021). Stirling et al. (2021) describe how clinicians who specialize in cancer care may lack knowledge about intellectual disabilities and vice versa. Vuattoux et al. (2021) also mention the lack of training specifically about autism spectrum disorder.
- They may experience difficulties adhering to “standard of care” strategies and guidelines due to behavioural manifestations, communication challenges, and perceived lack of cooperation (Abells et al., 2016; Stirling et al., 2021; Vuattoux et al., 2021).
- Healthcare providers may stigmatize and hold misconceptions about patients with intellectual disabilities and/or autism (Abells et al., 2016; Malik-Soni et al., 2022; Vuattoux et al., 2021). They may view patients as being “difficult” (Vuattoux et al., 2021) or attribute behaviours to autism rather than considering a separate illness first (Malik-Soni et al., 2022). Healthcare providers may hold paternalistic attitudes and withhold health information from patients, believing it is best to protect them from distress (Tuffrey-Wijne et al., 2010). This stigma can prevent autistic adults from engaging with the healthcare system (Malik-Soni et al., 2022).

Accommodating Individual Needs

Existing literature describes healthcare services and supports that would be beneficial for individuals with autism and intellectual disabilities. A central theme was providing accommodations and individualized support that is tailored to each patient’s needs (Abells et al., 2016; Dell et al., 2008; Millard & de Knecht, 2019; Stirling et al., 2021). This

can include personal support and assistance, as well as specialized intellectual disability services (Segerlantz et al., 2020; Tuffrey-Wijne et al., 2010).

Researchers highlight the importance of adapting communication strategies to help individuals with intellectual disabilities understand health information (Abells et al., 2016; Dell et al., 2008; Olsen et al., 2023; Vuattoux et al., 2021). Specific to cancer care, Tuffrey-Wijne et al. (2010) mention the “Books Beyond Words” series, which are picture books that use visual aids and simplified explanations on difficult topics such as cancer and dying. McEnhill (2008) also mentions resources for staff about disclosing terminal illness and a toolkit for communicating with cancer patients with learning disabilities.

Healthcare navigation is particularly helpful for patients that need to access multiple services. Examples include accompanying patients to their healthcare appointments (Taggart et al., 2011) and individual plans, like those in Norway, for coordinating multiple services (Olsen et al., 2023). Healthcare transition services can help individuals as they move from pediatric to adult care (Malik-Soni et al., 2022). The ECHO Autism program also helps patients access services sooner by connecting physicians to autism experts (Malik-Soni et al., 2022).

Researchers recognize that family members play a significant role in caring for cancer patients with autism and learning disabilities (Tuffrey-Wijne et al., 2010). Vuattoux et al. (2021) recommend that healthcare providers collaborate with caregivers when developing individualized care plans. The WHO Caregiver Skill Training program also helps family members be more aware of ASD needs and services in their local context (Malik-Soni et al., 2022).

Our Local Context

Our environmental scan identified resources for autistic adults and resources for cancer patients. Though we found some guidance related to cancer and developmental disabilities, we did not find specialized services for autistic adults with cancer. We categorized these resources by audience: 1) services and supports for patients; and 2) guidelines and resources for healthcare providers.

Services and supports for patients

Programs for patients heavily focused on collaboration between allied professionals. Adult Neurodevelopmental Services (ANS) at the Centre for Addiction and Mental Health (CAMH) in Toronto have Developmental Service Workers who assist the care delivered by other clinicians (Centre for Addiction and Mental Health, n.d.). ECHO Ontario Autism also facilitates collaborative practices/referrals and connects healthcare providers to autism experts (ECHO Autism, n.d.). Social workers play a key role in helping patients navigate through different services they may require. At Hamilton Health Sciences (HHS) and CAMH, social workers address the needs of patients throughout their healthcare journey (Centre for Addiction and Mental Health, n.d.; Hamilton Health Sciences, n.d.). Some programs connect patients to community resources beyond the healthcare system, including the HHS Wellwood program for

people living with cancer (Wellwood, n.d.) and the Ontario government's programs and services for people living with developmental disabilities (Ministry of Children, Community and Social Services, n.d.). Programs may also support families of patients, including CAMH ANS (Centre for Addiction and Mental Health, n.d.), child life specialists at HHS (Hamilton Health Sciences, n.d.), and the World Health Organization eLearning Caregiver Skills Training for Families of Children with Developmental Delays or Disabilities (World Health Organization, n.d.).

Resources for healthcare providers

In terms of resources for healthcare providers, we found two resources related to cancer and adults with developmental disabilities. In 2016, CAMH released a toolkit for primary care providers about implementing health checks, including cancer screening, for adults with developmental disabilities (Centre for Addiction and Mental Health, 2016). For oncology nurses, an article from Oncology Nursing News stresses the importance of person-centered care for individuals with developmental disabilities. Practical strategies include utilizing visual aids, ensuring effective communication, and conducting thorough medical assessments to better understand and address their unique needs (Tichich, 2020). Autism training for healthcare providers was also a key theme. A report from the Department of Health and Social Care in the UK advocated for mandatory learning disability and autism training for healthcare staff (Department of Health & Social Care, 2019). The ECHO Autism program also has webinars, events, and symposiums available to healthcare providers, in addition to connecting them with autism experts (ECHO Autism, n.d.).

Interview Findings

This section presents data collected from interviews with two healthcare providers in primary care settings within Hamilton. These interviews explored the availability of developmental oncology services for autistic adults with and without intellectual disabilities, focusing on challenges in communication, healthcare system navigation, and tailored care solutions. The findings are organized by key themes, addressing the unique needs of autistic cancer patients and existing gaps in service provision.

What are the developmental oncology services available, if any, to autistic adults with and without intellectual disabilities?

The interviews revealed that developmental oncology services for autistic adults, particularly those with intellectual disabilities, are significantly lacking. For example, one participant mentioned a 42-year-old man with severe autism and intellectual disability who required treatment for rectal cancer. The existing services were not adequately equipped to address his unique needs, leading to various challenges. The oncology team had to negotiate accommodations, such as permitting a family member to accompany him during chemotherapy despite pandemic restrictions. They also had to coordinate with an anesthesiologist for sedation during chemotherapy and MRI scans due to the patient's needle phobia and difficulty remaining calm. The participant remarked that:

"It ended up then he needed to be like, totally conscious sedation, which then required ... we had to, you know, get an anesthesiologist available at the time that he was scheduled for his chemotherapy, and because that's not a procedure that we typically do here in the Cancer Center, we had to work with the hospital for when the anesthetist was ready, get it done, he'd have to stay there and get kind of woken up a little bit so that you know they, you know, knew he was okay. Then he would have to be transported back here to the Cancer Center for his treatment and so it just, from an objective point of view, it was a very big ordeal to get this done."

This case underscored the absence of tailored developmental oncology services for autistic adults within the current healthcare framework.

What are the unique healthcare service challenges and needs of autistic adults?

The interviews highlight several unique challenges that autistic adults face within the healthcare system. One participant pointed out the significant communication barriers, as the patient had very limited speech, making it difficult for healthcare providers to understand his needs and discomforts. The need for specialized support was also emphasized, as the patient's needle phobia and difficulty staying calm during long treatments required sedation and the involvement of a child life specialist, even though he was being treated in an adult cancer center. The participant also noted the ethical and emotional concerns experienced by healthcare providers, including nurses, who felt morally conflicted about administering treatment that caused the patient significant distress. They revealed that:

"He was a little different from our usual patient and a lot of the nurses felt very ethically or morally conflicted by having to insert a needle into him every day and him screaming and then it was upsetting for the other patients who were in the vicinity, you know, and could hear the distress."

Additionally, the patient benefited from being in a private room during chemotherapy to reduce distress, which required special scheduling and coordination. Family involvement was another crucial factor, as the support of family members played a significant role in managing the patient's anxiety and treatment adherence. The participant shared that:

"Allowing the family to be there more, you know, like family walked him into the operating room as opposed to a nurse and that we felt - and the family, you know, agreed that that helped to maybe not make it such a scary situation for him."

Another participant noted that the hospital environment, including factors like loudness and lighting, can be overwhelming and increase anxiety, a concern likely shared by many autistic individuals. The interviews also emphasized the importance of allowing extra time for patients to process information and the crucial role of a support system during appointments. A participant advised that:

"Allowing time is important, if there's extra time to process things you might need it. Similar to the time not only time per visit, you might need an extra visit to sort

of get people familiar with what's going on. And to sort of get around the idea of the unknown."

Likewise, a different participant mentioned that:

"I think that parents need to ... think about the eventualities. You know that this child has always been with them at home and maybe now they have cancer, and they won't be. So, you know, is dying at home an option? Is going to hospice an option? You know what will that look like? Going to St. Peter's, you know, somewhere that's in more a palliative setting down the road. Or, you know, at some point when it's appropriate. So those conversations need to need to be - be had at some point in time and whether the individual themselves is able to understand that type of conversation."

What are the unique needs of autistic cancer patients?

Autistic cancer patients, particularly those with intellectual disabilities, have several unique needs. For instance, one participant noted that sensory and emotional support is essential, requiring environments that minimize sensory overload and distress. This might include private rooms, calming activities, or the presence of trusted family members. The participant explained that:

"Avoiding loudness and lighting can help reduce some anxiety... we have good availability of you know, you can have your support system around--whoever you like to bring to your appointments."

Another participant highlighted the need for tailored communication strategies, as autistic patients may have limited speech or understanding. Reflecting on a specific case, they mentioned, *"this gentleman was 42 maybe? Quite low functioning. Very little speech."* These strategies might involve family members or specialists to facilitate communication. Behavioural management is also critical, with one participant emphasizing the need for specialized approaches to manage phobias, such as needle phobia, which might require sedation or distraction techniques.

What policies/legislation/guidelines exist, if any, for the provision of cancer care or systems navigation to adults with developmental and/or intellectual challenges, e.g., autism?

The interviews suggest that there are no specific policies or guidelines for providing cancer care to adults with developmental or intellectual disabilities, including autism. One participant elaborated that in the case they described, the oncology team had to develop ad hoc solutions to address the unique needs of the patient. Another participant did not mention specific policies, legislation, or guidelines for the care of adults with developmental or intellectual challenges, including autism. However, the participant expressed a desire for better navigation within the healthcare system, such as the implementation of more nurse navigators to guide patients through the complex cancer care process. They state that:

"I would love to see more specific nurse navigator type systems at the cancer centre because I think that they make a big difference in being familiar with populations and sort of having a blueprint for the things that they need."

What policies/legislation/guidelines exist, if any, specifically for autistic adults with cancer?

According to the interviews, there are no established policies or guidelines specifically for autistic adults with cancer. One participant explained that the lack of predefined procedures led to a reactive approach to patient care, with the oncology team having to create a "loose protocol" in response to the challenges they encountered in this case. They described that:

"It was very eye opening in terms of should this ever happen again, we need to pay attention to sort of the needs and find out from the family more than the day before they're coming in that you know, the oncologist knowing that he was a special needs person should have alerted social work and or the chemo suite and or you know, so out of that we kind of develop at least a loose protocol."

Another participant did not reference any established policies or guidelines specifically for autistic adults with cancer. Instead, they pointed out the current system's limitations in providing fully tailored care for this population. The interviewee suggested that having nurse navigators familiar with the specific needs of different patient populations, including autistic adults, could significantly improve the quality of care. Specifically:

"A navigator or a patient advocate would be ideal because they would at least have some bridge between like a sort of a new healthcare provider and what's going on with the patient."

What cancer care or systems navigation services and supports are available to autistic adults in the Hamilton/Burlington area, if any?

The interviews indicate that there are no dedicated cancer care or systems navigation services specifically designed for autistic adults in the Hamilton/Burlington area. One participant described how healthcare providers had to improvise significantly to meet the patient's needs, including coordinating sedation, using passport funding for additional services, and extensively involving family members. This lack of specialized services placed considerable strain on both the patient and the healthcare team. While another participant did not provide specific details about the availability of services in the Hamilton/Burlington area, they referred to existing navigation services within the broader cancer care system, stating, *"we do have a navigator in one setting. It's called our PYNK Program for young women with breast cancer."*

Discussion

Overall, developmental oncology services for autistic adults do not seem to exist within the jurisdiction we investigated. Though our literature review and environmental scan found programs designed for autistic individuals and those with cancer, they often do not address the needs of individuals who fall into both categories. Our interviews with healthcare providers confirm this finding as neither interviewee was aware of specialized healthcare services available to autistic adults.

Our literature review suggests that there are some researched best practices for delivering healthcare services to individuals with intellectual disabilities. This includes accommodations, individualized support, communication strategies, and navigation services. Interviews with local healthcare providers suggest that these are used in practice to some extent. For example, they mentioned arranging sedation during chemotherapy for a patient with needle phobia and having family members accompany the patient to their appointments. The interviewees also emphasized the importance of navigation services, noting one existing program for young women with breast cancer and the need for more navigator roles in our healthcare system.

However, a major gap is the lack of comprehensive policies, legislation, and guidelines, which results in healthcare providers having to adapt general guidelines on a case-by-case basis. In one case described by an interviewee involving a 42-year-old autistic man with very limited speech and functioning at the level of a 10-year-old, the medical team was forced to improvise, resulting in a series of ethical and logistical dilemmas. This case highlighted the need for a more structured approach, as the team had to create an ad-hoc protocol to address the patient's needs. The development of these guidelines should also consider the varying levels of functioning among autistic adults and allow for flexible yet consistent approaches to care.

We also observed an imbalance in resources allocated to autistic children versus adults within Hamilton. Though we found few healthcare services for autistic adults, the Autism Program at McMaster Children's Hospital shares numerous programs and resources in their service guide (Autism Program, 2023). This disparity was also emphasized by one of our interviewees, who shared an experience with a 42-year-old autistic patient. The healthcare team considered referring him to McMaster Children's Hospital due to his developmental age, but ultimately, *"they kind of drew the line of well, he's really 42 so we can't treat him here because he's 42 in reality, even if he functions at a 10-year-old level."*

The lack of developmentally appropriate services for autistic adults also leads to ethical challenges. The interviews revealed instances where healthcare providers felt ethically conflicted about performing necessary procedures that caused severe anxiety and pain to the patient. The decision to treat this patient in an adult facility rather than a pediatric setting, where more appropriate resources were available, highlighted the ethical dilemma of adhering to chronological age over developmental needs. Informed consent is another critical ethical consideration, particularly when the patient has an intellectual disability and lacks familial or caregiver support. Healthcare providers often find themselves uncertain about who can provide consent on behalf of the patient, especially in urgent situations. As one interviewee highlighted, there needs to be a clear advocate or patient navigator to ensure that consent is truly informed and that the patient's wishes are respected. This gap underscores the need for designated patient advocates or navigators who can bridge the communication gap between the healthcare team and the patient, ensuring that consent is obtained in a manner that respects the patient's autonomy and comprehension levels.

Ultimately, the lack of services for autistic adults could result in unmet needs. Both our literature review and interviews highlight the unique healthcare challenges experienced by autistic adults. These include communication barriers, sensory sensitivities in healthcare settings, and lack of healthcare provider training. Our findings, though based on limited information, point to a need to address the gaps in our healthcare system to better support autistic adults with cancer.

Conclusion

In partnership with YAIJ, the McMaster Research Shop conducted a literature review, environmental scan, and key informant interviews to explore developmental oncology services available to autistic adults with and without intellectual disabilities. We did not find specialized services for autistic adults with cancer, although there are other services available that are geared to broader groups (e.g., neurodevelopmental services, support for cancer patients). We also aimed to better understand the unique needs of autistic adults and identify supports that are available to them. Autistic adults experience challenges such as limited knowledge and understanding of medical information, communication, and sensory sensitivities in healthcare settings. Healthcare providers may also lack knowledge about caring for autistic adult patients, hold stigma towards them, and experience ethical concerns due to difficulties adhering to “standard of care” strategies. We did not find specific policies or guidelines for providing cancer care to adults with developmental or intellectual disabilities. In practice, healthcare workers seem to use ad hoc solutions to address the unique needs of the patient. Overall, our findings point to a gap in developmental oncology services for autistic adults. Coupled with healthcare providers’ lack of knowledge about caring for this patient group, there is also a need for more healthcare provider training, policies, and guidelines to improve the healthcare experiences of autistic adults.

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Appendix A: Literature Search Terms

((autis* OR ASD OR autis* spectrum disorder*) OR
((developmental* OR cognitive OR intellectual) AND (challenge* OR disabilit*)) OR
(neurodivers*))

AND

((oncolog* OR cancer) AND (care OR treatment* OR support* OR management OR
service* OR unit*))

AND

(need* OR challenge* OR barrier*)

Appendix B: Interview Questions

Healthcare providers:

1. Please describe your role.
 - a. How long have you been in your role?
2. Have you had experience providing healthcare to autistic adults?
 - a. (If yes) Could you please elaborate on the experience you have?
 - i. In what ways, if any, do you adapt your approach to accommodate the needs of autistic patients?
 - b. If no, skip to question 3.
3. What unique challenges do you encounter or know of when providing healthcare services to this population?
 - a. (Skip if already answered in 2a) In what ways, if any, do you adapt your approach to accommodate the needs of autistic patients?
4. Have you observed or do you know of any specific barriers to accessing health care for autistic adults?
 - a. Specifically, cancer care?
5. Are there any specialized services or supports you believe are necessary for improving health care outcomes for autistic adults?
 - a. Specifically, cancer care?
6. Are you aware of any specialized healthcare services or supports available to autistic adults?
 - a. Are you aware of any specialized oncology services?
 - b. Are you aware of any supports specifically in the Hamilton/Burlington area?
 - c. Are you aware of any collaborations between healthcare providers and other support services/organizations to better meet the needs of autistic adult patients?
 - d. Are you aware of any gaps in existing support systems that you believe need to be addressed to better serve the healthcare needs of this population?

Social workers / personal support workers who have experience working with autistic adults:

1. Please describe your role.
 - a. How long have you been in your role?
2. What role do you play in assisting autistic adults with navigating the healthcare system?
 - a. Particularly in relation to cancer care (if at all)?
3. Can you identify any common challenges or barriers autistic adults face when accessing health care services?
 - a. Cancer care services specifically?
4. In your experience, what types of support services are most beneficial for autistic adults in accessing health care?
 - a. Specifically cancer treatment?

5. Are you aware of any specialized healthcare services or supports available to autistic adults?
 - a. Are you aware of any specialized oncology services?
 - b. Are you aware of any supports specifically in the Hamilton/Burlington area?
 - c. Are you aware of any collaborations between healthcare providers and other support services/organizations to better meet the needs of autistic adult patients?
6. Are there any gaps in existing support systems that you believe need to be addressed to better serve the healthcare needs of this population?