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UNCOVERING THE EXPERIENCES OF PATIENTS AND CAREGIVERS AS COUPLES

PATIENT ENGAGEMENT RESEARCH STUDY REPORT

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Contents

Introduction	3
Background and Literature Review.....	4
Methodology.....	6
Recruitment.....	7
Participants.....	8
Data Collection Procedures.....	8
Data Analysis	10
Findings	12
Overview	12
Ups and Downs - Finding the Core Script.....	13
Riding the Roller Coaster - The Core Script	13
Invisibility Cluster	14
Unseen in a Party of Two.....	14
Hide and Don't Seek	15
Losses Cluster	16
THE INCREDIBLE SHRINKING WORLD.....	16
OUT OF BALANCE.....	18
Intimacy.....	19
Barriers in the Bed	19
Weighty Matters Cluster	20
Should I Stay or Should I Go	20
Crash and Burn	21
Tough Going Cluster	22
Lost in Translation	23
TUG OF WAR.....	24
Caregivers as Patients	25
Who's On First	25
Findings Related to Couple's Relationships with Healthcare Professionals	27

Battle Lines27

Invisible People.....27

In the Dark28

Rocking the Boat.....28

Discussion.....28

Conclusions30

References32

Appendices.....35

 Appendix A: Recruitment 35

 A1. Recruitment Poster 35

 A2. Invitation Letter.....36

 A3. Study Summary for Service Providers37

 A4. Social Media Recruitment Invitation.....39

 Appendix B. Demographic Form40

 Appendix C. Patient and Community Engagement Research (PaCER) Model41

 Appendix D. Focus Group/Interview Guide42

 D1. SET Focus Group.....42

 D2. COLLECT Focus Group44

 D3. Narrative Interview45

 D4. Reflect Focus Group46

List of Tables

Table 1. Study Participants.....8

Table 2. Data Collection Procedures and Samples.....10

Table 3. Findings Summary12

Table 4. Findings Related to Couple's Relationships with Healthcare Professionals27

Uncovering the Experiences of Patients and Caregivers as Couples

Introduction

This qualitative study has been 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 PaCER program is supported by the Strategic Clinical Networks with Alberta Health Services. This project is supported by Saint Elizabeth Health Care in Toronto.

PaCER Toronto was formed in August of 2014 by Dr. Nancy Marlett, Dr. Svetlana Shklarov and Sara Shearkhani. Sara was a family caregiver from Toronto who reached out to PaCER and asked to join the program. Sara's situation did not allow her to move to Calgary, as she was taking care of her husband who had cancer. Sara decided to form a group in Toronto and recruit patients or caregivers who were willing to participate in a year of training and would be interested in conducting a research study on caregiving experiences. By January of 2015, the team was formed: Annette McKinnon and Alies Maybee, two patients, joined the group, and the classes started. By March 2015, Sara was able to initiate a sponsorship with Saint Elizabeth Health Care, and Dr. Paul Holyoke joined the team as a mentor. Although the initial topic of interest was caregiving, it was soon obvious that the PaCER members who were patients could not relate to the topic. With the help of Dr. Nancy Marlett and as a result of a series of brainstorming sessions, the group discovered that the experiences of couples struggling with an illness together was a common area of concern and research interest. The group realized that even though their experiences as patients and caregivers were different, they all had experienced a change in the dynamics of their marriage relationships after one partner became a patient and the other partner assumed the role of a caregiver. During class discussions and after consulting other PaCERs (patients and family caregivers) and holding a practice focus group, we decided to explore the experiences of couples during illness or injury. These initial group discussions with patients and caregivers also helped refine recruitment criteria and plans, and confirmed our data collection strategies. We included these insights in our research proposal.

As a result of this preliminary work, our broad research question in this study was, **How is the couple relationship affected when couples are dealing together with serious illness or injury?**

We took an online ethics course and wrote a proposal for our qualitative research study. The proposal was submitted first to the Conjoint Health Research Ethics Board of University of Calgary and was approved on June 22, 2015 (See Appendix A1). Then, the research proposal was submitted to the Mackenzie Health Research Ethics Board and was approved on August 28, 2015 (See Appendix A2). The research project started immediately after we received the ethics approval.

In total, we held three focus groups and five in-depth interviews. The data were analyzed and the final product was presented at the 21st Qualitative Health Research conference and Quality Forum 2016. The results were also shared with our participants.

Background and Literature Review

Research on caregiving and the informal caregiving dynamic was taken seriously in the 1980s and thrived in the 1990s. Previously, caregiving studies had 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). This emerging research suggests that the diagnosis and the illness trajectory can change the relationship between spouses and cause them to “reflect on their roles as an individual and as couples” (Li et al., 2014. p.2), as well as on new responsibilities they take on and the life itself that is changing:

“My life was irregular when I was an office worker. Now that I am self-employed, I can rush to my wife if anything should happen to her. I can take part in school activities more than before, and I don’t have to make my children sad anymore” (Mizuno et al., 2011, p. 5).

“Honestly, I did think about separating from her [my wife] at times, and it would be a great relief for me. But I cannot leave her alone after having stayed together for decades. It is too cruel for her” (Mizuno et al., 2011, p. 6).

Eventually, these changes can affect both patient’s and caregiver’s well-being, wellness and ability to cope (Li & Loke, 2014). It has been suggested that spouse-caregivers “are more likely than others to be experiencing difficulties as a result of their tasks” and “to experience psychological consequences, health effects, pressures on their personal finances and possible consequences in their career” (Turcotte, 2013. p. 11.). “They are also more likely to say that they had no choice but to take on their caregiving responsibilities” (Turcotte, 2013, p. 7):

“I have no way but to take charge of things my wife is unable to do” (Mizuno et al., 2011, p. 6).

In 2012, 8% of Canadian family caregivers, provided care for their spouses (Statistics Canada, 2012). 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. Martine Turcotte (2013) found that for some of these caregivers, caregiving was equivalent to a full time job; in Canada, for example, spousal caregivers spent a median of 14 hours a week on caregiving activities (Statistics Canada, 2012). According to Statistics Canada this is a measure of the intensity of care provided by spousal caregivers; out of the 9 common types of care provided by primary caregivers – transportation, meal preparation, house maintenance, personal care, treatment, managing care,

financial assistance, visit or phone call to make sure the patient is fine, and emotional support – 41% of caregivers helping their spouses provided at least 7 types of these services.

Caregivers experience a significant impact of their caregiving duties on their wellbeing because of their caregiver duties. According to Statistics Canada, in 2012, spousal caregivers reported more mental problems than other caregivers; for instance:

- 72% tired because of caregiving responsibilities
- 74% worried or anxious
- 55% sleep problems
- 48% overwhelmed
- 47% angry
- 38% isolated
- 34% depressed
- 28% unhappy
- 18% eating problems.

These caregivers also suffered from health consequences resulting from their caregiving tasks. However, only 33% of these caregivers sought out professional help (Statistics Canada, 2012).

Financial difficulties were another consequence associated with caregiving responsibilities, reported by Statistics Canada in 2012. Twenty percent of spousal caregivers experienced financial problems but only 14% received financial assistance from the government. Forty-two percent of them reported they would have liked more help than they received. These family caregivers struggled to balance between caregiving responsibilities and professional commitments.

The grey literature review provided findings similar to the statistics and problems mentioned in the literature review of scholarly works. Some authors reflected on sharing their feeling such as guilt about giving up (Comfort Life, 2014), isolation (Emrich, 2015), feeling of obligation (Blumer, 2014) uncertainty about future (Gruberg, 2014), feeling like a parent, not a spouse and lack of intimacy (Sotak, 2014).

Other issues that emerged are even more obviously relevant to the ultimate success of their status as a couple. As noted in a study by Karraker et al., (2009), the likelihood of divorce was 6% higher in couples where the wife was sick than in couples where the sick partner was a husband. In Karraker's study of 2,701 couples 32% were actually divorced by the end of the study. In another study by Mathiessen (2009), in a survey by caring.com 80% of respondents said there was a strain on their relationship:

"Even a strong marriage, like mine, suffers from the imbalance in household and child responsibilities because one of us is caring for a parent. Decreased time together, lack of opportunity for consistent communication, resentment of the needy parent, shift in the use of

financial resources, increased fatigue and stress all increase the strain on a marriage."
(Mathiessen, 2009, para. 7)

Even though all findings point to the intensity of spousal caregiving and the potential toll on the couples' relationship, little qualitative research has been conducted on this topic. Most research dedicated to this topic aims to understand the impact of caregiving stress or the disease on physical and mental health of patients and or caregivers, rather than on what exactly happens between spouses (Li et al., 2014) and to their relationships. This is surprising, as studies show the importance of focusing on couples' ways of coping with the illness, as well as an advantage of improving and encouraging communication between couples. For example, Li et al., 2014 demonstrated that "communication between couples may facilitate the reciprocal influences and promote congruence between the couples, which in turn can lead to beneficial caregiving outcomes for the couples" as well as "less distress and better material adjustment" (p. 6).

This study addresses the identified gap and tries to determine whether the experience of patients and caregivers as couples dealing with an illness or injury is an isolated event affecting only the patients or not. Couples go through the changes together and cope with the illness or injury together. We wanted to understand what really concerns people in the area of relationships including their beliefs and practices. In addition, with the direct guidance of our participants, we hoped to reveal gaps within society and the healthcare system that could become a cornerstone for further research and action to support healthcare practices and provide support for both spousal caregiver and patient. Ultimately we hoped to explore what types of help or coping mechanisms might enable them to maintain a healthy relationship.

Through our discussions based on own experiences as patients and caregivers, and from our participation in the current PaCER internship, some major questions that emerged included the following: what changed in the relationship after illness or injury appeared, what patients/caregivers do to handle or cope with the changes, what kinds of support would make this journey easier for them, and what is the importance of open communication between the couples? Other major research concerns that were identified were sex and intimacy, the transition from partners to patients/caregivers and back to partners, the impact on the couple of miscommunication among and with healthcare professionals, as well as the impact of the Internet and easy access to information on the relationship. Research studies conducted by Fletcher et al. in 2012 and Li et al. in 2013 and 2014 confirm most of the themes and trends we have identified. We hoped to discover the richness of these experiences and interactions from the patient and spousal caregiver perspective.

Methodology

Our research was an inquiry into the experiences of patients and caregivers as couples. All patient/caregiver engagement researchers engaged in this study had the relevant experience and were in a spousal caregiving relationship at some point in their lives.

Recruitment

To recruit participants, we sent a summary of the project, a recruitment poster (See Appendix B1), to the following groups or organizations:

- Saint Elizabeth Health Care (www.saintelizabeth.com),
- Patients Canada (www.patientcanada.ca),
- Brain Tumour Foundation of Canada (www.braintumour.ca),
- Wellspring Toronto (www.wellspring.ca),
- Come As You Are Co-operative (www.comeasyouare.com).

We also recruited through posting recruitment information online:

- Cancer Connection (www.cancerconnection.ca),
- Caregiver Exchange (www.caregiverexchange.ca),
- Virtual Hospice (www.virtualhospice.ca),
- Canadian Caregiver Coalition (www.ccc-ccan.ca).

We identified potential participants among members or clients of the abovementioned groups. We asked them to e-mail the recruitment poster to their group members, to share the recruitment video on their website and social media channels, and to place the recruitment poster at their location and website, or to use two or more of these means to spread the information about the study (See Appendix B2 & Appendix B3). We recruited by word of mouth and through personal contacts of PaCER researchers; we also recruited through social media such as Facebook, Twitter, and LinkedIn directing viewers to the recruitment poster (See Appendix B4).

Snowball sampling was also used, when participants referred other people with similar experiences to us. Participants self-identified by responding to the Poster and the Invitation Letter, or by indicating their interest in person to the PaCER researchers.

Our selection criteria were:

- Age 18 years and above;
- Self-identify as having the experience of a patient or caregiver within a couple dealing with a serious illness (acute or chronic) or injury;
- Speak fluent English.

We welcomed both patients and caregivers, men and women, to participate in focus groups together. It was important to include the perspectives of both sides. We 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 we were looking into couples' experiences as it relates to their relationship as a universal and emotional matter. For the same reason, we did not exclude people whose partner has passed away or who are no longer in a spousal relationship.

In order to provide our participants with a safe place to share openly and freely, we invited only one member of each couple to participate in any of the focus groups at a time. If both members of a couple were interested in participating in this study, we either assigned one to a focus group and the other for a narrative interview, or interviewed both separately with different interviewers.

Participants

There were 15 participants in this study: 10 participants were patients and spouses (including those who were both patients and caregivers to their spouses), four participants were members of the PaCER team (patients or caregivers themselves), and one participant was a daughter and caregiver of a patient (See Appendix C1 & Appendix C2).. All but one (the daughter) were in a spousal caregiving relationships.

Nine participants identified primarily as caregivers. Of these nine, three participants also were patients, although their primary self-identification was as caregivers. One participant identified equally as a patient and a caregiver (See Appendix D).

Five participants identified as patients.

Table 1. Study participants

#	Code	Gender	Patient/ Caregiver	SET	COLLECT	Interview	REFLECT
1	N1	F	C + P	Y			
2	K1	M	C	Y			Y
3	N2	F	C (daughter)	Y			
4	D1	F	C + P	Y	Y		Y
5	O1	F	C + P	Y			
6	F1	F	P		Y		
7	T1	M	C			Y	Y
8	D2	F	C			Y	Y
9	D3	F	P			Y	
10	Q1	F	C + P			Y	Y
11	F2	F	C			Y	
12	T2	F	C + P		Y		
13	T3	F	C	Y	Y		Y
14	B1	F	P	Y	Y		Y
15	B2	F	P	Y	Y		Y

Note: To protect participants' anonymity, we used codes to identify them throughout this report.

Data Collection Procedures

Our goal as Patient and Community Engagement Researchers (PaCERs) was to collaborate with the patients and caregivers by involving them throughout the entire process of this research. We tried

to explore the experiences of patients and caregivers as couples. The research team members have varying experiences of being either patients or caregivers in a spousal relationship. Our shared experiences provided an environment where participants could be comfortable uncovering the depth of their own experiences thereby leading to a more robust data set.

The research study's design followed the SET, COLLECT, REFLECT structure outlined in the book, *Grey Matters* by Marlett and Emes in 2010 (See Appendix E). 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 researchers in health care. This framework is called PaCER, Patient and Community Engagement Research.

The research procedures in this study, in accordance with the PaCER methodology, were as follows.

Set: For the initial focus group we gathered eight patients and caregivers (including the 3 PaCER interns) to become *advisors* and help *set the stage* for the study by refining the protocol, questions and data collection. The focus group lasted 5 hours (including a break for lunch).

During the Set focus group, participants shared their experiences. Together we identified the main areas of concern around the topic (See Appendix F1). As a result of the Set stage, we ensured the relevance and usefulness of our proposed question and our approach in the eyes of participants. The main areas of concerns were explored deeper in the Collect phase.

Collect: We collected data using a focus group and narrative interviews.

The first step of our data collection was **the Collect focus group** (See Appendix F2). Data from the Set focus group guided questions for the Collect focus group. We had six participants for this focus group (including four participants who had attended the Set focus group). The group session lasted 5 hours (including a break for lunch). This deeper conversation gave us the data we needed to explore the experiences of couples dealing with an illness/injury together with the participants.

For **the narrative interviews** (See Appendix F3) we invited five new participants, with whom we conducted one-hour narrative interviews. Narrative interview questions were refined through the analysis of the Set focus group data. Data from the Collect phase allowed us to analyze in-depth the experiences of couples during the illness/injury trajectory. This analysis formed the basis for the Reflect stage.

Reflect: At this stage, we invited the initial Set focus group participants and some of the participants from the Collect phase, for a total of eight participants, to the Reflect focus group. We opened up the findings and analysis for discussion and further input by the participants who had provided the direction and data for this research (see Appendix F4).

The outcome of this stage was the final analysis and research informed by the suggestions from the Reflect focus group. This completes the circle of collaboration with the participants.

Table 2. Data Collection Procedures and Sample.

Set Focus Group	Collect: 1 Focus Group & 5 Narrative Interviews	Reflect Focus Group	Total
8 participants	6 focus group participants (2 new + 4 same individuals who took part in Set group) 5 interviewees (new participants)	8 participants (same individuals who took part in previous stages)	15 participants

Data Analysis

At every focus group, participants engaged in discussion and were given time to reflect on the data by writing their opinions on the flip chart notes. They offered comments on how the engagement method helped them to talk about and share their experiences. They also wrote notes on the scripts and stories during the Reflect focus group adding more of their own experiences and their feelings. These notations became part of the data for analysis and informed the direction of the analysis.

There were three sets of data, each informing the other: 1) the *Set* focus group data, 2) the data from the *Collect* stage, which included the focus group data, complemented by the data from narrative interviews, and 3) the data from the *Reflect* focus group. We used our interpretation of each set of data to inform the collection and interpretation of subsequently collected data in a cascading fashion, with the interpretation of one set of data feeding into the next. In the final phase of analysis, we reviewed and refined our findings with the initial SET focus group participants, completing the circle of involving patients and caregivers in all aspects of the research. This method of analysis is generally consistent with the grounded theory method (Glaser, 1992; Glaser & Strauss, 1967).

The data were analyzed as follows:

Set: We analyzed three types of data from the SET focus group: digital audio-recording, flip chart notes, and process notes. During the SET focus group, participants were engaged in the analysis of their own experiences, and the facilitator guided them in exploring and defining their ideas. Participants had an opportunity to review the flip chart notes and, as a group, collectively determine the main topics that were important to the group. After the SET focus group, we transcribed the flip chart notes into a text document, listened to the audio recording and supplement the text document with additional details from the recording. The process notes were typed into a separate text document. We familiarized ourselves with all of the data, identified major themes, and refined the guiding questions we asked participants in the COLLECT focus groups and semi-structured interviews. This analysis was summarized to inform the strategy of the collect phase.

Collect: There were two sources of data to be consolidated: the Collect focus group data and the narrative interview data.

Focus group data. PaCERs transcribed the audio recording and the flip chart notes with the participants' comments, consolidating this data with the recording of process observations. Individually, we (PaCER research team members) read and re-read the text documents to get a general sense of the data. As a team, we worked together to assign codes to segments of texts that correspond to the themes in the group session (Glaser, 1992; Glaser & Strauss, 1967). The codes were not pre-determined, but emerged as we analyzed the data (Glaser, 1992). We grouped the codes together into higher order categories and compared text segments within the same coding category for similarities and differences. By working from the bottom up and by working back and forth between the emerging abstract categories and the data, we organized and grouped the data into increasingly abstract categories that described the experiences of patients and caregivers as couples.

Narrative interview data. The patients and caregivers who were interviewed had their narratives audio-recorded, transcribed, and analyzed collaboratively by the PaCERs. The strategy for analyzing the narratives followed the story analysis method presented by Marlett and Emes (2010). We analyzed the interview data using elements of narrative techniques, to uncover the meaning of many diverse stories through identifying common general *scripts* – recognizable patterns that play out in similar ways throughout many stories recounted by different storytellers, or the same storyteller. Bruner (1990) explained scripts as the “canonical events” which introduce the meaning, or frame of a story. Labov and Waletzky (1967) defined scripts as the referential core of personal narratives. Similarly to the analysis of focus group data, we worked as a team to analyze the transcripts identifying general scripts based on the couples' stories, and to cluster the emerging narratives corresponding to similar categories.

Consolidating data. PaCER researchers then reviewed, compared and consolidated the analysis from the Collect focus group and from the narrative interviews. All analysis was further informed by the experiences of the PaCER researchers as caregivers and patients in a spousal relationship.

Reflect: The consolidated analysis was completed by presenting the summarized results of the two first stages to the final Reflect focus group. We presented the main findings from our analysis of the COLLECT data to the original SET focus group participants to seek their reflections. The group explored whether the COLLECT findings resonated with their experiences and represented collective truths that recognize the diversity of the group. The Reflect focus group participants provided further reflections on the data. We reflected on whether we had met the original goals of the research and how the knowledge gained from the study could be disseminated and used. We analyzed the data from the REFLECT focus group using a similar process to the SET analysis and our final findings will incorporate this analysis.

Findings

Overview

PaCER is a new engagement research method in which PaCERS are both researchers and patient peers. PaCERS work to balance the power differential often seen in other research methods by power sharing and being guided by participant input. As peer researchers who share the experiences of our participants we have chosen to write our Findings in the first person to reflect our peer status and the analysis work done by all participants.

As we worked with our stories (the data) we found common scripts which exemplified the experiences many of us had in common. The complexity of our topic area meant we identified 1 core script, 10 main scripts. In order to understand our material better, we further grouped our scripts into clusters. (See Table 3 below.)

Table 3: Findings Summary

Cluster	Script	Description
<i>Ups and Downs: Core Script</i>		
	Riding the Roller Coaster	We felt this story is the core or common overarching story and all other stories flow from or are specific elements of the core.
<i>Invisibility</i>		
	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
<i>Losses</i>		
	The Incredible Shrinking World	Loss of function and loss of social interactions and often work
	Out of Balance	Loss of balance when the caregiver takes on more and more and the patient can do less and less
<i>Intimacy</i>		
	Barriers in the Bed	Impacts on intimacy including the sexual relationship
<i>Weighty Matters</i>		
	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
<i>Tough Going</i>		
	Lost in Translation	One partner has to translate for the other and still provide support as a couple
	Tug of War	The partners may all want the same thing but disagree on how to achieve it
<i>Caregivers as Patients</i>		
	Who's on First?	When caregiver is also patient

Ups and Downs - Finding the Core Script

During the process of analysis as we sorted through the stories to understand common story arcs affecting the couples' relationships, we uncovered one overarching script that we call the **Riding the Roller Coaster**. All the stories reflected the uncertainty and up and down nature of the impact of illness or injury on the couples' relationships. The roller coaster is not only reflective of the up and down nature of the illness or injury but most especially the ups and downs between the two of us as we deal with this unpredictable and stressful change in our lives. The dynamic between us shifts and changes as we struggle to absorb the health changes and our reactions to the imposition this makes on us both as individuals and as a couple. Even the distinct scripts that highlight specific aspects impacting some of our relationships displayed the underlying unpredictability between us.

We see this as the core script that defined all of our experiences in some way.

Riding the Roller Coaster - The Core Script

Every story is unique. They have, however, common elements from the initial jolt that changes our lives, to the series of adaptations we make as we come to grips with the sequence of medical challenges and the shifts in our relationship imposed by our evolving roles as patient and caregiver.

While each of us have our own approach, we are all driving towards some kind of balance or way to a "new normal". Some tackle this on our own; others team up and still others think about severing ties with each other to achieve balance and control over their lives.

For many couples, the journey seems to have no end except death. Others end with the patient cured or fixed. None of us finish the journey unchanged both as individuals but more particularly as couples.

The common script for a person in a relationship that is faced with the illness or injury of one of the partners is:

- ***When my partner and I are faced with the uncertain and often scary journey through illness or injury***
- ***I have to respond to the medical circumstances which changes my relationship with my partner***
- ***Then we are moving in and out of equilibrium as I work to find a way of living with this situation and the uncertainty and anxiety that remain***

As described by the study participants:

*"You go from planning what you are going to do next and living a normal life to suddenly having no plans other than dealing with the illness or injury. It's like a total shift in mindset."
[S K1 A40]*

"When he was first diagnosed, my first thought was he's going to get all better and he wouldn't need me anymore. I had a little panic attack about that." [INT F2 36-7]

Every new event or issue both positive and negative required some adjustment for the couple. And nothing was certain.

"It was such a roller coaster because he kept getting these repeated infections..." [C D1 A231]

"Every trip to the emergency department is so stressful for me. When (my husband) was declared palliative, I was devastated. Then a year later, he was declared cured. That was a shock too." [R Note 14 Pa]

"We had signed for (a private room) because they didn't think she would survive. And then she came out and we went on this trip and (returned to) a bill for \$3,500." [S K1 A101]

Each person and each couple tried to find ways to recover a sense of normal life.

"What is normal for us -- 'oh, you're paralyzed on one side. Do you want some coffee?' ...is the kind of things that would freak out other people." [S N1 A109]

"That was one huge adjustment when he was off work. I had to rethink everything in terms of that." [INT F2 49-50]

And the end of the journey...

"I don't think that we will ever be able to go back to the way we were because we are different people now." [C D1 A452-3]

"(When she died) it was a shock at the time. In a sense I was suddenly free." [R K1 R218-221]

Invisibility Cluster

In different ways, we found there was a thread of invisibility that impacted many of our stories. The following two scripts illustrate this.

Unseen in a Party of Two

Family and friends make assumptions about us as caregivers. Whether I am healthy or unhealthy as a caregiver, everyone wants to know how my partner is feeling and how they are doing. Even when my health gets worse and I signal this as a problem people assume I just want attention and don't take me seriously. This causes stress between us and can erode our relationship.

- ***When people contact us and only want to ask about my partner who is ill or injured***
- ***I feel unseen, overlooked and unacknowledged***

- ***Then I am inclined to be angry and resent my partner, which is not good for our relationship***

Main Story

People don't ask how I am doing or how I feel. My family and friends concentrate on my husband. Since he was advised that he should think of himself because of his cancer, he started to be really mean to our friends. Now they no longer want to meet with us as a couple. Everyone assumes I am doing fine because I am not sick.

"I was thinking well, I have my husband, how come I feel lonely? But I still do. I feel lonely..... I didn't know that I needed to take care of myself." [C T3 A123-133]

"After a while, I really couldn't handle it anymore. I want some of the attention as well. Feeling invisible is one of the things that happens when you are a caregiver." [C T3 A318-319]

Supporting story

I have inflammatory arthritis myself. However this did not stop our marriage from being a partnership. Now that I am taking care of my husband my family thinks I need to be strong for him, this is what I have to do now. All the focus is on him, though the added stress and work is making my arthritis flare up.

"Our social life dried up because everybody knew that (my husband) was on crutches or in a wheelchair so we couldn't go out -- as a couple. But no one invited me out for a meal or to go to a movie or anything. You're either a couple or you're out." [C D1 A303-305]

Hide and Don't Seek

Even when our issues as patients are quite visible no one wants to see or acknowledge them, so we try to hide them to fit in. When the illness or injury is not visible, people have a hard time believing it exists so we have a tendency not to call attention to our situation. In order to carry on with "normal" life, we ignore or minimize our health issues, sometimes to our detriment. When we hide our issues from our partners, they are in the dark about our needs. Worse, when we hide our issues from our partners because they overtly or covertly don't want to deal with them, it can be very destructive to our relationship.

We found that this need to hide the illness or injury was especially prevalent in the third of us who are also patients at the same time as we are caregivers. This makes it especially hard to find balance with our partner.

- ***When the illness or injury is hidden or invisible, no one realizes my pain and they assume I am fine***
- ***I feel isolated and lonely***

- ***This affects every relationship. Sometimes I feel guilty***

Main Story

When I was young and newly married, I was severely injured in a car accident. Once I healed I looked "normal". My husband wanted to carry on as before as soon as I was out of the hospital, so I pretended to be ok because I didn't want to be thought of as crippled. I felt isolated hiding my pain and fatigue. We couldn't talk about it. Denial became 2nd nature and I still can't get out of it. Later we divorced.

"As soon as I was out of the hospital, as far as he was concerned we were back to normal. If I winced from pain he got angry with me so I learned to hide that I was in pain." [C B2 B228-229]

Supporting Story

Now that I have had rheumatoid arthritis for over 30 years, nobody talks about it. Everybody thinks I'm lazy or that I don't care about them. When I was newly diagnosed with arthritis my husband was oblivious. I tried to find support and it was a bunch of old ladies who met in the daytime. I had a part time job, two kids, and I couldn't do that. I wear splints on my hands when I travel so people will realize I can't actually pick up my suitcase. In a sense it's like a badge so they will "see" that I have a problem.

"I take my splints off when I see my daughters. I don't want the eye rolling thing and them saying 'Oh, Mom!'" [C D1 B314]

"When both people in relationship have (health) issues, the one that's a caregiver as well is perceived as less importantthe issue that's hidden is the one that's perceived as less important'" [Flipchart Note 4]

Losses Cluster

Whether for the duration of an illness or injury where the losses may be only for a time or whether the losses continue due to a chronic condition, many of us experienced a sense of loss. This can be loss of function and things we can do, loss of our social network and loss of our ability to work and provide for our families. These losses are not only for the patient but also for what the patient and their partner are used to experiencing together and can no longer -- like long bike rides into the sunset. The following two scripts demonstrate types of loss.

THE INCREDIBLE SHRINKING WORLD

Patients bear the largest burden of the "shrinking world." Our abilities diminish as the disease progresses and we have to rely more and more on our spouses. As we become less able to participate in our usual activities we have to prioritize what we can do.

When our social life suffers, here my spouse feels the effects too. In addition to taking on more duties, my spouse also feels the lack of social contact. This puts even more strain on our relationship. We are together more than usual, but fun, cultural and family activities are much less frequent.

The caregiver spouse often does not understand the complex emotional and physical reasons behind these choices made by the patient as the disease or injury changes them.

- ***When I find that I am less able to participate in what I and others consider normal activities***
- ***I feel guilty for the effect on others and grieve for the loss***
- ***Then it takes time and effort to constantly adjust to these changes***

Main Story

When I began to have pain, fatigue and weight loss symptoms I was unable to keep up with my kids, my job and my hobbies. My doctor dismissed my concerns as those of a “normal busy mom”. When I was finally diagnosed the improvements in my condition were slow and I was told to stay out of the sun. The delay in diagnosis meant that I had joint damage and I kept finding new areas where I was unable to participate or restricted in my abilities. My husband also suffered losses. The impact is gradual – I have often thought my life is like a bonsai tree – good but very controlled, shaped and restricted.

"With rheumatoid arthritis you are always losing something... It happens gradually so you can't grieve and accept it because you keep losing things, you keep adapting..." [C B1 B200 - 215]

"Loss is a big issue. Loss of function, loss of role, loss of change of role, loss of relationship for both caregiver and patient. Lots of change is constant adjustmentYou are not the same after you go through this." [R B592-596]

Supporting story

My husband and I functioned as partners and shared everything. On retirement we expected to travel but my husband needed surgery. When he had the first surgery, we were all there but when you get into the 4th or 5th surgery, it's old news. Everyone else goes about their lives without us.

"Our social life dried up because everybody knew that (my husband) was on crutches or in a wheelchair so we couldn't go out -- as a couple. But no one invited me out for a meal or to go to a movie or anything. You're either a couple or you're out." [C D1 A303-305]

OUT OF BALANCE

We are comfortable in our relationship and then - boom - one of us gets ill or injured. It feels like the medical condition is a third party intruder in our lives. This upsets the balance of our relationship not unlike how the arrival of the first child disrupts things -- but without the joys.

I have to take on this new role of "caregiver". I have to learn so much just to manage my partner's care. And I have to do almost everything, my chores and theirs. On top of that, I am concerned I won't make the right choices and that my partner won't get what they need. Even organizing practical support seems too much sometimes. I fear for the future. I feel like it's all on me. The stress is overwhelming.

As the "patient", I am not happy at losing my independence and feel a bit like a child. I love my partner and resent that they have to do everything and I can no longer help. And I, too, fear for the future.

In the meantime, our new roles as "patient" and "caregiver" change how we deal with each other and alter our relationship - not always for the better. It is tough figuring out how to rebalance so that we don't lose why we are together in the first place.

- ***We were both equal partners able to cope when my partner's health status changed.***
- ***Now one of us takes care of everything with little or no help from our partner.***
- ***Then I feel the loss of how we were.***

Main Story

When we married, we both had disabilities but were able to cope since we complemented each other. My husband is a large man and paralyzed who now has cognitive impairment and short term memory loss. I am small and in a wheelchair.

I have to do everything and make all the decisions. I worry about the future especially if something happens to me. I find it stressful to manage the personal support workers. It is like being an employer.

At one point, my husband saw the stress I was under and asked "What will happen to my wife?" and I saw a flash of the wonderful man who loves me.

"I could have used a wife. I am so busy that I don't raise my head and say 'What do I need?'"
[R D1 R352]

"I am the decision-maker; he doesn't make good decisions. He does less and less without my help. It wears me down. I feel like I'm on my own in a sense.....I am in tears right now."
[INT F2 14-19, 53]

"If he didn't have cognitive impairment it would be very different. It's the key when you have to assume everything." [INT Pa 104]

Supporting Story

While my husband was quite happy to sit back and let me do it all, he resented that I was in charge. And I resented that he was not doing anything. We talked but there is nothing to be done. This is not like it was before when we shared everything including chores.

"You're 'I'm all out of feeling good about you. Sorry, I can't deal with this." [S N1 A116]

"I'm tired of thinking for you and for me and for us ... I know I've created this because I've had to speak up for him, but now I'm getting frustrated." [C D1 A327-238]

Intimacy

There is only one script that represents the issue of intimacy. This area of our lives is central to our relationship and can see us through rocky times normally. When illness or injury enters the picture, our sense of self and how we see each other changes dramatically impacting this core area of our lives and how we are with each other as sexual partners. It raises the question, if sex is less or never, are we still a couple? What holds us together if our physical intimacy is difficult or gone? How do we go on together now? Intimacy is the area that forces us to make the most profound readjustments in our relationship with our partner.

Barriers in the Bed

When illness or injury occurs the damage affects both of us. Sometimes the physical issues force me to create distance between us in bed for protection. Sometimes it is the way I feel about myself, I don't feel attractive or my partner doesn't seem find me attractive anymore. It's hard to talk with my partner about this and about our sex life. We worry about hurting or being hurt, and we can no longer 'see' ourselves in the same way as we did before. Some of us find ways through this on our own. Help is hard to obtain.

- ***When me or my partner are anxious about pain or physical changes***
- ***I build a barrier in the centre of the bed for protection or develop a mental barrier to close contact***
- ***Then it affects our intimacy***

Main Story

My husband and I were a team. When he broke his ankle, he needed an external fixator, so I put pillows down the middle of the bed so he wouldn't hurt me. As a result we stopped having sex. As his health problems continued that situation did not change

"I put pillows all down the middle of the bed as well because I didn't want him poking me with that big steel thing. It was very symbolic and I thought that at the time." [S D1 A94]

"I talked with (the doctor) and ... said 'We don't have sex.' And she said "Well, he's a really nice man.' I know that. I think what she meant was 'I hope you don't divorce him.' But there was no help. She didn't offer to talk to him... so she just dismissed it." [C D1 A500]

Supporting Story

When I developed rheumatoid arthritis I had a lot of pain and fatigue, and I felt both very ill and also unattractive. It took years before this improved and by then we were not as close. It was never a decision, it just happened. A few times I tried to bring this up with health care professionals but they seemed uncomfortable and never had any suggestions. Some wonder how to get

"When he would bump against my hands or my feet they would be so sore ... when we were in bed I built this little wall down the middle of the bed. That was not a really good sign for the relationship." [S B1 A93]

"I was terrified to ask (about sex). I felt ugly. Terrified to talk about it with my husband." [S N1 C19]

And yet some couples have the ability to deal with this in their own ways:

"He may have changed but I cannot feel that change when we are in relation together. He is still hot... although last year he was completely bald and lost around 20 Kgs. I still saw him as a sexy hot man. Sometimes I think I see my husband's spirit and not his physicality The person that I fell in love with, I still love." [C T2 A216-220]

"A marriage can go through ups and downs. ..If you have problems you can stay together. it's not a guarantee you're always going to break up." [S N1 A122]

Weighty Matters Cluster

The incredible stress of illness, injury and caregiving weighs on us as couples, so much so, that sometimes it seems as if we just can't continue. When we are mired in the fog of stress, our relationship shifts out of balance and that too, adds to the stress. The weight of all that stress on either or both us can derail our relationship. The two following scripts illustrate this.

Should I Stay or Should I Go

This is not what I signed up for. Our life was good and then this happened and I'm so angry. Sometimes I get angry at my partner; sometimes at the medical condition. Either way, I wonder if I should leave the relationship.

- ***When our relationship has completely changed because of the medical situation***
- ***I get angry and wonder what keeps me in the relationship***
- ***Then I think about leaving -- or finding reasons to re-commit***

Main Story

We were married 26 years when he got cancer. For a short time I blamed him for ruining our lives but then I accepted that this is now part of our lives and I decided to stick with him and give my support.

"It was a time that I was blaming him...but that was a very short period of time. Then I thought 'OK, we have to deal with this. This is part of our love.'" [C T2 A233]

"I'm here by choice... Life is ups and downs. What if I was the patient? This is an experience we share - unique, no one else is a part of it." [R R281-3]

Supporting Story

As a caregiver, I keep giving and giving and get nothing back. I don't feel valued and wonder if I should stay.

"When I give and give but take nothing, I do not feel valued and then I wonder what keeps me in the relationship." [R T3 R286]

Supporting Story

As a patient, I'm done. I don't want to stay.

"(I said to my husband, the patient) if you want to suicide, you can go ahead.....I'm going to help (care for) you but I have to help myself." [C T2 A 346-355]

Crash and Burn

Everyone has a breaking point. When the pressure and the stress get to be too much, I get beyond being able to cope. This is a crisis especially if I am the caregiver.

I need help. Help may come from surprising places like my partner. Sometimes reaching out for help may not work - or help may not come at all. Other times help moves me through the crisis and I carry on. If I am a mess, then my partner is not being looked after in a good way and the stress escalates. If one of us breaks, the consequences for our relationship are dire and it may not survive. Yet sometimes the importance of our relationship can lead our partner to heroic efforts to help us and put us and our relationship back on track so we can go forward. Sometimes it is our own healthcare providers who reach out and help enabling us to carry on.

- ***When I experience a build up of stress or hard life events, it puts pressure on an already stressful situation for us***
- ***I can't cope any longer and hit a breaking point***
- ***Then we hit a crisis and need help***

Main Story

Since my long time husband's 10 year decline leading to a diagnosis of bipolar 5 years ago, I have had to make all the decisions especially financial. My own anxiety grew and I felt I wasn't good for him because I was freaking out. I couldn't face going to work one day so he took me to my family doctor for help. I opted for anti-depressants and I feel now like I can handle what's going to come at me.

"I felt I wasn't good for him because I was freaking out about things -- and that with someone with bipolar. ... How can I take care of him when I can't even cope myself?" [INT F2 65-69]

"You are making me choose between my mom who has to go to emerge and you. You are in bed...safe'... I was caught in the middle being the caregiver for two people with extreme issues. I don't know how I'm still sane but I am. I worry that some day I will just crash." [INT Q1 48-50]

Supporting Story

What started out as a fix for an injury became a nightmare of repeated operations over a number of years. It never seemed to end. I hadn't realized I had become depressed until my own doctor pointed it out as I cried through our meeting.

"I became depressed about the whole thing last year. Didn't realize it until my rheumatologist ... wanted to send me to a psychiatrist. I thought 'I'm not crazy!' but I couldn't get through our meeting together without crying... so I knew something was wrong." [S D1 A34]

"There is consistent persistent stress.... stress is like 'white noise,' you just live with it. Then a stress event (like) the washing machine breaking is too much." [R R148-150]

Tough Going Cluster

Some of the situations and decisions we need to make are really hard and have a life and death impact. As we struggle with these situations, the struggle itself impacts our relationship and makes new demands on us apart from dealing with the illness or injury itself. The ups and downs between us as we fight to find the best way forward at times draw us together and at others, push us apart. The following scripts demonstrate two elements of the tough situations facing couples.

Lost in Translation

"I don't speak English." There are couples where one of us must translate for the other. Most often this is due to language but not always.

In other cases, one of us needs to jump in and correct facts for the healthcare professional because our partner, the patient, is unable to know the truth of their experience in spite of appearances to the contrary.

When I am doing the language translating I am in a conflict of role. Am I the "translator" required to do an accurate job of transmitting data between two parties? Am I the supportive partner who listens to the often distressing information and provides emotional support to my partner? How can I be both at the same time?

This conflict may lead me to "soften the blow" by slanting the information in a more positive way or even to omitting some information. And the healthcare professional may not realize that my partner, the patient, is not getting the full information.

In a similar way, as a caregiver I may be forced to correct my partner in front of the healthcare professional and then I'm caught between conflicting roles. Do I let my loved one speak for themselves knowing what they say is not accurate? Or, do I take charge and correct them in front of the healthcare professional in the desire to have the care decisions based on accurate information?

In this case I step out of my normal role as partner and becomes the authority figure. The healthcare professional may be left questioning who to believe. And my partner may be upset by the way I have treated them causing disruption between us.

The common script for a person in a relationship that is faced with the illness or injury of one of the partners is:

- ***When I need to interpret between a healthcare professional and my partner***
- ***I have to distance myself emotionally to do a good job***
- ***This leaves me distressed and in a conflict of roles between loving partner and "professional" interpreter of often bad news***

Main Story

My husband doesn't speak English and needs me to translate. He has no choice. So he can't protect me from bad news and doesn't like it when I'm so upset but he never talks about it. In order to translate, I have to think "he is a stranger"; I am interpreting something to a stranger. This hurts me. "This is not a simple thing." I have to be there for him. Since he is my husband, I am also thinking about how I can soften the news.

From those of us who did language translating for our partner:

"I feel bad to hear bad things. The worst thing is, I'm there to translate it to him." [C T2 B86]

"Sometimes it helps me like this: I just think he is a stranger and I'm interpreting something to a stranger, although it hurts me at first." [C SU B99-100]

"The only thing I didn't translate ... he (the doctor) told me to write his will." [C B124-130]

Supporting Story

My husband has mild cognitive impairment and no short term memory. He is also charming. When the doctor asks him questions, he answers incorrectly without meaning to -- and they believe him. I try to signal the doctor with my eyes that this is not the truth. Then I have to jump in and contradict him in front of the doctor. It hurts him. And I don't want to hurt him.

From those of us who have to reinterpret our partners:

"I can't avoid saying he has no memory. He gets mad...It's very difficult saying things in front of (him). I don't want to hurt him." [INT Q1 43]

TUG OF WAR

We are of two minds.

One of us thinks we should do or not do a treatment; choose or not choose something; and the other thinks differently. With so much at stake, both of us care passionately about the choice and want the best option. This is hard to reconcile when we are of different minds. It's upsetting and scary. And it's worse for our relationship if we expose our differences in front of healthcare providers.

We ask ourselves: What will the choice do to the health outcome? Who bears the responsibility for choosing when we don't agree? What is the consequence of the choice for our relationship? Is avoidance a good option?

- ***When we are deciding about treatment or next steps or the future and we don't see things the same way***
- ***I feel anxious, scared, unsure and sometimes angry or in denial***
- ***Then it is hard to know what the best decision or action is or even who should make the decision or take action***

Main Story

My wife was diagnosed with terminal illness and there were times in hindsight where we should have been talking about it. She probably wanted to talk about it but I was always trying to come up with an answer. I didn't want to admit that she would be gone and I would have to carry on so we never discussed it.

"There were probably times where what we should have been doing is talking about it (death). But my wife probably wanted to talk about it but I was always trying to come up with an answer." [S K1 A40]

(Wife passed away) His wife wanted to discuss "when you're not here so I essentially, did not discuss it with her. I did think about it. It just didn't seem right to discuss the future because all the way through you're trying to say 'we're in this together.'" [S K1 B355-358]

Supporting Story

My husband and I view illness or treatment very differently. He is a firm believer in not taking medication; I'm like, great! there's a medication...I've learned ... over the years that the first thing they offer might not be the right thing. we fought a lot about it to the point where there was times I thought we were just going to get divorced.

"He's flabbergasted because he really thought the system worked and he's becoming more and more scared seeing what's happening to me... The thing is, the system isn't always right....So ya, ...we fought a lot about it to the point where there was times I thought we were just going to get divorced." [C N1 A62-5]

"We have a totally different idea of how to approach the illness, how to go for the treatment, how much to respect the physician and not ask questions. He just wanted to accept whatever the say...and then it's hard for me because I need a lot of information to process." [C A473]

"If she doesn't want to try a new treatment, I'm angry. "If you don't watch what you're eating... you need to change, look at this." [R T1 R191-193]

Caregivers as Patients

This is about when a spouse is both caregiver and patient themselves and how they and the healthcare professionals handle this and the impact on the couple relationship. There is a single script to cover this.

Who's On First

Do we "allow" ourselves to be patients if we are caring for a partner with more pressing health needs?

Unless our health becomes terrible, we tend to put our own needs on the back burner and soldier on. In fact, we often don't allow ourselves to acknowledge or deal with our own health as we deem it unimportant compared to the struggles our partner is facing. What does "martyrdom" do for our relationship?

This is exacerbated by healthcare professionals who can't digest the fact that both partners could be dealing with health issues. As a result they have unreasonable demands on us who are caregivers. We really need the healthcare professionals to go to bat for both of us as a couple. The illness or injury impacts us both.

- ***When we are both have health issues but only one of us is seen as the primary and perhaps only patient***
- ***I don't allow myself to be seen (and am not seen) as having health needs if I am the designated caregiver and not the primary patient***
- ***Then I my health prevents me from being a good caregiver which may cause big problems for my partner***

Main Story

My husband was very ill with cancer and I was struggling with depression. Never mind that depression is a hidden illness, it doesn't have the urgency or profile that cancer does. So when I thought about my needs and balanced them with his needs -- his win out. I have to be strong for him, for what he is going through.

"I was thinking about my husband, it was all about him. I couldn't talk about myself, my worries, my depression. Like Depression -- Cancer. You start comparing and you feel like he's dealing with that monster." [C T3 A251-255]

"I'm going blind. I have macular degeneration but do I bring it up? what is the point? I deal with it." [INT Q1 9]

Supporting Story

I am generally healthy and use a mobility device. My husband who not well at all also uses a mobility device. He is a big and heavy man and he has cognitive impairment so is not as helpful as he was. When we go to the hospital, either the healthcare professionals assume I am a patient, or, worse, that I am able bodied and just fooling around in a wheelchair. Once they realize I am the caregiver, they seem to forget I have some limitations and ask me to do the obviously impossible like lift my husband onto the gurney. When they give us instructions for care at home, they don't discuss with me what I can and what I can't do but issue directives that may apply generally. I am constantly worried about what will happen to my husband if something happens to me and I die or can't care for him any longer. I live with this anxiety and I am alone with it.

"My life now is my partner's life. Mine is gone. There is no life for me anymore. My life is his. When you are caring for someone with that many medical issues, I rarely go to the doctor. I go to the doctor all the time with my partner. I'm pretty healthy. If I get sick and have to go to the hospital, the world will explode. He cannot live alone and no one is coming in. I'm hoping I don't get sick or get cancer." [INT Q1 44-48]

"Real assumption that one is disabled and one is not. the world is just oblivious about disabled caregivers. There are lots of us. we are the silent minority who struggles and people don't get it. Your disability is part of the picture but everyone concentrates on the very ill one and you are still dealing with your stuff. Nobody gets it." [INT Q1 5-7]

Findings Related to Couple's Relationships with Healthcare Professionals

We uncovered other stories and scripts that are more about the couple's relationship with the healthcare professionals than with each other. While it is clear that the relationship with professionals also impacts the couple, we found the impact more on the delivery of care and how that, in turn, impacts what happens between the partners. These could be areas for further exploration. (See Table 4 below.)

This is an area that deserves more study but is not the focus of our initial work.

Table 4: Findings Related to Couple's Relationships with Healthcare Professionals

Script	Description
<i>Scripts about the couple's relationship with healthcare professionals impacting the delivery of care</i>	
Battle Lines	Disputes between caregivers and healthcare professionals occurring when the patient is not capable of understanding or communicating
Invisible People	Healthcare professionals treat the caregiver as invisible or ignore them
In the Dark	Not getting information from healthcare professionals leaves the couple struggling to find the information they need
Rocking the Boat	This is may be an element of the Tug of War where the couple struggles with how much to demand of the healthcare providers and what repercussions they face if they choose to press their providers of if they don't

Battle Lines

There are times when the caregiver and the healthcare professional do not see eye to eye about decisions or treatment for the patient when the patient is incapable of making their own decisions. The patient may have dementia, may be in a coma or unconscious or may be "out of it" due to pain or medication.

Invisible People

We experienced time and again healthcare professionals treating the caregiver as though we are irrelevant, invisible or even a nuisance. This was a big issue for many participants. There are times when caregivers are the only ones who can provide the necessary information. They can fill out the perspective of what is going on with the patient who may not realize how they have changed. They are necessary team members in the care of the patient and need to be valued as such but often aren't.

In the Dark

We need our healthcare professionals to provide or point us to adequate information to understand and manage our health. As patients and caregivers in the age of the internet, we can get a lot of information. We expect our providers to help us parse through this material and point us to what is good.

Too often we are not told about side effects or options or what to expect over time. We feel kept in the dark.

Rocking the Boat

Both patients and caregivers struggle with how much to question or push their providers for fear of reprisals. If I become the "bad" patient or "nuisance" caregiver are we going to get the information and care we need? If I don't raise my concerns because of this fear, will we not get what we need because we didn't push?

While this struggle does affect the couple as seen in the Tug of War script, it is more about the couple and their relationship with the providers who hold the power.

Discussion

After working through the stories we shared and analyzing them, there were some key things that stood out.

1. The limits of labels: First of all, we don't think of ourselves as "patients" or "caregivers." These are roles imposed by the healthcare system which prefers to deal with us in these categories. When we go to the healthcare system for help we find we are labelled in these roles.

We think of ourselves as people who have an illness or an injury. We think of ourselves as a partner who cares. Several of us did not even know we are caregivers until a healthcare professional or friend pointed it out.

These labels help to limit the ability of healthcare professionals to see us as couples in a relationship that can, with support, contribute to the management and possibly the outcome of the illness or injury. If we define ourselves by these labels, we risk losing who we are as partners who love and enjoy each other and we let the roles and the disease dominate our relationship.

2. When both have health issues: A number of us who are caregivers also have health issues. We are patients in our own right. The strain of being a caregiver can exacerbate our health. Our health

issues are not acknowledged by our partner's health professionals as their focus is usually exclusively on their patient.

This inattention by healthcare professionals may lead them to assume inappropriately that we are able to provide the care required by our partner. If our healthcare professionals cannot see us as a couple, then their assumptions may actually jeopardize their patient's care. If our situation is accurately understood particularly by the physician for the primary patient, and both of us provided with support for our health and our caregiving needs, then we can better cope as a couple.

This all affects the balance of our relationship, our resilience and our ability to care or to manage our own health .

3. Age and stage matters: Our age and the stage of our relationship affects how we deal with illness or injury.

For younger people, we have more to lose -- jobs, future children, dreams. If our relationship is relatively new, we have less time invested, less experience handling the trials of life together. We may be more angry, more impatient.

For us older ones in longer relationships, we have a bank of many shared experiences both good and not so good, and probably the joy of children to sustain us through the changes. We may be more resilient, more accepting and adaptable.

4. Illness and injury affects our intimate selves: In most cases illness or injury affects our intimate lives and our sense of ourselves. This strikes at the core of who we are as humans. If my body is changed, am I still attractive to my mate? If my mental health is affected, am I still recognizable and loveable to my partner? A few of us find ways to discuss this deeply personal area with our loved one and maintain the intimacy we desire, but it is not easy. We come together in part because we are drawn to be intimate with each other. If that goes, are we still a couple or roommates?

Virtually none of us received any help either proactively or reactively from healthcare providers who were by and large very uncomfortable dealing with this area even when the illness or injury affected the sexual organs. Yet this deeply personal area of our relationship can strengthen or distance us from each other which impacts how we deal together with our health challenges.

5. The limitations of the new normal: All of us have had to adjust to how our circle of friends and family respond to us and our changing circumstances and any loss of our abilities and our scope of activity. As a society we are not great at dealing with illness, injury, dying, and death. So this means our supposed support group may or may not be there and we truly find out who friends are. With our new health challenges, our wider relationships may bring us loss and grief or unexpected joy but always readjustments.

If our situation continues for a long time, it can become a continuous cycle of adjustment to loss -- of function, of stamina, of ability to maintain outside relationships. We can do with help managing the emotional toll of the accompanying grief.

6. The strain of high stakes decision-making: For a number of us, we don't see eye to eye with our partner about treatment even though we are both committed to the same positive outcome. Some of us are willing to try any medication, any treatment the healthcare professionals suggest. Others are committed to working with Mother Nature looking to less intervention and more healthy living.

This tug of war about what to do and when to do it, puts a huge strain on us. It can crater the balance in our relationship. We don't want to expose our supposed lack of unanimity to our providers. If we do, they usually don't have a desire or ability to play marriage counsellor and may back off or impose their point of view. This places everyone in a quandary and there does not seem to be much help.

7. The burden of truth: While the issue of translation appears to affect only those with language differences, it also affects those of us in too much pain or fog to take in what is being said. In both cases we have to rely on our partners to be clear-headed and to provide us with a true understanding of what is being said to us by the healthcare professionals. I think we are both grateful and resentful at times. Grateful and trusting our partner on the one hand; resenting being reduced to childhood on the other.

For the one transmitting the information, there is the terrible burden of getting it right and the burden of choosing to tell, or not tell, some of the more dreadful information to protect our loved one. How does the healthcare professional know that the patient is or will receive the information as intended? There must be a better way.

Conclusions

The research we reviewed primarily looked at either the caregiver or the patient or the couple as a unit. We choose to go further by examining the dynamic between spouses when thrust into the roles of patient and caregiver. This 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.

This study highlights that the couple's relationship is dynamic, constantly fluctuating to achieve enough equilibrium to handle the vicissitudes of life and striving to nurture the relationship itself. For this reason we elected not to think of the couple as a "unit" which evokes "static" but rather as a relationship which implies mutability.

While there has been attention paid to the caregiver burden, it has 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.

When healthcare professionals focus solely on the patient without considering their home situation and relationship with their primary caregiver (usually the spouse), they miss accurately understanding what the true level of care and support can be. This can lead to very difficult situations around the patient, adding significantly to caregiver stress and adding an unnecessary level of strain to the couple's relationship and their ability to adapt their relationship to handle the changes. This inattention to the couple's relationship can lead to inappropriate decisions on the part of healthcare professionals.

The volatility and extreme highs and lows within the relationship as it goes through the demands of the illness or injury are different in orders of magnitude to the normal fluctuations between partners when all is well and "normal". The ups and downs of dealing with the practical demands of illness or injury are more known or assumed to be known -- for example, "caregiver burden" (or indeed the burden of being ill or injured). While it is clear both sets of ups and downs impact on each other and are interdependent, this study highlights that they are two strands and that they are both separate and interdependent.

A greater understanding of the challenges faced by couples, can help couples themselves better understand the fluctuations in their relationship and can help healthcare providers better leverage the power of these relationships while also providing the support they need. While it may be easier to simply deal with the patient and his or her health, those healthcare professionals who can work with the couple as a team, recognizing that within the team the relationship will constantly change, will provide a smoother journey through the uncertainties they face and potentially better outcomes for the health of both the partners and their relationship.

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Appendices

Appendix A: Recruitment

A1. Recruitment Poster



The poster features the University of Calgary logo on the left, the Saint Elizabeth logo in the center, and the PaCER logo on the right. A QR code is located in the top right corner. The main text is centered and asks if the reader is taking care of a spouse or partner, or if they are being cared for. It invites them to share their experience as a couple dealing with an illness or injury. Below the text is a line drawing of a group of people sitting around a table, with a speech bubble next to it that says 'Share your experience'. At the bottom, it states the study is conducted by PaCERs Toronto Team, provides contact information for Sara Shearkhani, and lists the ethics board approvals.

UNIVERSITY OF CALGARY

Supported by **Saint Elizabeth**

PaCER
www.pacerinnovates.ca



Uncovering the Experiences of Patients and Caregivers as Couples

Are you taking care of your husband, your wife or your partner?
Is your wife, your husband or your partner taking care of you since you became ill or injured?

Join us and share your experience as a member of a couple dealing with an illness or injury!



This study is conducted by
Patient and Community Engagement Researchers (PaCERs) Toronto Team – trained researchers with patient and caregiver experience.

We invite you to participate in a focus group, an interview, or both!
Focus Group: Time commitment 5 hours, free lunch will be provided
Interview: Time commitment 1 hour

Curious, interested? Do you live in Greater Toronto Area?
Contact Sara Shearkhani at 647 542 5628 or SaraShearkhani@saintelizabeth.com

[The University of Calgary Conjoint Health Research Ethics Board has approved this research study. Ethics ID: REB12-1416](#)

[The Mackenzie Health Research Ethics Board has approved this research study.](#)

A2. Invitation Letter

Uncovering the Experiences of Patients and Caregivers as Couples

Invitation Letter

Dear Friend,

We are seeking participants for our research study about the **experience of being in a couple that is dealing with an illness or injury**. In this study we will ask you to share your experiences as couples dealing with an illness or injury. We are investigating what issues make it difficult for patients and caregivers to manage illness or injury as couples. You are welcome to join us if you are a member of a couple, whether you are a patient or a caregiver.

All researchers in this study are themselves *patients or caregivers with similar experiences*. We are students in a university-based internship where we are trained to do this special type of research as part of the Patient and Community Engagement Program (PaCER). This study is part of our internship, which is supervised by our instructors at the University of Calgary and supported by Saint Elizabeth Health Care in Toronto.

If you decide to participate in this study, you will be asked to take part in group discussions where 8 – 10 participants will be talking about their experiences dealing with an illness/injury as couples. You might be also asked to give a one-hour interview to the researcher. The researcher then will come to meet with you at your home or another place that is convenient for you. Group conversations and interviews will be audio taped and then recorded into computer files, which will be safely stored. There will be no identifying information on the recordings, so all the information will remain strictly anonymous. The information collected will be used by the investigators for analysis.

Please consider this invitation to participate. If you are interested, please contact **Sara Shearkhani at 647 542 5628 or SaraShearkhani@saintelizabeth.com**

Thank you

PaCER Toronto Research Team

A3. Study Summary for Service Providers

Uncovering the Experiences of Patients and Caregivers as Couples Study Summary for Service Provider

Dear _____

We are seeking participants for our research study about the **experiences of patients and caregivers as couples**. In this study we will ask participants to share their experiences as couples dealing with an illness or injury.

Researchers undertaking this study are patients and caregivers with relevant experiences to the topic of study. We are being trained in an advanced one-year internship in peer-to-peer research with the Patient and Community Engagement Research Program (PaCER) based at the University of Calgary). This study is part of our internship.

Using PaCER methodology and through the use of focus groups and possibly narrative interviews, patient and caregiver participants will help us to understand the experience of illness and injury from the couples' perspective. Sharing the knowledge we will have gained through our partnership with patients and caregivers like ourselves, we hope to:

1. Uncover the experience of patients and caregivers as couples.
2. Identify possible areas of support in helping them to better cope with the illness and injury and to maintain the health of their relationship throughout the journey

In total the project will involve 16 to 20 participants – both caregivers and patients.

Our recruitment poster, short recruitment video, and a letter of invitation for potential participants are attached. We will ask you to please place our recruitment poster in visible spaces at your sites, share it and the video on your website and social media, and e-mail the letter of invitation to your patients when possible.

The poster, video, and the recruitment letter provide the contact information of the PaCER researcher. Potential participants can call or e-mail her. The PaCER researcher will then explain the procedures to the potential participants, answer their questions, and obtain their consent.

Please notice that participation in our study is completely voluntary.

More information about the study:

Primary Investigator:

Svetlana Shklarov, MD, PhD

PaCER: Patient and Community Engagement Research Program

Instructor, Community Rehabilitation and Disability Studies

Faculty of Medicine, University of Calgary

Tel: 403-220-5383 shklarov@ucalgary.ca

Co-Investigators:

Dr. Nancy Marlett, Director of Community Rehabilitation and Disability Studies, University of Calgary, 403-220-5657 marlett@ucalgary.ca

Dr. Paul Holyoke, Director – Saint Elizabeth Research Centre, Saint Elizabeth Health Care, 905-968-6551, PaulHolyoke@saintelizabeth.com

PaCER Investigators:

Sara Shearkhani, Lead for PaCER Toronto, PaCER Researcher, 647 542 5628,

SaraShearkhani@saintelizabeth.com

Annette McKinnon, PaCER Intern, a.mckinnon@sympatico.ca

Alies Maybee, PaCER Intern, amaybee@sideren.com

Natalia Sim, PaCER mentor, natasha_sim2003@yahoo.com

If you require more information, please contact **Sara Shearkhani** at 647 542 5628 or SaraShearkhani@saintelizabeth.com or **Svetlana Shklarov** at 403-220-5383 or shklarov@ucalgary.ca

Thank you very much for your support.

PaCER Toronto Research Team

A4. Social Media Recruitment Invitation

Uncovering the Experiences of Patients and Caregivers as Couples Social Media Recruitment Invitation

Members of GTA¹ couples dealing with illness or injury. See our poster. Please RT²
(Add the link to the poster and video here)

The poster features the University of Calgary logo on the left, followed by 'Supported by Saint Elizabeth' with its logo and 'PaCER' with the website www.pacernovatis.ca and a QR code on the right. The main text asks if the reader is taking care of a spouse or partner, or if a spouse or partner is taking care of them due to illness or injury. It invites them to share their experience as a member of a couple dealing with illness or injury. Below this is a line drawing of a group of people sitting around a table, with a speech bubble pointing to them that says 'Share your experience'. The text continues: 'This study is conducted by Patient and Community Engagement Researchers (PaCERs) Toronto Team - trained researchers with patient and caregiver experience. We invite you to participate in a focus group, an interview, or both! Focus Group: Time commitment 5 hours, free lunch will be provided Interview: Time commitment 1 hour'. It then asks if the reader is curious and interested and if they live in the Greater Toronto Area, providing contact information for Sara Shearkhani at 647 542 5628 or SaraShearkhani@saintelizabeth.com. At the bottom, it states that the University of Calgary Conjoint Health Research Ethics Board and the Mackenzie Health Research Ethics Board have approved the research study.

¹ Greater Toronto Area

² ReTweet

Appendix B. Demographic Form

Uncovering The Experiences of Patients and Caregivers as Couples

Demographic Information Form

PaCER

Participant Pseudonym _____

(to be filled by researcher)

Age _____

Gender _____

Level of education _____

Your age when illness or injury occurred _____

Diagnosis (optional) _____

Please Note:

- All participants will be assigned a pseudonym.
- All contact and identifying information will be stored separately from the data gathered.
- Only the researchers and their supervisors will have access to the contact and demographic information and the data.

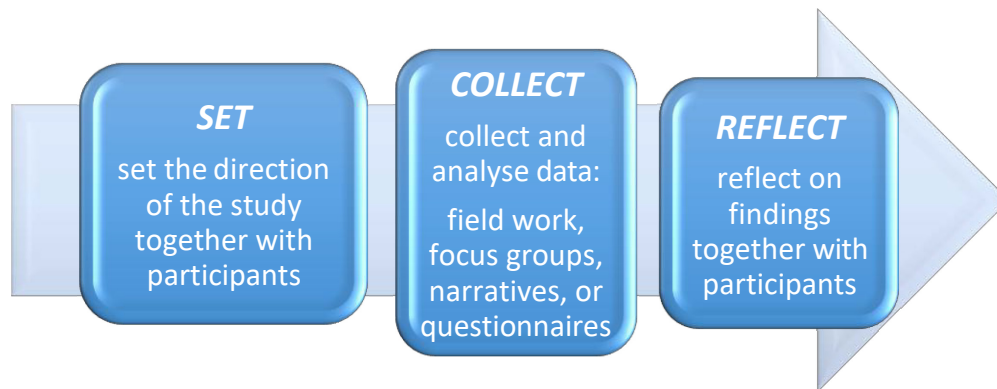
Thank you for your participation!

Appendix C. Patient and Community Engagement Research (PaCER) Model

Patient and Community Engagement Research Program (PaCER) is part of the Institute for Public Health in the Faculty of Medicine at the University of Calgary. Academically, it is also part of the Community Rehabilitation and Disability Studies in the department of Community Health Sciences. The PaCER mandate is to provide research development, supports and services to health researchers and teams, research foundations and Alberta Health Services and health care providers interested in adopting patient and community engagement methods as part of their research and planning processes.

PaCER achieves this by teaching patients and caregivers to become skilled in engaging other patients, caregivers and communities in research and, upon graduation, making PaCER graduates available to health care and research clients.

The PaCER method has a distinct structure defined as **set, collect, reflect** (see the diagram below) to ensure that participants are meaningfully engaged throughout.



1. **Set:** This opening procedure, generally a focus group, invites representative patients and other relevant participants to become advisors and help *set* the stage for the study by refining the particular protocols (recruitment, locations, alliances), questions and data collection.
2. **Collect:** Particular techniques of data collection and analysis depend on the specifics of research questions and purposes of each given study.
3. **Reflect:** At this stage, participants from the initial *set* focus group (item 1) review findings and analysis with the PaCER team and suggest knowledge utilization and recommendations for further research. This stage completes the circle of PaCER procedures and prepares the data to be shared with the relevant health system.

SET and REFLECT focus groups are the hallmarks of the PaCER method, serving to ensure a *meaningful patient involvement and contextual validity*.

Reference: Marlett, N. J., & Emes, C. (2010). *Grey Matters: A guide to collaborative research with seniors*. Calgary, AB: University of Calgary Press. Available through open access at <http://uofcpress.com/books/9781552382516>

Appendix D. Focus Group/Interview Guide

D1. SET Focus Group

Uncovering The Experiences of Patients and Caregivers as Couples

SET Focus Group Guide

10:00 - 10:15	<p>OPENING</p> <p>Coffee, sign off on consents, demographic forms</p>
10:15 - 10:30	<p>INTRODUCTIONS</p> <p>Introduce briefly researchers and participants and cover:</p> <ul style="list-style-type: none"> • Purpose of this focus group • Role of research advisors (the SET focus group): guide the content and process for the next stages; they will be invited to come back for the REFLECT group at the end of the study, to reflect on the findings • Explanation of the process; focus group ground rules. Participants will be asked to respect everyone's confidentiality by not repeating any part of the discussion outside the focus group.
10:30 - 12:00	<p>WORKING SESSION</p> <p>Participants share:</p> <p style="text-align: center;"><i>What is it like for you as a couple to deal with the illness/injury?</i></p>
12:00 - 1:00	<p>WORKING LUNCH</p> <p>Involve the group in the analysis of flip chart notes and in adding personal experiences to the flip chart using sticky notes (markers)</p>
1:00 - 2:00	<p>SUMMARY</p> <p>Summarize the information from the participants (presentation of the flip chart information)</p>
2:00 - 2:30	<p>DISCUSSION</p> <ul style="list-style-type: none"> • Discussion of flip chart information: explore, define, refine. • Developing key topics for COLLECT focus group and narrative interview questions. • Advice from <i>set</i> group on how to open the discussion on the experience of being in a

partner relationship when one partner has an illness or injury.

2:30 - 3:00

WRAP UP

Validation of new discoveries through engagement:

What did you discover or learn from today's discussion?

What can we take away from this session?

D2. COLLECT Focus Group

Uncovering The Experiences of Patients and Caregivers as Couples Collect Focus Group Guide

Please note: the questions in this guide are suggested as preliminary, and will be updated and changed based on the results of the SET focus group.

10:00 - 10:30	<p>OPENING</p> <p>Coffee, sign off on consents, demographic forms</p>
10:30 - 11:00	<p>INTRODUCTIONS</p> <p>Introduce briefly researchers and participants and cover:</p> <ul style="list-style-type: none"> • Purpose of this focus group: Why this research is unique, the patient perspective • The role of participants in creating data sets on the experience of cardiac-related chest pain. Participants may be invited to come back for the REFLECT group at the end of the study, to reflect on the findings. • Explanation of the process; focus group ground rules
11:00 - 12:00	<p>WORKING SESSION</p> <p>Participants share their experiences and perspective: <i>What is it like for you as a couple to deal with the illness/injury?</i></p>
12:00 - 1:00	<p>WORKING LUNCH</p> <p>Involve the group in the analysis of flip chart notes and in adding personal experiences to the flip chart using sticky notes (markers)</p>
1:00 - 2:30	<p>DISCUSSION</p> <p>Discussion may include:</p> <ul style="list-style-type: none"> • Variety of experiences • Common themes in regard to the experience of being a couple dealing with illness or injury
2:30 - 3:00	<p>WRAP UP</p> <p>Validation of new discoveries through engagement: <i>What did you discover or learn from today's discussion?</i> <i>What can we take away from this session?</i></p>

D3. Narrative Interview

**Uncovering The Experiences of Patients and Caregivers as Couples
Narrative Interview Guide**

Please note: the questions in this guide are suggested as preliminary, and will be updated and changed based on the results of the set focus group.

Information about the interviewee _____
Name of PaCER Researcher _____
INTERVIEW QUESTIONS: <i>What is it like for you as a couple to deal with the illness/injury?</i>

Story Analysis

TITLE
CONTEXT
PLOT: Triggers or events
SUMMARY: Outcomes/Consequences/Lessons - researcher's summary
STORYTELLER'S REACTION: Reaction to telling the story/what they learned:
INTERVIEWER'S REACTION: Reaction to the story, what you learned:

D4. Reflect Focus Group

Uncovering The Experiences of Patients and Caregivers as Couples

Reflect Focus Group Guide

10:00 - 10:15	<p>OPENING</p> <p>Coffee, sign off on consents, demographic forms</p>
10:15 - 10:30	<p>INTRODUCTIONS</p> <p>Introduce briefly researchers and participants and cover:</p> <ul style="list-style-type: none"> • The purpose of this focus group • The role of research advisors: review the findings, analyze together and make suggestions • Explanation of the process; focus group ground rules. Participants will be asked to respect everyone’s confidentiality by not repeating any part of the discussion outside the focus group.
10:30 - 12:00	<p>SUMMARY of COLLECT PHASE</p> <p>Feedback on process, participants, findings and participant feedback on each item</p> <p>Participants share their experiences and perspective:</p> <p>Guiding questions:</p> <ul style="list-style-type: none"> • How do these findings fit with your experience of being a couple dealing with illness or injury? • How might these findings be used? • What other observations and thoughts do you have? • What future research can you suggest?
12:00 - 1:00	<p>WORKING LUNCH</p> <p>Involve the group in the analysis of flip chart notes and in adding personal experiences to the flip chart using sticky notes (markers)</p>
1:00 - 1:30	<p>PRESENTATION</p>

Present flip chart information

1:30 - 2:30

DISCUSSION

Discussion of flip chart information:

- Categorizing and prioritizing
- Participants' recommendations
-

2:30 - 3:00

WRAP UP

Validation of new discoveries through engagement:

*What did you discover or learn from today's discussion?
What can we take away from this session?*