

Editor's key points

▶ The ability to form a positive, professional patient-physician relationship is an essential part of family medicine. Developing this relationship with patients living with profound intellectual and developmental disabilities (IDD) who have very limited communication, practical, and social skills poses challenges to conventional relationship development.

▶ This qualitative study explores family physicians' perspectives on the development of the patient-physician relationship with adult patients with severe or profound IDD.

▶ For family physicians working with patients with severe or profound IDD, acceptance was the core process of relationship development. They accepted their patients as individuals worthy of their respect, attention, and empathy despite their limitations, and they sought signs that their patients accepted them in return. Defining their role and adapting practice were required, and this involved spending more time with patients, finding alternate forms of communication, involving caregivers without excluding patients, developing informal support networks, building trust with patients, considering contextual stimuli, and advocating for patients' particular needs.

Primary care of adults with severe and profound intellectual and developmental disabilities

Family physicians' perspectives on patient-physician relationships

Katherine Stringer MB ChB MCLSc CCFP FCFP Bridget L. Ryan PhD
Amanda L. Terry PhD Andrea Pike MSc

Abstract

Objective To explore family physicians' perspectives on the development of the patient-physician relationship with adult patients living with severe or profound intellectual and developmental disabilities (IDD).

Design Constructivist grounded theory.

Setting St John's, NL, and across Canada.

Participants Fifteen family physicians currently caring for patients 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 family physicians, the core process in the development of the patient-physician relationship was acceptance. This acceptance was bidirectional. With respect to family physicians accepting patients, family physicians had to accept that their patients with severe and profound IDD were as equally deserving of their respect as any other patient—as unique individuals with their own goals and potential. With respect to patients accepting their family physicians, family physicians had to seek out signs of acceptance from their patients to fully appreciate and develop a trusting relationship. This bidirectional process of acceptance required family physicians to adapt the way they practised (eg, by spending more time with the patient and finding alternate forms of communication). It also required family physicians to define their role (eg, building trust and being an advocate) in a relationship that had the patient as the primary focus but simultaneously acknowledged the important involvement of the caregiver.

Conclusion For family physicians, the process of acceptance seems to underpin the development of the patient-physician relationship with adult patients with severe or profound IDD. Findings highlight the need for family physicians to adapt the way they deliver care to these patients and define their role in these complex relationships. Ultimately, this study highlights family physicians' acceptance of their patients' humanity regardless of the nature of the relationship that was created between them.

Soins primaires pour adultes ayant des déficiences intellectuelles et développementales sévères et profondes

L'opinion de médecins de famille sur la relation médecin-patient

Katherine Stringer MBChB MCISc CCFP FCFP Bridget L. Ryan PhD
Amanda L. Terry PhD Andrea Pike MSc

Résumé

Objectif Connaître l'opinion de médecins de famille sur le développement de la relation patient-médecin lorsqu'il s'agit de patients adultes présentant des déficiences intellectuelles et développementales (DID) sévères ou profondes.

Type d'étude Théorisation ancrée constructiviste.

Contexte Saint-Jean de Terre-Neuve et ailleurs au Canada.

Participants Quinze médecins de famille travaillant déjà avec des patients présentant des DID sévères ou profondes.

Méthodes Les données ont été obtenues à l'aide d'entrevues en profondeur, semi-structurées, en personne ou au téléphone. Ces entrevues ont été enregistrées et transcrites mot-à-mot. Les sujets notés ont été consignés immédiatement par l'interviewer et discutés avec l'équipe de recherche. Les mémos, sous la forme de sujets de réflexion, constituaient une autre source de données.

Principales observations Les médecins de famille estimaient que l'acceptation est l'élément de base du développement de la relation médecin-patient. L'acceptation était bidirectionnelle. Pour ce qui est des médecins de famille, ils devaient accepter que les patients souffrant de DID sévère ou profonde méritent leur respect autant que leurs autres patients, en tant que personnes uniques possédant des objectifs et un potentiel de développement. Pour ce qui est de l'acceptation du médecin par le patient, il incombait au médecin de chercher chez le patient des signes de cette acceptation afin de mieux l'apprécier et de développer une relation de confiance. Pour favoriser cette acceptation mutuelle, le médecin doit modifier sa façon de pratiquer (p. ex. en passant plus de temps avec le patient et en imaginant d'autres façons de communiquer). Il devra aussi mieux définir son rôle (p. ex. en favorisant une meilleure confiance mutuelle et en appuyant les patients dans leurs besoins particuliers), et ce, dans une relation où le patient est le sujet central, tout en reconnaissant la contribution importante du soignant.

Conclusion Pour les médecins de famille, le processus d'acceptation serait l'élément déclencheur de l'établissement de la relation patient-médecin chez les adultes présentant une DID sévère ou profonde. Nos observations indiquent la nécessité pour le médecin d'adapter la façon dont il traite ces patients et de mieux définir son rôle dans une relation aussi complexe. Enfin, cette étude souligne le fait que les médecins de famille doivent accepter que ces patients sont des personnes humaines, et ce, sans égard à la relation qui s'est développée entre eux.

Points de repère du rédacteur

► Il est essentiel pour un médecin de famille de créer une bonne relation professionnelle avec son patient. Pour les patients qui présentent des déficiences intellectuelles et développementales (DID) profondes et très peu de compétences pratiques, communicationnelles et sociales, cela représente d'importants défis.

► Cette étude qualitative voulait connaître l'opinion de médecins de famille sur le développement de la relation patient-médecin lorsqu'il s'agit de patients adultes présentant des DID sévères ou profondes.

► Pour les médecins qui travaillent avec des patients présentant des DID sévères ou profondes, accepter le patient tel qu'il est était l'élément de base pour développer une telle relation. Ils acceptaient donc ces patients comme des personnes qui méritaient du respect, de l'attention et de l'empathie, malgré leurs limitations, et cherchaient à savoir si ces patients les acceptaient en retour. Ils devaient donc définir leur rôle et adapter leur pratique, ce qui signifie qu'ils devaient consacrer plus de temps à ces patients, trouver d'autres formes de communication, faire participer des aidants sans exclure les patients, développer des réseaux de soutien informels, améliorer la confiance mutuelle, envisager des stimuli en fonction du contexte et plaider en faveur de leurs besoins particuliers.

Family medicine is defined by a focus on the patient-physician encounter and resultant relationship.^{1,2}

The ability to form a positive, professional patient-physician relationship is an essential clinical skill requiring the physician to communicate; be compassionate, caring, and empathetic; and inspire trust between both parties.^{3,4} The success of this relationship and patient-centred care has been linked to a number of objective, positive patient health outcomes.^{5,6}

Individuals with intellectual and developmental disabilities (IDD) represent one of the largest groups of people with lifelong disabilities, estimated at approximately 60 million people worldwide and 1% to 3% of Canadians.^{7,8} Evidence of considerable health disparities in this group exists internationally and in Canada.^{9,10} These disparities, including morbidity and mortality, are more severe in the population of patients with severe IDD.^{10,11} Despite this, research focusing on patients with IDD is limited and has primarily focused on challenges associated with delivering primary care to this population.¹²⁻¹⁵ More particularly, while the patient-physician relationship has been well studied in the general population,⁶ it has been examined very minimally in those with IDD. Two studies report on this relationship to date: one involved patients with mild IDD¹² and the other is our own paper discussing the development of this relationship from the perspective of caregivers of adults living with severe or profound IDD.¹⁶ Patients with severe or profound IDD have very limited communication, practical, and social skills, which poses challenges to conventional relationship development.

The purpose of this study was to explore the development of the patient physician relationship between adult patients with severe or profound IDD and their family physicians, as perceived by family physicians.

— Methods —

We used constructivist grounded theory to examine the processes of relationship development between adult patients with severe or profound IDD and their family physicians.¹⁷ This methodology encouraged the active involvement of the lead author (K.S.), a family physician involved in the primary care of adults with severe and profound IDD, in the generation of the data. The project was approved by Newfoundland and Labrador's Health Research Ethics Board.

Sampling

Participants were sampled purposefully. Participants eligible for the study included family physicians with experience caring for and developing relationships with patients with severe or profound IDD. Sampling was designed to encourage a range of perspectives including both national and local representation and a range of clinical experience with this population. Recruitment

occurred through e-mail requests to local urban and rural community and academic practices, as well as to members of the College of Family Physicians of Canada's Developmental Disabilities Program Committee. Sampling and data collection continued until the point of saturation, after which no additional concepts relevant to the central themes emerged.¹⁸

Data collection

Data were collected via 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 their patients.

The semistructured interview guide was regularly updated with emerging ideas from the simultaneous data analysis. Telephone or in-person interviews ranged from 45 to 60 minutes.

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

Data analysis

Data were analyzed by K.S., A.L.T., and B.L.R., who independently read and coded the transcripts to identify themes and concepts; this was followed by discussion at regular group meetings. The lead author (K.S.) incorporated the resulting information to iteratively create the final theoretical codes and develop a coordinated constructive grounded theory. The lead author regularly reflected on her own experience of clinical work with patients with IDD and how these experiences informed the analysis. Trustworthiness and credibility of the data were ensured by audiorecording of interviews, review of verbatim interview transcripts, detailed field notes, team data analysis, and regular group meetings that included group reflection on the process and the influence of personal experience.

— Findings —

A total of 15 family physicians met the inclusion criteria and participated in a total of 15 interviews with the researcher. **Table 1** presents participant demographic characteristics.

Relationship development through acceptance

Study findings revealed that from the perspective of family physicians, the core process in the development of the patient-physician relationship was *acceptance* (**Figure 1**). Family physicians had to accept and respect their patients as any other unique individual with their own specific goals and potential to even consider the possibility of a relationship: "Part of that relationship is an attitude toward what I would call just human vulnerability and that, that's OK." (Interview 15)

Table 1. Participant demographic characteristics: N = 15.

CHARACTERISTIC	VALUE
No. with specialized training	4
Mean (SD) years in practice	25.9 (11.7)
Mean (SD) years caring for patients with severe and profound IDD	21.3 (11.7)
No. with experience in NL in outpatient and inpatient care of adults with severe or profound IDD	3
No. practising comprehensive family medicine in NL	7
No. with special interest in primary health care of adults with IDD from across Canada	5

IDD—intellectual and developmental disabilities, NL—Newfoundland and Labrador.

Family physicians also sought signs of acceptance from the patient in order to fully appreciate and develop a trusting relationship. This required family physicians to accept different and varied amounts of feedback according to each patient's level of ability: "It's been harder to get to know these people because you don't have some of the normal cues that you ... pick up from them by talking to them and having them respond." (Interview 11)

The process of acceptance required family physicians to *commit to adapt* to the patient's level of functioning or ability. It also required that family physicians *define their role* specifically within this unique and complex relationship that, by virtue of the patient's level of ability, always involved a third party.

Committing to adapt to the patient's level of functioning and ability

Patients with severe or profound IDD have considerable limitations in adaptive functioning. For this reason, family physicians need to be the ones to adapt and they did so in the following ways.

Dedicating more time to these patients. As one physician described, "Sometimes we just need to give them more time so that they can answer in the way they know how." (Interview 2)

This posed a potential challenge for family physicians, by far most of whom were working in fee-for-service health care systems not designed to remunerate family physicians for this extra time.

He [a family physician colleague] had dedicated time for this patient population and he could take an hour with each patient; that's something I may not be able to do in a fee-for-service model That time pressure can significantly influence your interaction. (Interview 14)

Adapting to the presence of the caregiver in the relationship. Family physicians valued caregivers as essential role models and teachers when developing rapport with their patients. They noted that recognizing the importance of caregivers without ignoring the patient as an individual was challenging: "One of the risks perhaps is to direct all one's attention to them [caregivers] and forget about, kind of bypass [the patient] because they're [caregivers] such good spokespeople." (Interview 13)

Practising a mandatory higher level of patient-centred care. Physicians were challenged to find new ways to connect with their patients whom one physician described as "nontraditional communicators." This required family physicians to respect a patient's age and individual worth, while simultaneously adjusting their communication style to match the patient's level of comprehension: "So you have to use language that they comprehend, but you still have to have an approach that gives them the respect of being an adult." (Interview 10)

Patient-centred care also required family physicians to be acutely aware of contextual influences, including visual, sensory, and olfactory cues, that strongly affected their interactions with their patients.

For example, one family physician described using a patient's favourite scented body cream during her abdominal examination to help her feel calm and safe: "That was just so very powerful because it was all about the scent and connecting with her and having her trust me." (Interview 12)

Another described figuring out how the noise of a metal food tray was linked to a patient's experience of pain, which was then communicated through a behavioural disturbance.

They said every time around lunch hour he would start hitting himself ... he would hear the metal tray on the floor and he would start hitting himself ... which would then be the pain; he would be afraid of that; that's all he remembered when he'd hear that sound. (Interview 1)

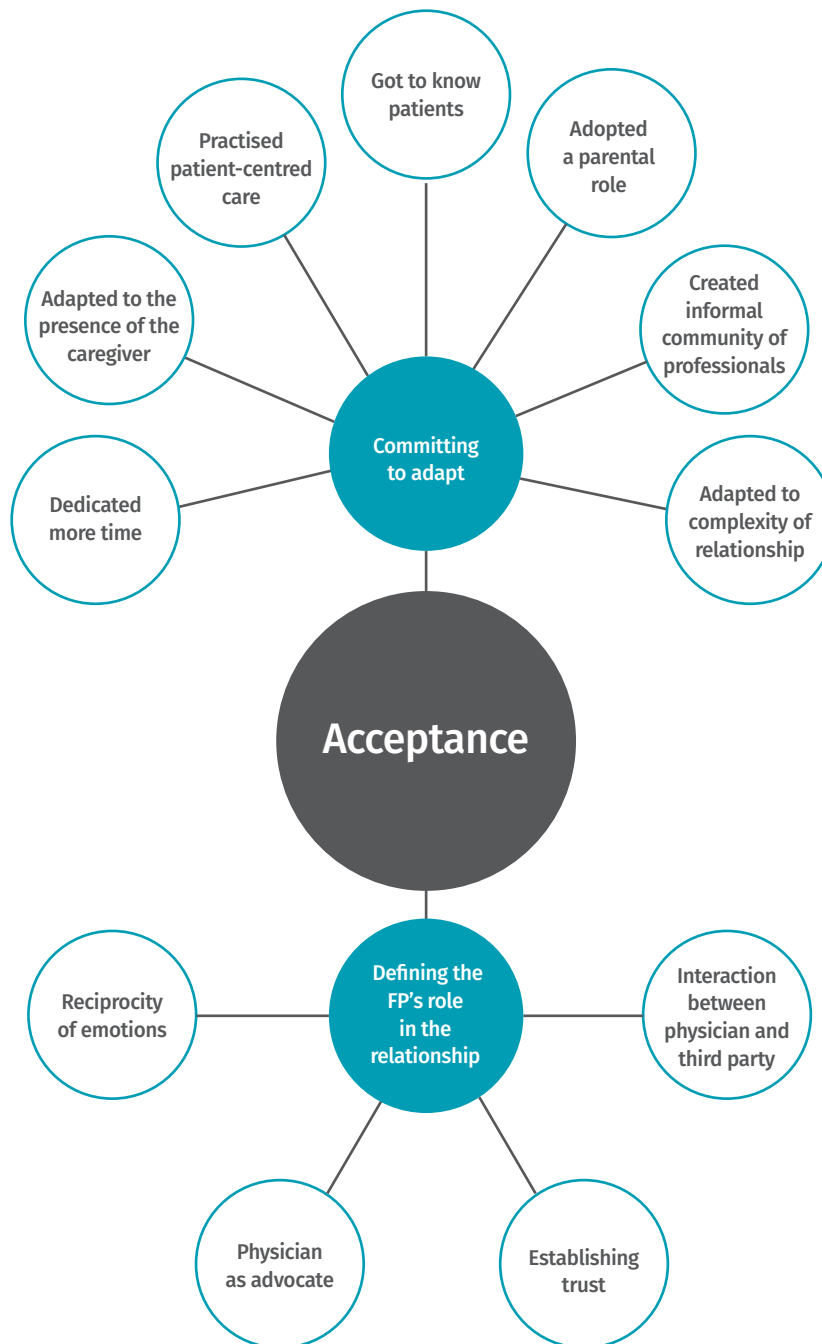
Getting to know patients personally. This deep personal knowledge, for example of the patient's idiosyncratic likes or dislikes, allowed family physicians to adapt the way they delivered health care and maximize success in potentially challenging encounters. It was also family physicians' way of showing that they respected these patients as individuals worthy of being known: "It is not so much what you can do for them; it's how well you can get to know them." (Interview 12)

Reaching out to create an informal community of health care professionals. True interprofessional Patient's Medical Homes were rare in this study.

Most family physicians also had no formal training in caring for this population. To cope with this lack of training and support, family physicians described unique ways of adapting in resource-deficient health care contexts. They realized that the only way to cope, without

feeling “alone,” “frustrated,” and “hopeless,” was to actively seek out and create informal supportive networks within the medical community: “Align yourself with key individuals [specialized health care professionals] who can help you.” (Interview 1)

Figure 1. Family physicians’ perspectives on the process of developing the patient-physician relationship in patients with severe and profound IDD



IDD—intellectual and developmental disabilities.

Adapting to the complexity of the relationship. Family physicians had to be aware of the complex interaction between the limitations posed by the disability and standard management guidelines for other medical comorbidities and adapt their approach accordingly: “These are complex people. And you know, it’s one thing to be renewing medications, but it’s not so simple.” (Interview 13)

Defining the family physician’s role in the relationship

Defining their role in relationships with each of their patients was described as an important subprocess of acceptance: “Part of the difficulty in looking after this group of people for me is figuring out what the role is.” (Interview 11)

Family physicians reported having to consider various aspects of their role in the development of these complex and varied relationships with patients living with IDD.

Role of the family physician in relation to interactions with the patient and the caregiver. Family physicians had to balance their interactions with caregivers (who were inspiring role models on how to form their own connections) with a strong desire to ensure that the patient remain the primary focus of the patient-physician relationship.

[I recognize] how important it is that we are able to work together, coordinate, and so on. But also, I think, there is something about the individual relationship [with the patient] that ought not to get lost in all these other relationships. (Interview 13)

Role of the family physician in establishing trust. As family physicians could not assume that their patients had any pre-existing understanding of trust in the medical profession, they had to make concerted efforts to establish a personal level of trust, even if this was very fragile: “So you know initially it’s that being very tentative and trying to find the ways that you can help that person relate to you and trust you and that type of thing.” (Interview 10)

Role of the family physician as advocate. These patients’ vulnerability while interacting within health care and social contexts not designed for them heightened the need for the family physician’s advocate role. One family physician said simply, “You are their voice.” (Interview 12)

Examples of advocacy included the deprescribing of medications and accessing required resources for patients.

Role of reciprocity of emotions in the relationship. Family physicians’ sense of well-being resulting from the relationships they developed with their patients with

severe and profound IDD went beyond that of knowing a medical problem had been solved. It included the appreciation of the experience of being with that human being and the joy that brought to the family physician: “Just one of the most rewarding things, I think you know, when you see someone [with severe or profound IDD] that’s doing well, for them.” (Interview 2)

— Discussion —

Research on the patient-physician relationship in patients with IDD is extremely limited. We have added to this limited research by focusing on patients who, by virtue of their severe or profound IDD, could often not connect in any conventional way with their family physicians.

For family physicians working with patients with severe or profound IDD, acceptance was the core process of relationship development. They accepted their patients as individuals worthy of their respect, attention, and empathy despite their limitations. They described “being with their patients” and “connecting with them beyond their disability.” Jean Vanier described this learning process as “becoming human.”¹⁹ Ian McWhinney described connectional moments in family medicine that occur when a family physician begins to relate to a patient as a fellow human being.¹ Previous research confirms that patients with mild IDD desire acceptance as equals.^{14,20}

This process of acceptance was bidirectional. That is, family physicians also looked for signs of acceptance from their patients. They had to be open to interpreting acceptance by their patients in accordance with each patient’s individual level of ability or by involving the caregiver as a guide. This is consistent with previous literature on the essential role of caregivers in interpreting behavioural indicators as part of developing relationships with these patients.^{21,22}

The overall process of acceptance required family physicians to do 2 things: to commit to adapting the way they practised and to define their role in the relationship. Adaptations included spending more time with the patient and finding alternate forms of communication, both consistent with previous literature.^{1,12-14,23-25} Practising an exceptionally high level of patient-centred care required family physicians to be aware of the potentially profound effects of all contextual stimuli, such as the scent of a body cream or the sound and texture of dishes. Adaptations also included finding the balance between patient autonomy and caregiver input to provide appropriate professional care. This could be challenging, as seen in previous studies.¹⁴

To cope with the challenges inherent in caring for adult patients with severe and profound developmental disabilities with complex health issues, family physicians adapted their practice further by developing their own informal support networks. They described proactively aligning themselves with key individuals who

could help them. Developing unique ways of coping with the lack of training and support in this area was consistent with previous literature.²⁶

The second part of the overall process of acceptance required family physicians to define their role in the relationship. For example, family physicians in this study appreciated caregiver input, but highlighted their role of ensuring the primacy of the patient-physician relationship. Previous studies acknowledge that caregiver involvement in patient-physician relationships can be both positive and challenging.^{27,28}

Health care relationships have been negatively affected by failures to protect vulnerable patients.²⁶ Family physicians noted their role in establishing trust where negative or no experience of this concept existed for some of their patients with severe and profound IDD.

The family physician's role as advocate is an accepted competency in all patient-physician relationships.²⁹ The considerable health disparities that exist for these patients with IDD^{9,10} and the unfortunate lingering negative perspective on these patients within the medical community²⁶ contributed to the strengthening of the advocate role for participants in this study.

The role of advocate was challenging but was eased by the role of reciprocal emotions within these relationships. The sense of personal and professional appreciation and accomplishment experienced by family physicians (noted in one previous study)¹² encouraged the continued development of the relationship.

Conclusion

This study used a grounded theory approach to discover the process of acceptance that underlies the formation of the patient-physician relationship in adult patients with severe or profound IDD. Findings highlight the need for family physicians to adapt the way they deliver care to these patients and define their role in these complex relationships. Ultimately, this study highlights the family physician's acceptance of their patients' humanity regardless of the nature of the relationship that was created between them.

Dr Stringer is Associate Professor and Chair in the Discipline of Family Medicine at Memorial University of Newfoundland in St. John's. **Drs Ryan** and **Terry** are Assistant Professors in the Centre for Studies in Family Medicine, the Department of Family Medicine, and the Department of Epidemiology and Biostatistics at the University of Western Ontario in London. **Ms Pike** is Research Manager in the Primary Healthcare Research Unit at Memorial University.

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

Correspondence

Dr Katherine Stringer; e-mail Katherine.Stringer@med.mun.ca

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