



# Communication Barriers and Challenges for Accessing Autism Care: Conventional Versus Alternative Medicine

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## **ABSTRACT**

**Background:** Despite the widespread use of complementary and alternative medicine (CAM) for autistic children, little is known about the communication flow between the different parties involved in the care (i.e., parents/caregivers, conventional providers, alternative practitioners). This study aimed to describe how communication occurs through the first year of care to identify challenges and potential barriers to communication that may affect the care of autistic children.

**Methods:** From an ecological perspective, we collected qualitative data through 12 semi-structured interviews with six parents/caregivers, three conventional providers (family doctor, neurodevelopmental pediatrician, psychologist), and three alternative practitioners (naturopath, occupational therapist, speech and language pathologist) operating in Ottawa, Canada. The data was interpreted using thematic analysis.

**Results:** Findings revealed that parents and caregivers are the only links between the health professionals of both streams. The communication between parents/caregivers and conventional providers faces a perceived lack of knowledge of these professionals relating to CAM, a lack of care integration, flexibility, and time constraints. In alternative care settings, care integration and time constraints are an issue. From the five contexts examined, only the organizational and interpersonal contexts influence communication flow within the system.

**Conclusions:** The increasing interest in alternative medicine is forcing changes in the healthcare system. Within the identified themes in the current study, the necessity for communication between all parties involved in the care of autistic children is evident. More ASD and CAM-related training for providers and openings for information-sharing between the two streams would support effective parent/caregiver-care provider communication. These findings contribute to a better understanding of the role of communication in the care management of autism, which has implications for effective autism care.

## RÉSUMÉ

**Contexte:** Malgré l'utilisation répandue des médecines complémentaires et alternatives (MCA) pour les enfants autistes, on sait peu de choses sur le flux de communication entre les différentes parties impliquées dans les soins (c.-à-d. les parents/soignants, les fournisseurs conventionnels, les praticiens alternatifs). Cette étude visait à décrire la façon dont la communication se déroule au cours de la première année de soins afin d'identifier les défis et les barrières potentielles à la communication qui peuvent affecter les soins aux enfants autistes.

**Méthodes:** Dans une perspective écologique, nous avons recueilli des données qualitatives par le biais de 12 entretiens semi-structurés avec six parents/soignants, trois prestataires conventionnels (médecin de famille, pédiatre spécialisé dans le développement neurologique, psychologue) et trois praticiens alternatifs (naturopathe, ergothérapeute, orthophoniste) exerçant à Ottawa, au Canada. Les données ont été interprétées à l'aide d'une analyse thématique.

**Résultats:** Les résultats ont révélé que les parents et les soignants sont les seuls liens entre les professionnels de la santé des deux courants. La communication entre les parents/soignants et les prestataires conventionnels se heurte à la perception d'un manque de connaissances de ces professionnels en matière de MCA, à un manque d'intégration des soins, de flexibilité et de contraintes de temps. Dans les contextes de soins alternatifs, l'intégration des soins et les contraintes de temps posent un problème. Parmi les cinq contextes examinés, seuls les contextes organisationnel et interpersonnel influencent le flux de communication au sein du système.

**Conclusions:** L'intérêt croissant pour les médecines alternatives impose des changements dans le système de soins de santé. Parmi les thèmes identifiés dans la présente étude, la nécessité d'une communication entre toutes les parties impliquées dans les soins aux enfants autistes est évidente. Une formation plus poussée des prestataires en matière de TSA et de MCA et des possibilités d'échange d'informations entre les deux courants favoriseraient une communication efficace entre les parents, les soignants et les prestataires de soins. Ces résultats contribuent à une meilleure compréhension du rôle de la communication dans la gestion des soins pour l'autisme, ce qui a des implications pour une prise en charge efficace de l'autisme.

## INTRODUCTION

There is no such thing as a typical autism disorder.<sup>1</sup> Autistic children do not require the same care, and interventions do not yield the same results.<sup>2</sup> Autism care requires a multidisciplinary team<sup>3</sup> comprising parents and a range of health professionals. In Ontario, when a diagnosis is posed by qualified professionals (i.e., family physicians, pediatricians, developmental pediatricians, psychiatrists, psychologists, psychological associates, and nurse practitioners), it is usually followed by planning for the implementation of a care plan. Conventional medicine, considered “mainstream” medicine, supports several therapies, including interventions such as developmental programs, speech-language therapy, occupational therapy, physical therapy, etc.). This type of medicine is generally provided in hospitals and specialty or primary care practices. It is sometimes also referred to as “evidence-based.”<sup>4</sup>

Although conventional medicine is the dominant healthcare delivery system, it coexists with many other approaches in the care of autistic children.<sup>5</sup> In cases of autism, complementary and alternative medicine (CAM) is often used to supplement or replace conventional therapies. CAM includes all such practices and ideas self-defined by their users as preventing or treating illness or promoting health and well-being.<sup>6</sup> Current literature notes a high usage rate of alternative treatments in autism<sup>7,8</sup> and a lack of information sharing between parents and conventional

providers.<sup>9</sup> Regardless of the approach, autism care requires coordination between a number of health professionals,<sup>10</sup> making communication in this context an area of interest. Communication is key to the delivery of quality care.<sup>11-13</sup> Nevertheless, the literature relating to the communication flow between parents/caregivers and professionals of conventional and alternative streams is relatively poor.

According to Rickel and Wise,<sup>14</sup> the key to the proper functioning of a system is effective communication between its various elements. Then, the current study aims to gather information to describe how communication occurs between the parties involved in the care of autistic children within the healthcare system in Ottawa during the first year of care to identify challenges and potential barriers to communication.

### The Current Study

Autism is a complex developmental disorder that occurs very early in life, as early as 18 months.<sup>15</sup> It lasts a lifetime.<sup>16</sup> The presence and intensity of the disorder may change over time and vary from one individual to another. Most often, parents are the ones who express the first concerns about their child's development<sup>17</sup> and consult a healthcare professional. However, because autism is not a disease, it is not cured by medical interventions and medications.<sup>18</sup> Available interventions/treatments are specific to the stream through which they are offered. Nevertheless, experts

agree on the importance of early intervention, which may reduce the intensity of the syndrome or minimize its effects on the child's development.<sup>19</sup>

Conventional medicine is practiced by medical degree holders and allied health professionals. The recommendations focus on behavioural therapies to modify specific behaviours in affected children. These include special education programs based in Applied Behavioural Analysis (ABA) or Intensive Behavioural Intervention (IBI), which are widely accepted.<sup>2</sup> Providers may add occupational therapy, speech therapy, or physical therapy to the care plan which are generally funded through specialized centres.<sup>20</sup> Medication is only discussed when co-occurring developmental, mental, and physical health conditions are present.

A separate stream, known under different designations (e.g., natural, alternative, unconventional, traditional, parallel, or complementary medicine), advocates using vitamins and normal body constituents in large quantities as the main treatment.<sup>21</sup> The treatments used for individuals include diets (e.g., gluten-free diet), dietary supplements (e.g., vitamins), mind-body medicine (e.g., hypnosis, shamanism), homeopathic remedies, acupuncture, and animal-assisted therapy (e.g., dolphin therapy, therapeutic horseback riding).<sup>22</sup> Although the Canadian healthcare system is an integrated system that allows for the addition of several disciplines considered complementary to conventional healthcare services, alternative medicine for autism is not one of them.

Alternative treatments are not scientifically proven and pose safety concerns due to potentially dangerous side effects.<sup>7</sup> However, they are used to supplement the care of a high number of autistic children.<sup>8</sup> Conventional therapies may be put on hold or discontinued in favor of alternative treatments.<sup>10</sup> In some instances, parents may follow alternative recommendations without consultation with the conventional healthcare professional. In this context, we question the communication dynamic between parents/caregivers, conventional providers, and alternative practitioners to identify potential challenges and barriers to communication that may impact the care of autistic children.

In general, communication is the act of communicating with someone, relating to others through language; it describes the interpersonal nature of human experience.<sup>23</sup> For us, communication represents dialogue, discussion, rapport,

exchange, collaboration, knowledge-sharing, information-sharing, and any other that research participants identified as communication in their interactions.

## Theoretical Framework

A system refers to a set of elements standing in interrelation among themselves and with the environment.<sup>24</sup> According to the general theory of systems, a system can establish equilibrium if it has the capacity to regulate itself after a disturbance.<sup>25</sup> The interest in alternative treatments and their use opens the door to a stream that operates outside the norms of the traditional healthcare system. Which not only forces change in conventional settings but may impact the entirety of the system.

The theoretical framework refers to the ecological model of communication developed by Street, an approach that examines the interrelation between organisms and their environment. An ecological perspective examines the interaction between health professionals and patients in different social contexts and their influence on communication.<sup>26</sup> Street identified five contexts: interpersonal, organizational, media, politico-legal, and cultural.

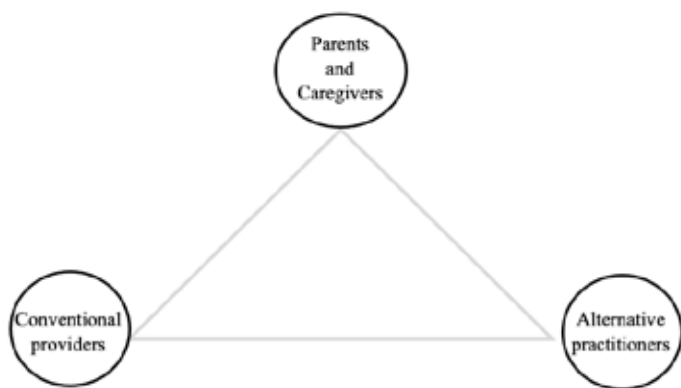
The interpersonal context looks at the patterns of provider-patient communication relating to the attributes of the patient (e.g., education, age, health status), the provider (gender, medical specialty), and their relationship (rapport, trust). In addition, it examines relationships between providers' and patients' communicative actions and the various outcomes (mostly patient-focused) resulting from the consultation (e.g., satisfaction with care, commitment to treatment, health improvement).<sup>26</sup> The organizational context refers to the healthcare environment. The size of the facility, the types of service offered, location, clientele, healthcare standards, etc. In the media context, the medium examined under the ecological model is the Internet for its potential in significantly changing the way healthcare providers and patients interact with each other. The politico-legal context encompasses the legal and juridical actions relevant to delivering medical care. The cultural context involves any situation where attitudes about ethnicity and stereotypes held by healthcare providers and patients may impact communication.<sup>26</sup>

For Street, communication is central to the delivery of healthcare.<sup>26</sup> However, the environment in which it

occurs can be disruptive. To that end, our study of the communication flow amidst the disturbances created by the use of two different streams in the care of autistic children aims to shed light on the challenges and potential barriers to communication within the system.

**METHODS**

In this study, we aim to describe how communication occurs between the parties involved in the care of autistic children within the healthcare system in Ottawa during the first year of care to identify challenges and potential barriers to communication. Considering that individuals experience situations according to their position, expectations, needs, and reading, we opted for triangulation of sources for this study<sup>27</sup> (Figure 1).



**Figure 1. Triangulation of sources (parents and caregivers, conventional providers, alternative practitioners) - the actors involved in children autism care in Ottawa.**

Data source triangulation involves collecting “data from different types of people, including individuals, groups, families, and communities, to gain multiple perspectives.”<sup>28</sup> The use of different sources allowed for a sample of each group of actors involved in the care of an autistic child. It facilitated an analysis within each context and in different settings with all parties involved. Each end of the triangle represents a category of participants (parents/caregivers, conventional medicine providers, alternative medicine practitioners). We placed the parents/caregivers at the top of the triangle because they are the gatekeepers for their child’s treatment.<sup>29</sup> Various studies highlight the importance of parents/caregivers’ role in the care of children.<sup>30-32</sup>

From an ecological perspective, we collected qualitative data through semi-structured interviews with participants from each source of our triangulation (interview guides

in Appendix). The data collected were analyzed through thematic analysis.<sup>33</sup> Each side of the triangle represented the communication between two parties involved in the care. Thus, we examined each side per each of the five contexts of the ecological model to extract commonly recurring themes from the meanings given to their experiences by the participants.

**Participants**

The Ministry of Children and Youth Services (MCYS) provides funding for the following five components: autism treatment, family support services including training, transition and support services, school support program, and respite services. Most of these services are accessible through the Children’s Hospital of Eastern Ontario (CHEO) and its Children Treatment Centre (CTC). Therefore, through purposive sampling, we ensured the participation of healthcare providers and parents/caregivers through these services and selected alternative practitioners operating in Ottawa.

Twelve participants gave consent to this study. Parents/caregivers of an autistic child using conventional medicine only (n = 3), parents/caregivers of an autistic child using conventional and alternative medicine or alternative medicine (n = 3), conventional medicine providers (n = 3), alternative medicine practitioners (n = 3).

**Table 1. Participant Information**

PARTICIPANT	GENDER	ROLE
PC01	F	Mother
PC02	F	Mother
PC03	M	Father
PCA01	F	Mother
PCA02	F	Aunt
PCA03	F	Mother
MC01	F	Family doctor
MC02	M	Developmental doctor
MC03	M	Psychologist
IA01	M	Speech pathologist
IA02	M	Naturopath
IA03	F	Occupational therapist

## Recruitment

We recruited parents/caregivers through contacts at the Faculty of Health Sciences at the University of Ottawa, word of mouth, and advertisements on social media. Research information sheets were provided along with a consent form. Additional information was provided by phone or in-person when required.

*Inclusion criteria:* All participants were to consent to participate in the study. Parents/caregivers had to be Ottawa residents using services in the region, conventional or alternative medicine only or a combination of both streams. All parents were at least six months post-diagnosis because it usually takes that long before a follow-up appointment if the child presents no medical concerns. In addition, this allowed time for a care plan to be put in place in conventional settings and for parents/caregivers to possibly gather information, which could lead to using alternative treatments. Conventional and alternative care providers had their practices in the Ottawa region and had/have had at least one autistic child as a patient.

## Recruitment Difficulties

For conventional care providers, our goal was to secure the participation of CHEO's CTC, which offers government-funded autism services, including diagnosis and care management. Though confidentiality was assured, the Centre refused formal participation in the study due to the controversies surrounding alternative medicine. However, we secured the participation of at least one doctor from the Centre. In addition, talking about alternative medicine represented an issue for conventional medicine providers who indicated not knowing enough on the subject to participate in the research, although they felt that the investigation was warranted. Several parents/caregivers declined to participate because they felt too emotional to discuss their child's diagnosis. These refusals considerably reduced the number of confirmed participants in the study. However, we were able to obtain an equal number of participants per group.

## Procedures

Participant categories were coded to ensure confidentiality (Table 2). The interviews with the care providers lasted 20-30 minutes.

**Table 2. Participant Coding**

TYPE	ROLE	CODE
Source 1	Parents or caregivers of a child with autism using conventional medicine only	PC
	Parents or caregivers of a child with autism using conventional and alternative medicine or alternative medicine only	PCA
Source 2	Conventional providers in the Ottawa area who have or have had at least one autistic child with autism as a patient	MC
Source 3	Alternative practitioners in the Ottawa region who work or have worked with at least one autistic child	IA

We obtained ethical approval from the University of Ottawa Office of Research Ethics and Integrity (IRB 06-10-23). The interviews were scheduled based on participants' availability. The twelve participants completed individual interviews conducted by the researcher in French or English, depending on the participant's preferred language. The confidential nature of the face-to-face interviews facilitated the process and made it easier to register the participants' opinions and descriptions of their experiences. Interviews were recorded on an iPhone and confidentially transcribed for analysis.

## Materials

Semi-structured interview guides specific to each group of participants were developed in both French and English. The questions were designed to allow flexibility for the researcher to follow up on participants' answers and prompt for more in-depth information, when required, during the semi-structured interview process. The verification questions were formulated to address the communication process specifically; thus, they were only used when more information or clarifications was required (n = 12).

For the parents/caregivers, sixteen questions and two verification questions were used, as needed, to explore the communication with conventional or alternative medicine providers, between conventional and alternative medicine providers, and the general communication process through the system.



For providers, eighteen questions and two verification questions were used, as needed, to explore the communication with parents/caregivers and with other care providers conventional or alternative involved in the care of their autistic patients.

**Analyses**

This study required a good understanding of the situation in order to describe and interpret communication practices between parents/caregivers, conventional providers, and alternative practitioners. We analyzed the data collected from the interviews according to the six steps of thematic analysis put forth by Braun and Clarke (2006): (1) Becoming familiar with the data, (2) generating coding categories, (3) generating themes, (4) reviewing themes, (5) defining and naming themes, and (6) locating exemplars. This process allowed to generate themes from the collected data and interpret patterns. Some words or concepts were used during the coding phase because they were repeated during an interview or in several interviews. The frequency of occurrences was considered, but no themes were suppressed, even if they only appeared once in the participant’s discourse.

**Table 3. Themes emergence by participant category**

		THEMES			
		Provider knowledge	Care integration	Flexible care	Time constraints
Source 1	PC01	x	x		x
	PC02	x			x
	PC03	x	x	x	x
	PCAO1	x	x		x
	PCAO2	x	x	x	x
	PCAO3	x	x	x	x
Source 2	MC01	x	x	x	x
	MC02	x	x	x	x
	MC03	x	x	x	x
Source 3	IA01	x	x	x	x
	IA02	x	x	x	x
	IA03	x	x	x	x

Street’s ecological model guided the analysis providing keys allowing us to place the relationships between the

different actors in a larger context, relational, organizational, and societal, guiding through the various possible contexts in which there can be communication and the influence of these contexts on the communication.

**RESULTS**

The qualitative data analysis led to the emergence of four themes: provider knowledge, care integration, flexible care, and time constraints. These themes symbolize the participant’s discourse as well as our interpretation.

**Table 4. Themes emergence in participant discourse**

Themes	At least one appearance under each source of our triangulation
Provider knowledge	<p>“Physicians are not knowledgeable when it comes to alternative practices.” (PCA01)</p> <p>“I am not well-versed in alternative practices, and I do not keep up-to-date with advances in that area,” “all we know is from parents; we must rely on their reports.” (MC01)</p> <p>“Doctors couldn’t do anything with the information because they are very busy.” (IA02)</p>
Care integration	<p>“I find that alternative practitioners are willing to share, and they do share with each other [...] but, doctors are kept out of it.” (PCA03)</p> <p>“I have to admit there is some overlap between the two approaches.” (MC03)</p> <p>“I never contacted a doctor in all my years of service.” (IA01)</p>
Flexible care	<p>“I feel pushed aside because there is nothing they can do for my son.” (PC01)</p> <p>“Any parent may be somewhat apprehensive about disclosing certain alternative treatments if they think the doctor is not going to approve.” (MC01)</p> <p>“The College has established a way to talk with parents.” (IA01)</p>
Time constraints	<p>“Communication is limited. They focus on their work with my child, but alternative practitioners take the time to answer questions and make suggestions.” (PCA02)</p> <p>“I don’t have time to do everything during a visit, especially since visits are now shorter, there is not enough time.” (MC02)</p> <p>“My workload is considerable because there are very few Speech-language pathologists, we want to spend more time on the intervention, but there is little time left to talk to the parents.” (IA01)</p>

In this section, the themes are described, supported by excerpts taken directly from the interviews.

## Themes

The themes were found under each source of our triangulation. At least one appearance under each of the three categories of participants was required.

### *Theme 1 – Provider knowledge*

Parents/caregivers perceive their healthcare provider's silence relating to alternative medicine as a lack of knowledge on their part. They *"do not make recommendations about alternative medicine."* *"Physicians are not knowledgeable when it comes to alternative practices."* *"The doctor doesn't really understand what's going on, he's always trying to prescribe drugs, trying to make life easier for me and my husband."* Moreover, they do not feel able to speak freely with their child's doctor, *"there is almost a taboo when it comes to questioning about alternative medicine."* Which causes them to worry about what they don't know, *"I didn't want the doctor to have a monopoly and not give me all the information."*

Conventional care providers agree that they lack knowledge about alternative medicine. *"I am not well-versed in alternative practices, and I do not keep up-to-date with advances in that area,"* *"all we know is from parents; we must rely on their reports."* In addition, *"there is no magic cure; if there were a form of healing, we would be using it."*

While knowledge is not a concern for parents/caregivers in alternative care settings, alternative providers indicate that families should discuss alternative treatments with their doctors. However, *"it would depend on his or her level of knowledge about it."* Although they feel that regardless, *"they couldn't do anything with the information because they are very busy."* It would also depend *"on the trust relationship established."* *"Knowing that the doctor is open and would be willing to discuss it is a good thing; it helps to build trust."*

### *Theme 2 – Care integration*

Overall, participants agree on a lack of continuity in the system. Health information is not shared with all professionals involved in the care. Conventional providers do not share communications with alternative practitioners

and vice versa. Parents/caregivers indicate that *"alternative practitioners are willing to share, and they share within their stream, but the doctor is kept out of it."* They report being able to share with alternative practitioners but often choose not to. The same occurs with conventional providers because parents and caregivers say: *"I feel rushed,"* *"it is hard to focus with my son in the room,"* *"there is not enough time."*

Conventional care providers admit that they do not initiate talks about alternative treatments with parents/caregivers. The financial implications play a significant role *"I don't want parents to have to bear this burden or be overwhelmed by the cost of such treatment if it is not realistic for them."* It is *"a very heavy financial burden on families. Everything is paid for out of their pocket and can be very expensive."* However, they are open to information-sharing, *"I would like to receive letters from these practitioners."* Some alternative processes are used in conventional settings. *"I have to admit there is some overlap between the two approaches ... we prescribe OMEGA 3 fatty acids, ... massage, multivitamins, and B-complex vitamins for our autistic patients."* Nevertheless, there is no provision for information-sharing between healthcare professionals of both streams, *"we would not be paid for the time allocated to exchange with alternative practitioners."*

Alternative practitioners confirm no contact with conventional providers: *"I never contacted a doctor in all my years of service."*

### *Theme 3 – Flexible care*

Health professionals of both streams admit to a lack of flexibility in their practices. They must abide by the policies guiding their practice. Parents/caregivers expressed their frustration about appointment scheduling. *"The routine appointments are scheduled every six months or more."* This approach does not help, *"I feel pushed aside because there is nothing they can do for my son."* Professional referrals are also an issue. In conventional settings, referrals are limited to specific professionals. Alternative medicine choice is mainly done through *"auto-reference."* Alternative practitioners indicate that *"the College of Professionals has established a way to talk with parents, ... we cannot write recommendations,"* *"we are not allowed to write to conventional physicians."* Beyond systemic restrictions, the interpersonal aspect also comes into play. Conventional providers note that *"any parent may be*

somewhat apprehensive about disclosing certain alternative treatments if they think the doctor is not going to approve.” “Parents may think that asking about alternative medicine will diminish my opinion of them.” Nevertheless, parents/caregivers experience fewer restrictions in alternative care settings, “there is more time for appointments,” and “more openness on topics of conversation.”

Theme 4 – Time constraints

Time is a significant concern for parents/caregivers. They generally feel that they do not have enough time with conventional providers: “communication is limited. They focus on their work with my child, but alternative practitioners take the time to answer questions and make suggestions.” Conventional providers also feel that there is not enough time to address all parental concerns during visits. “I don’t have time to do everything during a visit, especially since visits are now shorter; there is not enough time.” “We used to have more time in the past, but not anymore.” Time is also an issue in alternative care settings, “my workload is considerable because there are very few speech-language pathologists; we want to spend more time on the intervention, which leaves little time to talk to the parents.”

DISCUSSION

Parents/caregivers communicate with health professionals of both streams. However, there are no formal communication channels between the two streams. Conventional providers and alternative practitioners do not communicate. Where communication does exist, it faces several challenges and barriers (Figure 2).

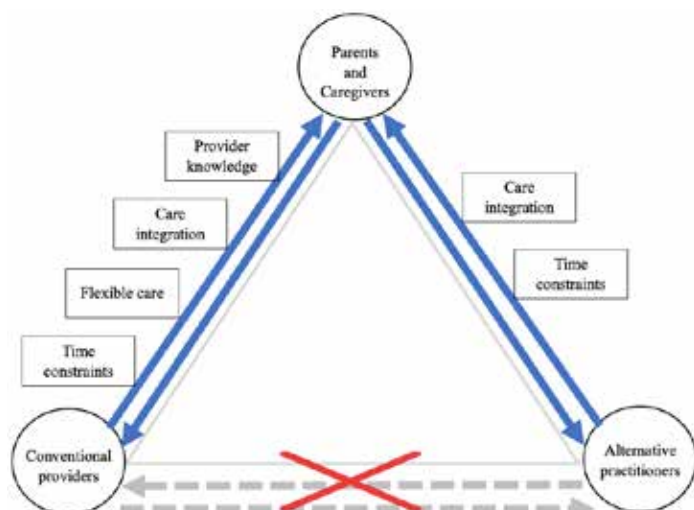


Figure 2. Communication flow between the actors involved in children autism care in Ottawa.

Between parents/caregivers and conventional providers, there is a perceived lack of knowledge of these professionals relating to CAM. There is no continuity of care where CAM is added to supplement care since there is no communication between the professionals of the two streams. There is little flexibility in care. The conventional system offers few openings for alternative medicine use in autism care, making the subject a taboo between most professionals and parents. Finally, time constraints with respect to the length and frequency of visits. Professionals and parents report concerns relating to time. While parents/caregivers perceive that they experience better communication flow with fewer challenges in alternative care settings, care integration and time constraints are an issue. The themes identified closely link to each other, with two themes influenced by two contexts of the ecological model (Figure 3).

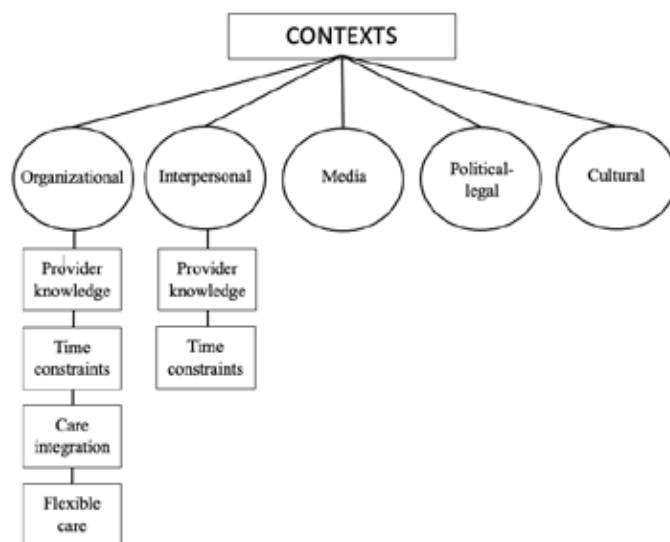


Figure 3. The ecological model and participant identified barriers to communication within the system.

Knowledge links to time and trust. Parents see conventional providers as not particularly knowledgeable regarding alternative medicine, undermining their trust in the provider. In general, autism poses a problem for healthcare professionals who report only moderate levels of autism knowledge.<sup>34,35</sup> Levy et al. indicated that pediatricians and families report knowledge gaps by pediatricians about ASD treatments and community resources and ambiguity regarding the pediatrician’s role in ASD care.<sup>9,36</sup> Further, there is little communication between parents and pediatricians about treatment choices. However, a lack of knowledge is not the only reason conventional providers do not discuss alternative medicine. Organizational constraints, financial costs, and a lack of time create barriers to



information-sharing. In general, there is not enough time to discuss everything during a visit.<sup>9,37</sup> The high financial cost of CAM treatments is another concern for providers.<sup>29</sup> They tend to steer away from these costly, unproven treatments.<sup>9</sup>

Knowledge is not a factor in alternative care settings. However, a lack of continuity and time constraints influence communication. Besides the restrictions inherent to the profession, the number of professionals providing alternative treatments is not enough to respond to the increased prevalence of autism cases as reported, making time an issue during visits.

Parents/caregivers experience a lack of flexibility in conventional settings. Many parents report feeling unsupported or uninformed by their general practitioner, specialist or other healthcare professional regarding CAM use with their child.<sup>6</sup> Although perceived as an interpersonal issue, the lack of flexibility on the provider's side stems from organizational constraints, lack of time, and knowledge. While alternative practitioners show more flexibility in terms of time, they are also limited by organizational constraints. These constraints also prevent communication between the two streams. Parents/caregivers are solely responsible for ensuring continuity if they choose to share with the professionals.

From the five contexts examined: organizational, interpersonal, media, political-legal, and cultural, we found that the organizational and interpersonal contexts are the only contexts influencing communication flow within the system. The media, political-legal, and cultural contexts produced no themes in this study. During a parent interview, the media context was briefly reported relating to information searches over the Internet. However, at the time of this study, there were no reported consultations over the internet or email exchanges with care providers or among healthcare professionals. The different sources reported no political-legal issues. Lastly, the cultural context was difficult to assess in the context of this study (limited participants n = 12).

## Organizational Context

Barriers such as provider knowledge, care integration, flexibility in care, and time constraints are identified related to this context. The policies and regulations in place for both streams prevent the possibility of communication leading to the perception of a lack of flexibility on providers'

parts. Furthermore, parents/caregivers find appointments too short and far apart in conventional care settings. There is not enough time to alleviate their worries. Myers et al. reported parental feelings of not being listened to, including feeling that their concerns were disregarded or doubted.<sup>37</sup> The provider did not take the time to listen to the specific details related to their child. The administration sets the time allotted for each appointment. Parents/caregivers can book a time to discuss specific issues. However, it can take months before they can meet with the provider.

Time constraints also make it difficult for providers to oversee every aspect during appointments. Due to a lack of resources, they must do more in less time. Though generally aware of the existence of alternative medicine and the fact that parents are, in most cases, attracted to its promises, they find it is best not to initiate talks on the matter with the families. The evidence regarding the outcome of such treatments has no scientific basis. Nevertheless, it is reported that parents deplore the fact that there is no real authority on treatments; it would be helpful to know which one to spend all time and money on.<sup>38</sup>

Time is an issue in alternative care settings due to a lack of available service providers. However, parents/caregivers are generally satisfied with the amount of time provided and the timeliness of appointments. Nevertheless, these appointments are paid out-of-pocket. Funding is only allocated through specialized centers for complementary services (e.g., occupational therapy, speech pathology). Because alternative treatments are costly, providers do not initiate talks on the subject to avoid unnecessary expenses for parents/caregivers. They find that directing parents to alternative medicine would imply a rather heavy financial burden when they may not obtain the expected results or even miss out on treatments supported by research.<sup>29,39</sup> However, their silence is perceived as a lack of knowledge of alternative medicine, creating doubts and undermining trust in their relationship with parents/caregivers.

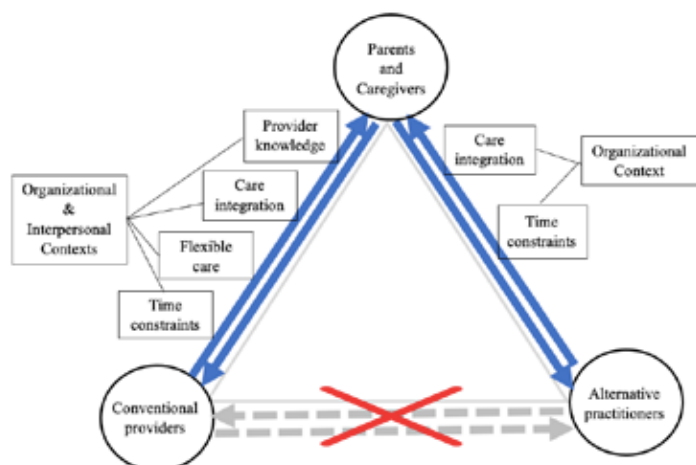
## Interpersonal Context

On an interpersonal level, the parents/caregivers' perceived lack of conventional providers' knowledge about alternative medicine makes trust an additional challenge. Trust is the cornerstone of the doctor-patient relationship. It is strongly influenced by what happens during consultations.<sup>26</sup> The *don't ask, don't tell* approach<sup>40</sup> significantly influences communication in conventional settings. Parents/caregivers

perceive the difficulties of finding enough time to discuss and share information with providers in both streams as a lack of flexibility. The professionals on both sides do not communicate with each other either. Providers are open to sharing with alternative medicine practitioners, but there are no provisions for communication between the two streams. Any time spent consulting or preparing files for an alternative practitioner would be unpaid. In general, unless a treatment can show evident benefits, it cannot become part of conventional medical practice and be eligible for financial coverage. For example, exceptions have been made in heart surgery,<sup>41</sup> and some CAM treatments are used in conventional practices.<sup>42</sup> However, with the lack of evidence relating to CAM treatments paired with the heterogeneous nature of ASD, which makes it so that all treatments do not work for all, a potential integration of the two streams is yet to be possible.

While communication is more open in alternative care settings since practitioners are more readily accessible, it also faces barriers. Parents/caregivers may decide to discontinue treatment without communicating their doubt or concern to the practitioner, creating a lack of continuity within the stream.

In sum, looking at our communication flow triangle (Figure 1), a cross-reference of the different themes and the five contexts of the ecological model (Figure 4):



**Figure 4. Communication flow and barriers within the system per the contexts of the ecological model.**

There is communication between parents/caregivers and conventional providers with influences from the organizational and interpersonal contexts. The identified barriers to communication are lack of knowledge, care integration, flexibility, and time constraints. The

organizational context influences communication between parents/caregivers and alternative practitioners, with barriers stemming from a lack of care integration and time constraints. There is no communication between conventional providers and alternative practitioners due to organizational influences. No themes referred to the media, political-legal, and cultural contexts in this study (Figure 3).

Nevertheless, parental beliefs and preferences<sup>43,44</sup> play a significant role in autism care. Despite the lack of evidence relating to CAM usage, many parents use these treatments for their autistic children. Studies focusing on parental decision-making regarding treatment options highlight the parental need for information.<sup>44-46</sup> More opportunities for open communication between all parties involved in the care of autistic children, regardless of CAM status within the system, would be beneficial. These findings align with Wilson et al., who report the necessity of open discussions between parents and providers relating to treatment decisions.<sup>29</sup> In addition, as reported in research over the past decade, more ASD and CAM-related training for healthcare professionals<sup>9,47</sup> would allow better understanding and promote effective parent/caregiver-provider communication.

## CONCLUSION

Twelve participants allowed us to describe the communication flow between the parties involved in the care of autistic children in Ottawa, Canada. Despite an underlying resistance to change, the increasing interest in alternative medicine is forcing changes in the healthcare system. Within the themes, the necessity for increased communication between all parties involved in the care of autistic children is evident. These findings contribute to a better understanding of the role of communication in the care management of autism, which has implications for effective autism care. More openings allowing for time to discuss alternative treatments in conventional settings are necessary. CAM-related training for providers would support effective parent/caregiver-provider communication to improve the quality of care for autistic children.

## Study Limitations

This study outlines several barriers to communication flow during autism care management in the system in Ottawa. Because this is a perception-based study, participant bias must be considered. Although we were able to have an equal number of participants for each category, the recruitment

difficulties for this study limited our scope of action. Other barriers include a small sample size. The study is specific to Ottawa; it may not be generalizable across the province or other regions in Canada. The parental perceptions are reported from parents/caregivers of young autistic children only; findings may differ with older children.

## Implications and Future Directions

Our results provide leads for a better understanding of the role of communication in the care management of autism. Despite several communication barriers, providers increasingly feel the need to communicate with alternative practitioners, if not to work together, to at least gather information about their practices. The lack of evidence of alternative practices remains of great concern, though not diminishing the interest in their use, making communication crucial in this context. Further investigation into ways to promote effective communication may increase care quality for children with autism. Finally, the focus of this research could be replicated in other Canadian cities to establish national results.

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## APPENDIX - INTERVIEW GUIDE PER PARTICIPANT CATEGORY

### **Parent or caregiver of an autistic child using only conventional medicine**

1. Your child was diagnosed with autism. How old is he/she?
2. When was the child diagnosed?
3. Have you heard about alternative medicine?
4. What is your definition of alternative medicine?
5. Do you use any alternative methods?
6. What were the doctor's recommendations after the diagnostic?
7. Was a care plan put in place - what does it entail?
8. How often do you have appointments with your child's doctor?
9. What happens during a regular clinical appointment?
10. Can you describe your communication with the doctor?
11. Has alternative medicine been discussed during your appointments?
12. Do you feel comfortable, or would you feel comfortable discussing alternative medicine with your child's doctor?
13. How informed do you feel your child's doctor is about alternative medicine?
14. Do you think integrating conventional and alternative methods would benefit your child's care?
15. What do you feel would be the advantages?
16. What would be the means to allow the integration of conventional and alternative medicine?

### **Verification questions (If there is no mention during the interview)**

- Have you had communications with the care providers in between appointments by phone or e-mail?
- How did you hear about alternative medicine?

### **Parent or caregiver of an autistic child using only conventional medicine and alternative medicine or alternative medicine only**

1. Your child was diagnosed with autism. How old is he/she?
2. When was the child diagnosed?
3. Have you heard about alternative medicine?
4. What is your definition of alternative medicine?
5. Do you use any alternative methods?
6. What were the doctor's recommendations after the diagnostic?
7. Was a care plan put in place - what does it entail?
8. How often do you see your child's doctor and/or alternative practitioner?
9. What happens during a regular appointment with the doctor and/or your child's alternative practitioner?
10. Can you describe your communication with the doctor and/or practitioner?
11. Has alternative medicine been discussed during your appointments with the doctor, and/or has the alternative practitioner asked about the care plan in place for your child during visits?
12. Do you feel comfortable, or would you feel comfortable discussing alternative medicine with your child's doctor?
13. How informed do you feel your child's doctor is about alternative medicine?
14. Do you think integrating conventional and alternative methods would benefit your child's care?
15. What do you feel would be the advantages?
16. What do you think would be the means to allow the integration of conventional and alternative medicine?

### **Verification questions (If there is no mention during the interview)**

- Have you had communications with the care providers in between appointments by phone or e-mail?
- How did you hear about alternative medicine?

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**Developmental doctor, psychologist, pediatrician, family doctor, who works, or has worked with at least one autistic child**

1. What is your area of expertise?
2. Have you had or do you currently have any autistic patients?
3. How often are appointments scheduled with the patients? How long does an average appointment last?
4. After a diagnosis of autism, what does a typical care plan entail?
5. Do you have experience with alternative methods?
6. What is your definition of alternative medicine?
7. Can you describe your communication with the parents?
8. Do you take the initiative to discuss alternative treatments with your patients' parents during regular appointments?
9. Have some parents approached you on the subject of alternative medicine?
10. Do you make prescriptions and/or recommendations about alternative methods?
11. Do you think parents feel comfortable bringing up the subject of alternative medicine during regular appointments?
12. Do you think parents have enough time to discuss the alternative treatment of their child?
13. Would it be advantageous for your patients if their parents discussed the alternative treatments used with you?
14. Would you be ready for a collaboration/exchange with your patients' alternative practitioner?
15. Would the integration of conventional and alternative methods benefit your patients?
16. How would that impact the healthcare system?
17. Do you think the healthcare system has the capacity to support a continuum of integrated care in autism cases?
18. What do you think would be the means to allow the integration of conventional and alternative medicine?

**Verification questions (If there is no mention during the interview)**

- Have you had communications with the parents in between appointments by phone or e-mail?
- How did you hear about alternative medicine?

**Doctor/practitioner using alternative methods, medical and paramedical personnel, who works, or has worked with at least one autistic child**

1. What is your area of expertise?
2. Have you had or do you currently have autistic patients?
3. What is your definition of alternative medicine?
4. Why alternative methods for autism care?
5. How often are appointments scheduled with the patients? How long does an average appointment last?
6. Do parents have a choice of alternative treatment, or are there typical methods used in autism cases?
7. Can you describe your communication with the parents?
8. Do you keep informed about new alternative methods and discuss them with your patients' parents?
9. Do you feel that parents are comfortable questioning the alternative methods prescribed during appointments?
10. Are you knowledgeable about the conventional medical care plan process?
11. Do you make any prescriptions and/or recommendations about conventional medicine?
12. Do you allow time during appointments for the parents to discuss the medication prescribed by your patients' doctors?
13. Would it be advantageous for the children if their parents discussed the alternative treatments used with the doctor during appointments?
14. Would you be ready to collaborate/exchange with your patients' doctors?
15. Do you think integrating conventional and alternative methods would benefit autistic children?
16. How would that impact the healthcare system?
17. Do you think the healthcare system has the capacity to support a continuum of integrated care in autism cases?
18. What do you think would be the means to allow the integration of conventional and alternative medicine?

**Verification questions (If there is no mention during the interview)**

- Have you had communications with the parents in between appointments by phone or e-mail?
- How did you hear about alternative medicine?