

# Patient-centred primary care of adults with severe and profound intellectual and developmental disabilities

## Patient-caregiver-physician relationship

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### Abstract

**Objective** To explore the process of the development of the patient-physician relationship in adult patients with severe or profound intellectual and developmental disabilities (IDD), from the perspective of the patients' caregivers.

**Design** Constructivist grounded theory.

**Setting** St John's, NL.

**Participants** Thirteen primary caregivers (5 males, 8 females) of 1 or more adults with severe or profound IDD.

**Methods** Data were collected via in-depth, semistructured interviews conducted in person or by telephone. Interviews were audiorecorded and transcribed verbatim. Field notes were documented immediately by the interviewer and discussed with the research team. Memos in the form of reflective notes served as additional sources of data.

**Main findings** From the perspective of the caregivers, the core process in the development of the patient-physician relationship was protection. This process began as a result of the caregiver's recognition of the patient's vulnerability and moved through a number of stages before resulting in the development of a dynamic triangular interaction between the patient, caregiver, and family physician. First, the caregiver provides extreme nurturing to the patient, which results in the development of a strong bond between them. The patient and caregiver approached the family physician together as one unit, and then decided together on whether or not to open the patient-caregiver bond to the physician. The resultant dynamic triangular interaction formed the starting point from which 1 of 4 different relationship-development trajectories began. Which trajectory was taken and, therefore, the character of the relationships that developed was determined by how the caregiver and patient experienced their interaction with the family physician.

**Conclusion** Findings highlight the process of protection and the centrality of the patient-caregiver bond within the development of a triadic relationship involving the patient with IDD, the caregiver, and the family physician. How a physician approaches this bond can influence the trajectory of the resulting relationship.

### Editor's key points

- ▶ The patient-physician relationship is an important aspect of family medicine, but those with severe intellectual or developmental disabilities (IDD) have very limited communication, practical, and social skills, and these patients always present to their family physicians with caregivers. The caregiver's active role is essential to the patient's health outcomes, and his or her presence likely influences the character of the patient-physician relationship.
- ▶ This qualitative study aimed to understand caregivers' perspectives on the development of the patient-physician relationship for adult patients with severe or profound IDD.
- ▶ Caregivers' main concern was the protection of the patient with IDD; family physician awareness of this dynamic is essential. To ensure development of trust between the patient-caregiver unit and the physician, physicians should focus initially on acknowledging the patient's vulnerability and the resultant protective nature of the patient-caregiver bond by providing a unique safe place for both patient and caregiver. As trust is built, the patient-caregiver bond should open more easily, allowing the physician more meaningful access to the patient. The caregiver can then be drawn in as a facilitator of the relationship.

### Points de repère du rédacteur

► La relation médecin-patient est un aspect important en médecine familiale, mais les patients qui ont des déficiences intellectuelles et développementales (DID) sévères sont très limités sur le plan de la communication et des compétences pratiques et sociales. De plus, ils se présentent toujours à leur médecin de famille accompagnés d'un soignant. Il est important que le soignant joue un rôle actif compte tenu des conséquences pour la santé du patient, car sa présence aura vraisemblablement une influence sur la nature de la relation patient-médecin.

► Dans cette étude qualitative, on voulait connaître l'opinion des soignants sur le développement de la relation patient-médecin, quand il s'agit de patients qui ont des DID sévères ou profondes.

► La principale préoccupation des soignants était la protection des patients qui ont des DID; Il est important que le médecin de famille soit conscient de cette dynamique. Et si on veut qu'il se développe un lien de confiance entre l'unité patient-soignant et le médecin, les médecins devraient d'abord reconnaître la vulnérabilité du patient et la nature protectrice du lien patient-soignant en accordant au patient comme au soignant un rôle unique. À mesure qu'un lien de confiance s'établit, le lien patient-soignant devrait devenir moins étanche, permettant ainsi au médecin d'avoir un meilleur accès au patient.

# Soins primaires centrés sur les patients qui ont des déficiences intellectuelles ou développementales sévères

## La relation médecin-soignant-patient

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### Résumé

**Objectif** Étudier le processus de développement de la relation patient-médecin chez les adultes ayant des déficiences intellectuelles et développementales (DID) sévères, du point de vue des soignants des patients.

**Type d'étude** Théorie constructiviste reposant sur les faits.

**Contexte** St. John's, Terre-Neuve.

**Participants** Treize soignants du milieu primaire (5 hommes et 8 femmes) qui s'occupent d'au moins 1 adulte ayant des DID sévères.

**Méthodes** On a recueilli les données à l'aide d'entrevues semi-structurées en présence du soignant ou au téléphone. Les entrevues ont été enregistrées sur bandes magnétiques et transcrites mot-à-mot. Les notes prises durant les entrevues ont été immédiatement documentées par l'intervieweur, pour ensuite être examinées par l'équipe des chercheurs. Les mémos sous forme de sujets exigeant réflexion ont constitué une autre source de données.

**Principales observations** D'après les soignants, l'élément principal qui permet le développement de la relation patient-médecin est la protection. Ce processus commence lorsque le soignant reconnaît que le patient est vulnérable pour ensuite évoluer à travers plusieurs étapes et enfin permettre à une relation triangulaire dynamique de se développer entre le patient, le soignant et le médecin de famille. En premier lieu, le soignant doit s'occuper du patient le mieux possible, ce qui permet d'établir un lien solide avec lui. Le patient et le soignant rencontrent le médecin de famille ensemble, comme une unité, pour ensuite décider ensemble si le lien qui les unit doit aussi s'étendre au médecin. L'interaction triangulaire dynamique qui en résulte devient alors le point de départ d'une des 4 voies permettant le développement de la relation. En fonction de la voie choisie, et donc de la nature de la relation développée, cette relation dépendra de ce que pensent le soignant et le patient de leur contact avec le médecin de famille.

**Conclusion** Ces observations soulignent l'importance du processus de protection et le rôle central du lien patient-soignant dans le développement de la relation triangulaire entre le patient ayant des DID, son soignant et le médecin de famille. La façon dont le médecin tiendra compte de ce lien peut déterminer comment la relation s'établira.

Individuals with intellectual and developmental disabilities (IDD), estimated at approximately 60 million people worldwide and 1% to 3% of Canadians, represent one of the largest population groups of those with lifelong disabilities.<sup>1-3</sup> Recently, the first large Canadian study of persons with IDD confirmed previous local and international findings of considerable health disparities among this group<sup>4</sup>; those with severe IDD are more severely affected by these disparities.<sup>5</sup>

In Canada, adults with IDD are cared for primarily by family physicians. Research on the practice of family medicine for patients with IDD has largely concentrated on the perspectives of, and challenges faced by, family physicians.<sup>6</sup>

The patient-physician relationship is an important aspect of family medicine but it has been explored only to a limited extent in patients with severe or profound IDD, where issues such as communication have been the focus.<sup>6-9</sup> Only one study has reported on the patient-physician relationship in patients with mild IDD.<sup>10</sup>

Patients with severe or profound IDD have very limited communication, practical, and social skills.<sup>11</sup> The abilities of a person with severe and profound IDD have been compared to someone aged 0 to 6 years old without IDD.<sup>12</sup> As a result, these patients always present to their family physicians with caregivers. The caregiver's active role is essential to the patient's health outcomes<sup>10,13</sup> and his or her presence likely influences the character of the patient-physician relationship.<sup>14</sup> While the importance of the role of the caregiver has been highlighted in the Canadian consensus guidelines for the primary care of adults with IDD, the nature of his or her role in the patient-physician relationship has yet to be explored.<sup>2</sup>

The purpose of this study was to explore the process of the development of the patient-physician relationship in adult patients with severe or profound IDD from the perspective of the patients' caregivers.

## — Methods —

This study used constructivist grounded theory to examine the specific processes of relationship development between patients with severe or profound IDD and their family physicians.<sup>15</sup> This methodology encouraged the active involvement of the research team members: K.S., a family physician researcher from Memorial University of Newfoundland in St John's involved in the care of adults with severe and profound IDD, and B.L.R. and A.L.T., doctorate-level primary health care researchers at the Centre for Studies in Family Medicine at the University of Western Ontario in London. The project was approved by Newfoundland and Labrador's Health Research Ethics Board.

### Sampling

Participants were sampled purposefully; they were identified and recruited by family physicians in St John's. Eligible

participants for the study included primary caregivers who had experience caring for, and had developed relationships with, their family members or clients with severe or profound IDD. Sampling was designed to ensure variation of participant demographic characteristics including age, sex, and nature and duration of the relationship with the person with IDD and the family physician, enabling the broadest range of information and perspectives on the topic. Sampling and data collection continued until the point of saturation, after which no additional concepts relevant to the central themes emerged.<sup>16</sup>

### Data collection

Data were collected using in-depth interviews. The relative lack of research in this area prompted an open and exploratory, but gently guided, approach as participants shared their experiences of interacting with the family physicians.

The semistructured interview guide was regularly updated with emerging ideas from the simultaneous data analysis. Interviews ranged from 40 to 80 minutes in length and were conducted either in person or by telephone.

Interviews were audiorecorded and transcribed verbatim. Field notes were documented immediately by the interviewer (K.S.) and discussed by the research team. Memos in the form of reflective notes also served as important sources of data.

### Data analysis

Data were analyzed by K.S., B.L.R., and A.L.T. who independently read and coded the transcripts to identify themes and concepts, followed by discussion in regular group meetings; K.S. incorporated the resulting information to iteratively create the final theoretical codes and develop a coordinated constructive grounded theory. Trustworthiness and credibility of the data were ensured by audiorecording interviews, review of verbatim interview transcripts, detailed field notes, team data analysis, and regular group and individual reflection. This maximized researcher transparency.

## — Findings —

A total of 13 individuals meeting the inclusion criteria of primary caregiver to 1 or more adults with severe or profound IDD participated in 11 interviews. Two of the interviews were completed with couples. See **Table 1** for a breakdown of participant demographic characteristics.

### Process of relationship development

Study findings revealed that from the perspective of the caregivers, the core process in the development of the patient-physician relationship was that of protection. This process began as a result of the caregiver's recognition of the patient's vulnerability and moved through a number of stages resulting in the development of a dynamic triangular interaction between the patient,

**Table 1. Demographic information**

PARTICIPANT CHARACTERISTICS	VALUE
No. of parents of children with IDD	6
No. of other family members	4
No. of paid caregivers	3
No. of those who received formal training in caring for those with IDD	4
No. of male caregivers	5
No. of female caregivers	8
Mean (SD) age, range, y	61 (12), 49-82
Age range of patients and family members being cared for by study participants, y	24-67

IDD—intellectual and developmental disabilities.

caregiver, and family physician. This interaction formed the starting point from which 1 of 4 trajectories of relationship development was followed.

### Protection

The process of protection moved through 4 stages before resulting in the development of a dynamic, triadic patient-caregiver-physician relationship.

**Extreme nurturing.** Caregiver nurturing was very intense and developed from the dependence of the adult with severe or profound disabilities on those caring for them and included the need to minimize vulnerability and provide protection, involving constant, lifelong vigilance, advocacy, and support.

But given that he is an adult now, he just looks like a little boy and that's what he communicates to them. He communicates that I am very vulnerable right now and I'm only little so you got to do whatever it is you got to do to take care of me. (Interview 6)

Caregivers used words such as *fought* and *begging* to describe the extreme measures they had to use to ensure appropriate health care and maximize quality of life for their family members or clients.

**Development of the patient-caregiver bond.** Extreme nurturing led to the development of a close bond between the caregiver and his or her family member or client. This resulted in the caregiver becoming the most equipped to understand the family member or client's attempts at communication. As illustrated in one interview, "the caregiver is the person that knows the patient best ... you have to be very, very familiar." (Interview 5)

**Patient and caregiver encounter the family physician together.** To ensure continued protection when

interacting with someone outside the patient-caregiver bond, caregivers encountered the family physician together with the patient. They appreciated the physicians who recognized the importance of the patient-caregiver bond and its crucial role in developing their own relationships with the patients:

[The physicians] recognize that he [the patient] cannot communicate with us so you [the caregiver] communicate and tell us and teach us ... they have been very good with understanding me and our relationship. (Interview 6)

**Deciding to open the patient-caregiver bond to the physician.** After encountering the physician together, the patient and caregiver then decided whether (and the degree to which) they felt safe enough to let the physician into this bond. This decision was affected by factors related to the physician, the patient, and the caregiver. Caregivers allowed physicians who practised empathetic, patient-centred care into this bond more than physicians who did not: "When you start to personally engage, you start to care. You know, on a personal level. I think when a doctor can do that, it's really, really good." (Interview 9)

Caregivers described how the appearance, ability to communicate, and sometimes unpredictable behaviour of the patient either helped or hindered the creation of a safe environment.

He's [the patient is] handsome; all that makes a big difference. (Interview 8)

If you have somebody in your office that's screaming or attempting to bite you, you know like, all of the behaviours that the patient can have as an individual, can be offsetting [*sic*] to a doctor. (Interview 5)

Finally, caregivers also described themselves as individuals with their own physical and emotional needs and concerns that affected their ability to protect the patient and open the bond. "People forget staff are people you know. I [as a caregiver] have to bring a client to the doctor. I don't like doctors, right?" (Interview 4)

### Creation of the patient-caregiver-physician dynamic triangular interaction

In protecting the patient, caregivers realized the potential benefit of involving the family physician in the patient's care. They also recognized the potential for increasing the patient's vulnerability by exposing him or her to a system of health care delivery not designed for those with IDD. They therefore set out to create a dynamic triangular interaction (**Figure 1**) where they expected the physician to be aware of this vulnerability and respect the patient-caregiver bond by interacting

primarily with the patient and caregiver as one unit in the process of shared care and protection.

### Relationship trajectories

The dynamic triangular interaction (Figure 1) formed the starting point from which different trajectories of relationship development were followed. Which trajectory was taken was determined by how the caregiver and patient experienced their interaction with the family physician (Figure 2). The trajectories included the following.

**Up-front knowledge acquisition.** This trajectory began instantly and actively, often involving a family physician and caregiver with experience and an interest in dealing with patients with severe or profound IDD. The patient and caregiver were incorporated into the patient's care right from the start, as the family physician asked relevant and probing questions leading caregivers to report an immediate "gut feeling" of trust and safety: "And you can tell, yeah, he's building. This is a guy I'm going to be able to trust." (Interview 4)

**Familiarization with time.** On this trajectory, the key features were time and continuity of care, allowing a very deep, stable, and dependable relationship to develop. Knowledge and familiarity developed at a fairly constant rate over successive clinical encounters. This familiarity drew the family physician into the patient's family and the patient and caregiver into the health care team's "family." Caregivers' use of the word *family* portrayed a deeply personal level of acceptance of each team member in this process of knowledge acquisition: "He [family physician] was part of the family, you know?" (Interview 1)

**Creation of a stable and functional resource.** On this trajectory, the caregiver took the lead role, involving the family physician as a passive but stable and supportive resource when required (eg, to adjust medications

or provide additional medical care). There was no need expressed to build an ongoing relationship between times of need or beyond the functional requirement of medical care for the patient. Knowledge acquisition in the form of the family physician getting to know the patient and caregiver did occur with time, but it was fairly superficial and experiences were too infrequent to include the patient getting to know the family physician: "There really isn't a big relationship. He is just my prescription writer." (Interview 8)

**Assumption of physician authority or physician-centred care.** Here, the physician assumed the authority, making all the decisions affecting the patient's care, without overtly respecting or including the patient and caregiver. The resultant tension and sense of an unsafe environment that developed damaged the dynamic interaction and resultant relationship. Caregivers believed both they and the patients were "disrespected" and "dismissed" and reacted by either trying to turn this process around or by giving up and feeling helpless and dependent on a medical system with minimal options for the care of the patient: "You know the [group home] staff are saying, you know, dump this guy [family physician]. Can't. We need someone to prescribe the friggin' medication. That's what it comes down to." (Interview 9)

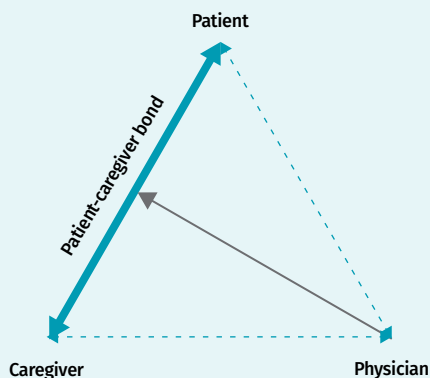
## — Discussion —

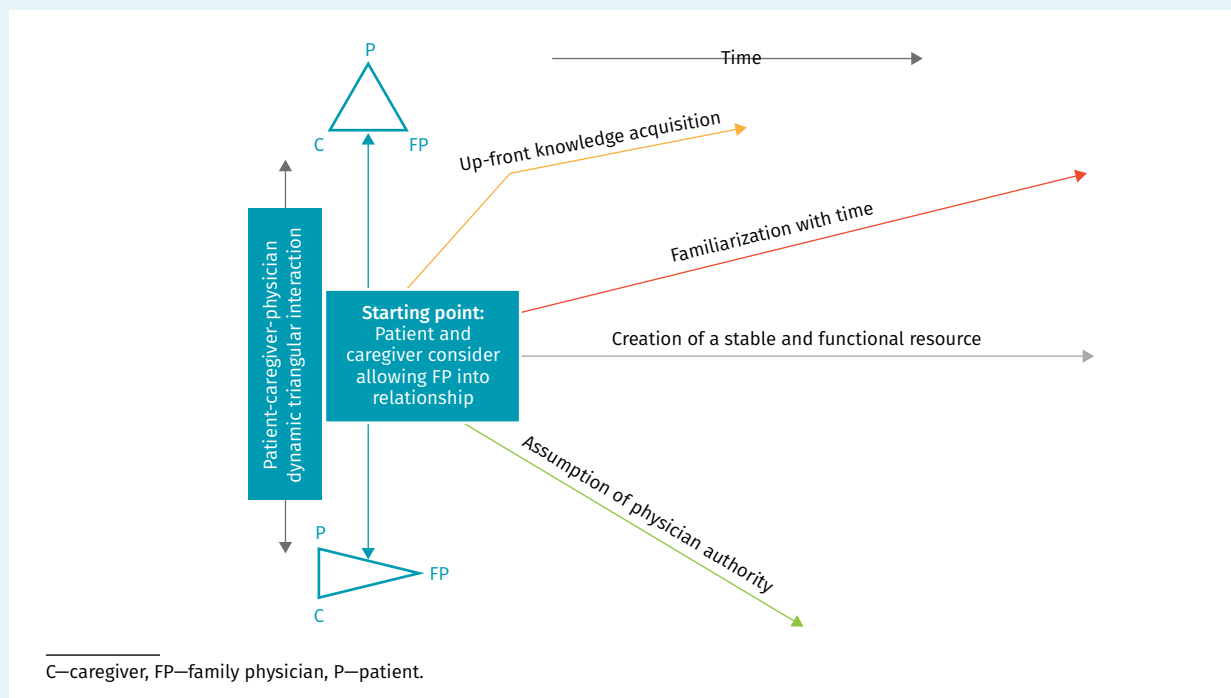
In this study, caregivers recognized the vulnerability of those living with severe or profound IDD and reacted by nurturing their family members or clients in extreme ways, where necessary, to protect them from a health care system not designed to address their needs. This extreme nurturing led to the formation of a strong protective bond between the caregiver and the family member or client. The caregivers in this study perceived themselves as encountering the family physician as one caregiver-patient unit. This unit then decided whether to let the physician into that bond.

This study extends the concept of family physicians actively involving the caregiver when caring for adults with IDD to include an acknowledgment of the importance of the patient-caregiver bond.<sup>2,13,17,18</sup> To the caregivers, this inextricable connection with their family members or clients meant that they should be included in all levels of interactions between the family physician and the patient. Any sense of a lack of acknowledgment by the family physician of the primacy of this patient-caregiver bond was interpreted by the caregivers as increasing the patient's vulnerability. The caregivers reacted to this by either taking back total control of the medical care of the patient, including the relationship with the family physician, or by giving in to a sense of hopelessness as the physician assumed authority.

A caregiver's main concern is the protection of the patient; family physician awareness of this dynamic is

Figure 1. Dynamic triangular interaction: Caregiver perspective.



**Figure 2. Patient-caregiver-physician relationship trajectories over time**

essential. Early attempts by the physician to interact with the patient independent of the caregiver might be interpreted as a threat to the patient-caregiver bond, and hence the safety of the patient. To ensure the most rapid development of trust between the patient-caregiver unit and the family physician, family physicians should focus initially on acknowledging the vulnerability of the patient and the resultant protective nature of the patient-caregiver bond by providing a unique safe place for both the patient and the caregiver. As trust is built, the patient-caregiver bond should open more easily, allowing the physician more meaningful access to the patient. The caregiver can then be drawn in as a facilitator of the relationship as opposed to solely the protector of the caregiver-patient unit.

The importance of the role of a patient's family, particularly in those with IDD,<sup>19</sup> in the provision of medical care has been well documented.<sup>20,21</sup> This study highlighted a new finding of the family physician being incorporated into the patient's family and the patient being incorporated into the "health care team" family. This deep, personal, and familial relationship trajectory reflects the importance of the personal aspect of the patient-physician relationship in family medicine.<sup>22,23</sup>

### Strengths and limitations


The greatest strength of this study is that it illuminates the process of relationship development—a hereto unexplored aspect of the care of these patients. The use of constructive grounded theory methodology allowed us to highlight the process of relationship development over time.

While the participants in this study were all from one relatively small geographic area in Canada, the breadth and variety of the sample population allowed an in-depth exploration of the process of relationship development. The inherent limitation of not being able to rely directly on the views and perspectives of the patients themselves was mitigated by ensuring that participants close to the patients were recruited for the study.

### Future steps

Future research and knowledge translation should focus on gaining a deeper understanding of the theory of relationship development within this population with the goal of informing evidence-based relationship-development guidelines for family physicians. To ensure a full understanding of the relationship, these guidelines should also be informed by further studies in different regions of Canada and within diverse cultural groups.

### Conclusion

This study used a constructivist grounded theory approach to discover the process of protection that underlies the formation of patient-physician relationships in adult patients with severe or profound IDD. Findings highlight the centrality of the patient-caregiver bond within a triadic relationship involving the patient, caregiver, and family physician and how a physician's approach to this bond can influence the trajectory of the resulting relationship. 

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#### Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, or interpretation; and preparing the manuscript for submission.

#### Competing interests

None declared

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