

**RESEARCH ON THE RUN**

Caregivers

# The experiences of patients and caregivers as couples

How is the couple relationship affected when couples are dealing together with serious illness or injury?

## Key Learnings

While there has been attention paid to caregiver burden, it has generally been looked at from the point of view of the individual as caregiver without adequate regard to the impact of the spousal relationship on the burden.

Addressing the caregiver outside the context of their relationship with their partner misses that the impact of relationship changes, also adds to, or diminishes the burden.

The relationship can in some cases provide the caregiver with critical support contributing to resilience; in other cases it can add to the burden even to the point of personal or relationship breakdown.

## Project overview

In 2012, 8% of Canadian family caregivers, provided care for their spouses. This low percentage of spousal caregivers is a result of underreporting since some spouses do not see their tasks as "caregiving" but as an extension of their spousal role.

Caregiving studies have traditionally focused on the caregiver as an individual and the patient, the disease, and demands of caregiving duties as sources of stress. It is only recently that the focus of spousal caregiving studies has shifted to both patient and caregiver as a "unit of analysis" (Fletcher et al., 2012).

In this project, the researchers chose to examine the dynamic between spouses when thrust into the roles of patient and caregiver, and looked at how the dynamic and the interplay between partners contributes to how well the patient does, and how well the relationship does, under the strain of the illness or injury.

## What did the researchers do?

The researchers welcomed both patients and caregivers, men and women, to participate in focus groups together. It was important to include the perspectives of both sides. They did not exclude people with relevant experiences based on disease, acute or chronic, or whether the caregiving was as a result of medical trauma or injury, because they were looking into couples' experiences as it relates to their relationship as a universal and emotional matter. For the same reason, they did not exclude people whose partner has passed away or who are no longer in a spousal relationship.

## What did the researchers find?

On the basis of the focus groups and iterative analysis, the researchers found an overarching story that drew together all the experiences of patient and caregiver couples: "Riding the Roller Coaster." They found that there are ups and downs in the illness trajectory and in the couple's relationship, and they are not always the same.

There were 10 subsidiary themes.

### *Invisibility*

- "Unseen in a Party of Two" – the couple's social network does not see the caregiver
- "Hide and Don't Seek" - The patient (and sometimes the caregiver) hides their illness from the world

### *Losses*

- "The Incredible Shrinking World" – There is a loss of function and loss of social interactions and often work
- "Out of Balance" – there is a loss of balance when the caregiver takes on more and more and the patient can do less and less

### *Intimacy*

- "Barriers in the Bed" – There are significant impacts on intimacy, including the sexual relationship

### *Weighty Matters*

- "Should I Stay or Should I Go?" - When the burden becomes high, the caregiver and also sometimes the patient wonder if they should remain in the relationship
- "Crash and Burn" - When the caregiver is stressed to the breaking point, what happens to the couple?

*Tough Going*

- “Lost in Translation” - One partner has to translate for the other and still provide support as a couple
- “Tug of War” - The partners may want the same thing but disagree on how to achieve it

*Caregivers as Patients*

- “Who’s on First?” – When the caregiver is also a patient, the patient still is first

**Innovative approach**

This qualitative study was undertaken by the Patient and Community Engagement Research (PaCER) Toronto Team to fulfill the requirements of internship training with the PaCER Program, O’Brien Institute for Public Health, Community Health Sciences, Cumming School of Medicine of the University of Calgary.

The research study’s design followed the SET, COLLECT, REFLECT structure outlined in the book, *Grey Matters: A Guide for Collaborative Research with Seniors* by Nancy Marlett and Claudia Emes. This Canadian innovation in engagement research offers a method to fully engage patients and caregivers in all aspects of research by training them to become peer researchers in health care. The Toronto PaCER Team was the first team to participate in the PaCER program from outside Alberta.

**IMPACT: How are we moving Knowledge to Action?**

The researchers have presented the findings at several conferences and meetings of healthcare managers

**Who were the researchers?**

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- Nancy Marlett, University of Calgary
- Svetlana Shklarov, University of Calgary
- Paul Holyoke, Saint Elizabeth Research Centre

**How was this project funded?**

Saint Elizabeth supported the research through a grant as an element of its social innovation mission.

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**For more information about PaCER, see this webpage:**

<http://www.pacerinnovates.ca/>

<http://www.familycaregiversvoice.ca/pacer-toronto/>

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Our goal is to improve people’s health and care. We work on innovative solutions for tough problems.

*We see possibilities everywhere.*