

### Editor's key points

► In most models of family practice, family caregivers are underrecognized, undersupported, and underused. Few health care professionals have received training in caregiver engagement, and typically there is a reluctance to collaborate with caregivers and an unwillingness to involve caregivers in the care process in a meaningful fashion.

► In this study, actively including family caregivers as members of the interprofessional care team resulted in enhanced caregiver experience and expanded caregiver capacity. Family caregivers became increasingly engaged and empowered in their roles. Through collaboration with the team, caregivers' levels of confidence increased and they felt more hopeful.

► The synchronous interprofessional team model of the IMPACT (Interprofessional Model of Practice for Aging and Complex Treatments) clinic provides an effective approach to integrating caregivers within an interprofessional team and to supporting, educating, enhancing, and sustaining family caregivers who care for elderly patients with complex needs.

# Effect of an innovative model of complexity care on family caregiver experience

## Qualitative study in family practice

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### Abstract

**Objective** To investigate the experiences of family caregivers who participated in an innovative model of interprofessional team-based care specifically designed for elderly patients with complex care needs.

**Design** Qualitative study.

**Setting** Large academic family practice in Toronto, Ont.

**Participants** Family caregivers of elderly patients who had attended the IMPACT (Interprofessional Model of Practice for Aging and Complex Treatments) clinic (N=13).

**Methods** Individual semistructured interviews, which were conducted face-to-face, audiorecorded, transcribed verbatim, and analyzed using the constant comparative method.

**Main findings** Family caregivers who attended the IMPACT clinic believed it enhanced caregiver experience and capacity. Caregivers experienced increased validation and engagement with the treatment team. Feelings of isolation were reduced, resulting in increased confidence and greater feelings of empowerment in their caregiver role.

**Conclusion** While the needs and value of caregivers are increasingly acknowledged, health care teams continue to struggle with how to relate to and engage with family caregivers—how best to support them and work with them in the context of their family members' care. Interprofessional teams who adopt the IMPACT model—providing synchronous, real-time interventions that include the caregiver—can facilitate increased caregiver capacity, confidence, and empowerment.

# Effets d'un modèle novateur de soins complexes sur l'expérience des aidants de la famille

## Étude qualitative en pratique familiale

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### Résumé

**Objectif** Étudier les expériences d'aidants familiaux qui ont participé à la mise en application d'un modèle novateur de soins en équipe interprofessionnelle, spécifiquement conçu à l'intention de patients plus âgés ayant des besoins de soins complexes.

**Type d'étude** Étude qualitative.

**Contexte** Grande clinique universitaire de pratique familiale à Toronto (Ontario).

**Participants** Les aidants membres de la famille de patients plus âgés qui ont fréquenté la clinique IMPACT (Interprofessional Model of Practice for Aging and Complex Treatments) (N = 13).

**Méthodes** Des entrevues individuelles semi-structurées, effectuées en personne, qui ont fait l'objet d'un enregistrement sonore, d'une transcription mot à mot et d'une analyse à l'aide d'une méthode comparative constante.

**Principales constatations** Les aidants de la famille qui ont participé à la clinique IMPACT croyaient que cette intervention avait amélioré leur expérience et accru leurs capacités. Les aidants ont vécu une validation et une mobilisation accrues au sein de l'équipe thérapeutique. Leurs sentiments d'isolement ont été atténués, ce qui a eu pour résultats une plus grande confiance et une plus grande responsabilisation dans leurs rôles d'aidants.

**Conclusion** Bien que les besoins et l'utilité des aidants soient de plus en plus reconnus, les équipes de soins de santé continuent d'éprouver des difficultés quand il s'agit d'établir des rapports et de collaborer avec la famille, notamment les meilleurs moyens de les soutenir et de travailler avec eux dans le contexte des soins à un membre de leur famille. Les équipes interprofessionnelles qui adoptent le modèle IMPACT, c'est-à-dire la prestation d'interventions synchrones en temps réel avec la participation de l'aidant, peuvent contribuer à accroître les capacités des aidants, leur confiance et leur responsabilisation.

### Points de repère du rédacteur

► Dans la plupart des modèles de pratique familiale, les aidants de la famille sont peu reconnus, mal soutenus et sous-utilisés. Peu de professionnels de la santé ont reçu de la formation en mobilisation des aidants, et ils sont habituellement réticents à collaborer avec les aidants et peu réceptifs à les impliquer dans le processus thérapeutique d'une manière significative.

► Dans cette étude, l'inclusion active des aidants de la famille à titre de membres de l'équipe de soins interprofessionnels a eu pour effet d'améliorer l'expérience des aidants et d'accroître leurs capacités. Les aidants de la famille se sont de plus en plus mobilisés et responsabilisés dans leurs rôles. En collaborant avec l'équipe, les aidants se sont sentis plus confiants et optimistes.

► Le modèle synchrone en équipe interprofessionnelle de la clinique IMPACT (Interprofessional Model of Practice for Aging and Complex Treatments) représente une approche efficace pour intégrer les aidants au sein d'une équipe interprofessionnelle, et aussi pour soutenir, éduquer, perfectionner et épauler les aidants de la famille qui s'occupent de patients plus âgés ayant des besoins complexes.

Nearly half (46%) of the Canadian adult population has, at some point in their lives, provided care to a family member or friend with a chronic condition.<sup>1</sup> Caregivers provide assistance for an array of personal and functional needs of the care recipient—and providing this care is not without risk.<sup>2,3</sup>

*Caregiver burden* is defined as “a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience.”<sup>4</sup> Among the known risk factors contributing to caregiver burden, such as high number of care hours, lack of existing coping skills, multiple dependents, and low education levels, it is increasingly recognized that the degree of burden is critically related to the complexity of the caregiving tasks.<sup>5-10</sup> Evidence suggests that providing medically complex care for family members without having adequate training can be particularly stressful.<sup>11</sup> Recent studies also suggest that caregiver burden tends to increase over time.<sup>12,13</sup> There is growing recognition that caregivers’ needs should be considered alongside those of the patient and that services and supports specific to the context of care should be provided; however, there is limited understanding of how best to accomplish this within current models of care.<sup>14-17</sup>

The IMPACT (Interprofessional Model of Practice for Aging and Complex Treatments) clinic is an interprofessional care model in which the clinical team works synchronously in real time with the patient, family caregiver, and referring family physician. (A full description of the IMPACT model was published previously.<sup>18</sup>) During the 1.5- to 2-hour appointment, both the patient and the caregiver are encouraged to play active roles by raising concerns, asking questions, and discussing options. We have previously evaluated the IMPACT model for patient experience and team function<sup>18</sup>; the current study specifically aims to explore the experience of family caregivers.

## — Methods —

### Study design

Given that the objective was to elicit the personal stories and lived experience of family caregivers of elderly patients enrolled in the IMPACT clinic, a qualitative design was deemed most appropriate. The constant comparative method of grounded theory<sup>19</sup> was used to capture comparisons across different family caregivers (ie, their views and experiences) as well as comparisons across time for individual caregivers (ie, experiences in the IMPACT clinic compared with previous models of care). Ethics approval was received from the research ethics board at Sunnybrook Health Sciences Centre in Toronto, Ont.

### Participant recruitment

The team identified a convenience sample of 20 patients who had attended the IMPACT clinic with a caregiver. Study inclusion criteria stipulated that participants

must be the patient’s primary caregiver and must have personally attended the IMPACT clinic at least once. Paid caregivers were excluded. An attempt was made to include a diverse cross-section of caregivers based on age, sex, relationship to the patient, and living arrangement. A demographic profile of the 13 study participants is presented in **Table 1**. Ten of the caregivers (77%) were adult children (6 daughters, 4 sons) and 3 were spouses (2 husbands, 1 wife). Six caregivers lived with the patient; among the others, the distance from the patient ranged from 5 blocks to out of province. A little more than half of the caregivers were retired and the rest were in some form of paid employment.

A research coordinator (S.H.B.) telephoned each patient for permission to contact the patient’s caregiver to discuss the caregiver’s experience with the IMPACT clinic. The caregivers were provided a description of the study and invited to participate. Interviews were scheduled at the convenience of the caregivers, and transportation or parking was covered by the funding grant if they chose to meet at the clinic rather than at their home.

### Data collection and analysis

Based on a review of the literature, a semistructured interview guide was developed by the team and then pilot-tested and revised. Topics included the caregiver role (both past and present), health status of the patient, caregiver strain and well-being (physical, emotional, social, etc), and caregiver experience with the IMPACT clinic. For 2 months, individual face-to-face interviews were conducted jointly by a social worker and a researcher (S.H.B.) trained in qualitative methods (neither of whom were employees of the clinic). Interviews were transcribed verbatim by a professional transcriptionist and then verified by the research team to ensure accuracy. After each interview, the transcript was coded independently by 3 members of the research team (L.A.N., C.S.T., S.H.B.) to identify key themes and categories. Data collection and analysis were performed iteratively such that emerging themes were pursued in later interviews using the constant comparative method<sup>19</sup> to seek corroborating evidence and identify outlier cases. A total of 13 interviews were conducted, as saturation was reached at that point and no new additional themes were emerging. To enhance the credibility of the interpretation that emerged through the analysis, a member check was performed by sending a written summary of the key findings to each of the interviewees.

## — Findings —

The interviews revealed patterns of experience consistent with primary themes identified in the academic literature on family caregivers. Specifically, interviewees reported feeling alone and isolated in their roles as caregivers. The need for support and information was emphasized:

**Table 1. Demographic profile of participants**

CODE	CG AGE, Y	CG SEX	RELATIONSHIP TO PATIENT	PROXIMITY TO PATIENT	EMPLOYMENT STATUS OF CG	SHARED RESPONSIBILITY	ESTIMATED CARE TIME	TYPICAL CAREGIVER ACTIVITIES
CG01	< 65	M	Son	3-4 km	Retired	Shares with hired care provider and sister	15 h/wk	Mobility, socialization
CG02	< 65	F	Daughter	45 min	Full-time	Shares with hired care provider	12 h/wk	Meals, socialization
CG03	≥ 65	M	Spouse	Together	Retired	No	21 h/wk	Meals
CG04	< 65	F	Daughter	Together	Part-time	Shares with husband and sons	20 h/wk	Meals, laundry, shopping
CG05	< 65	M	Son	1 km	Retired	No	20 h/wk	Shopping, mail, finance, outings, transport
CG06	≥ 65	M	Spouse	Together	Retired	No	NA	Dressing, driving, meals
CG07	< 65	M	Son	5 miles	Full-time (flexible)	Shares with sister	60 h/wk	Walking, mail, cleaning, calls, socialization
CG08	< 65	F	Daughter	Together	Full-time (self-employed)	Shares with 4 siblings	18 h/wk	Meals, insulin, cleaning
CG09	< 65	F	Daughter	50 min	Retired	Shares with daughter and neighbour	2 d/wk	Finances, shopping
CG10	< 65	F	Daughter	Together	Retired	No	84 h/wk	Laundry, cooking, housekeeping, supervising, bathing, medical monitoring, driving, outings
CG11	≥ 65	F	Spouse	Together	Retired	No	Daily	Meals, errands, driving, medication pickup and supervising
CG12	< 65	M	Son	5 blocks	Full-time	Shares with neighbour	NA	NA
CG13	< 65	F	Daughter	ON-BC	Not working	Shares with hired care provider	3 times/wk	Finance, groceries, other shopping

BC—British Columbia, CG—caregiver, F—female, M—male, NA—not available, ON—Ontario.

basic information about resources and equipment as well as more specialized information regarding particular medical symptoms and treatment options.

Unique to this study is the participants' experience of the IMPACT care model. When asked to share their perceptions of IMPACT (both positive and negative), 3 primary themes emerged: caregiver validation, caregiver engagement, and caregiver empowerment.

### Caregiver validation

A common theme that wove through the interviews was that the IMPACT clinic provided "space" for caregivers to tell their own stories and contribute to clinical encounters. Many interviewees recounted how they had been expressly encouraged by the team to voice their views and opinions and to share their ideas and suggestions; in most cases, it seemed that this approach differed substantially from the caregivers' previous experiences. One interviewee, the sole caregiver for his 88-year-old mother, stated the following:

I think the team approach was super .... We were all together and I was able to absorb and hear and discuss and question and that sort of thing .... They didn't make me feel shy either, you know, so I didn't feel reluctant to be forthcoming. I mean, my understanding was that's what was wanted. Everybody wanted me to say stuff so there was nothing I should be concerned about. So that access was huge. I was amazed that it was possible and that it could happen this way. I think it's a huge benefit. (Caregiver 5 [CG05])

Participants noted the importance of listening to caregivers' voices and attending to caregivers' needs, distinct from those of patients. This was emphasized by a participant who was experiencing caregiver strain after taking a work leave of absence to provide daily care to her 82-year-old mother who lived at home alone and had recently become wheelchair dependent:

From the team standpoint, the way everybody works together, the way they hear not just the patient, but whoever happens to be the family .... They work with Mom and with me so it's like they have 2 patients, especially at first because I was a basket case then. It provides emotional security and support not only for the patient, but the family too. (CG02)

Another interviewee, who was caring for her mother while working full-time, expressed relief for the support of the team and appreciation of the opportunity to contribute important pieces of information that were missed:

I think it made me feel, I guess, somewhat relieved that everybody was on top of things. And I had a chance to ask questions, too. I remember saying to my mother, "You didn't mention something" and she said, "Oh, I forgot." So if I wouldn't have been there, she wouldn't have mentioned it. (CG08)

### Caregiver engagement

The second key theme extends from the first. Feeling validated and acknowledged as valued members of the care team, these caregivers reported taking full advantage of the opportunity to ask questions, raise concerns, and undertake challenges. For many, the role of caregiver was a new role and brought with it considerable uncertainty and anxiety, as the husband of a 73-year-old woman recently diagnosed with dementia explained:

I generally feel much calmer. Up until IMPACT, I had no help at all in trying to deal with what was happening and I didn't really have a good understanding of how to respond to it. After the 2 IMPACT visits, particularly the part where I was interviewed individually away from my wife, I found that very, very helpful and calming and I think it created a much healthier situation in our home environment. (CG03)

He went on to describe his own evolving role as caregiver:

I've paid more attention to what is going on. I've been on the Internet looking up things. I've learned some of the terms, like *hippocampus*. I feel that without the IMPACT team I don't know where this would have gone because I was really feeling isolated. So I don't know how much that IMPACT program costs, but as far as I'm concerned it was worth the money in lessening my anxiety and maybe helping me provide better care for my wife as we move along here. (CG03)

The participants' accounts clearly indicated that effective caregiver engagement requires a flexible care model in which the unique preferences and circumstances of each case can be best accommodated. The salience of this point was illustrated by the

contrasting feedback provided by caregivers regarding the timing of follow-up visits:

The time between our visits to the IMPACT clinic was far between. It would have been much more helpful had it been a more consistent process ... [with visits] closer together and they could have followed through on each recommendation. (CG01)

I had the sense that there could have been more time between sessions, not necessarily less often, but the interval could have been maybe a little longer. I thought that the time between sessions was a little short. You didn't get a whole lot of time to sort of put stuff into practice. (CG05)

This caregiver elaborated by pointing to the inherent challenge involved:

So that's hard to judge, you know, that's really hard to schedule because I think it's very individual. Each case is unique so how do you ... how do you systematize that? It's got to be real difficult to approach that. (CG05)

### Caregiver empowerment

Finally, caregivers' accounts of their experiences with the IMPACT clinic strongly reflected a greater level of understanding of the caregiver role and an enhanced level of confidence in their own ability within the role:

I certainly believe in IMPACT ... I think it's a real confidence booster. (CG06)

Before I came to the IMPACT program, I had some reservations about [my husband's] behaviour. I was not sure of what was happening so I was a bit concerned ... especially in my culture, it's something that you never talk about and so it made it very difficult. But when I listened in to the different disciplines, everything was made clear to me and I found that his condition is an illness and I get a basic understanding that it's an illness ... then I have to know about it to deal with it a bit better. (CG11)

[I'm] more confident in knowing what I'm doing and if I'm thinking of doing some things I have a better understanding of what impact they might have. Just more confidence in going ahead with those kinds of things .... I'm not reluctant about wasting my time. I've seen responses. I've seen impacts of activities and things that I've done for her. I just feel more comfortable—more comfortable and confident. (CG05)

This caregiver described how his new-found confidence empowered him to become substantially more involved in caregiving for his housebound mother:

I feel I'm doing the right things and I have a better understanding of how to get involved on a day-to-day basis. I mean, I call her every day if I'm not there. I go twice a week, sometimes 3 times, but I call her every day as well and I think that makes a difference to her outlook and her attitude so I know she appreciates it. (CG05)

## — Discussion —

This study identified 3 key themes related to the experience of family caregivers who attended an interprofessional model of care for community-residing elderly patients with complex needs. The data suggest that the IMPACT model is effective in validating caregivers' experiences of caring, meaningfully engaging caregivers in patients' care teams, and empowering caregivers in their current and future roles.

According to the participants' accounts, the IMPACT clinic allowed caregivers to feel acknowledged and "listened to" by the clinical care team. For some, it was the first opportunity to express their fears and concerns and to have their questions answered. The synchronous team-based model of IMPACT, which explicitly incorporates caregivers as members of the team, validates caregivers' roles and thereby promotes active participation. In addition to the support and validation for caregivers, creating a space for caregivers to voice concerns and observations provides important information to the team that would often otherwise be unavailable. Participants reported that, over time, they became increasingly comfortable engaging in discussions with the team and being active participants, whereas initially they were more tentative and played the role of "information recipient" rather than active "team member." In short, greater engagement *with* caregivers at IMPACT appeared to foster greater engagement *by* caregivers in their roles. This increased level of engagement subsequently reduced the feelings of isolation that are common among family caregivers.<sup>16</sup> Likewise, the level of caregiver confidence increased; interviewees reporting feeling an increased capacity to initiate changes and to adapt as the situation demanded. Caregivers appeared to discover a new sense of themselves as caregivers, which empowered them to engage in other forms of support that, in turn, resulted in renewed hopefulness and increased resilience.

There is growing recognition among health care providers of the needs of family caregivers and, thus, the attention of health policy makers is increasingly directed toward the social challenges of caregiver burden and burnout.<sup>2,3</sup> Typically, however, this attention is separate from that given to the care recipient (ie, the patient). Treatment teams for patients often resist involving caregivers in the discussion and planning of patient care or, at best, include caregivers only to provide them with information. Not only does this

result in added frustration and burden for caregivers, it fails to recognize and use the expertise that caregivers bring: their in-depth knowledge of the care recipient and the home or community context. In addition to acknowledging caregiver needs, it is essential for health care teams to include caregiver perspectives and knowledge of the care recipient as a standard component of the assessment and plan.<sup>15,18</sup>

In this study, we demonstrated that the IMPACT model meaningfully enhances the experience and capacity of family caregivers. Involving caregivers as part of the interprofessional team assessment increased caregiver validation, engagement, and confidence. Providing the space to listen to and work together with the caregiver and to collaborate on patient care goals resulted in increased caregiver confidence and greater ability to sustain caregiving. In turn, the engaged caregivers became an even greater resource to the care recipient and likewise to the treatment team.

### Implications


The IMPACT model is ideally suited to family practices with access to an interprofessional team, but the following key principles could be adapted for individual family physicians: routinely involve caregivers in visits, allow space to hear caregivers' perspectives, and develop care plans together (ie, physician, patient, and caregiver). Follow-up research could involve larger study samples across multiple sites and geographic locations and variable caregiver-patient populations.

### Limitations

Although the current study provides insight into the potential benefits of interprofessional practice models for family members caring for complex patients, the relatively small sample size and convenience sample, as well as data collection from one site, might limit generalizability. Further, the catchment area of the study setting skews toward populations of higher socioeconomic status. Finally, most of the caregiver participants were older and did not have the additional demands of child care, and most were retired or working reduced or flexible hours.

### Conclusion

It is well recognized that family caregivers play a critical role in maintaining complex patients at home; however, less is known or has been done to effectively support and sustain caregivers in their role within the larger health care system. This study provides evidence that actively including family caregivers as members of the interprofessional care team results in enhanced caregiver experience and expanded caregiver capacity. Family caregivers became increasingly engaged and empowered in their role. Through collaboration with the team, caregivers' levels of confidence increased and they felt

more hopeful. The synchronous interprofessional team model of the IMPACT clinic provides an effective approach to integrating caregivers within an interprofessional team and to supporting, educating, enhancing, and sustaining family caregivers who care for elderly patients with complex needs in the community. 

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#### Contributors

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

#### Competing interests

None declared

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