

People's Stories of Health & Illness

Web launch and celebration

www.healthexperience.ca

19 October 2016

McGill Department of Family Medicine



FONDATION DE
L'HÔPITAL
ST. MARY



ST. MARY'S
HOSPITAL
FOUNDATION



McGill

Department of
Family Medicine

Département de
médecine de famille

Outline



- Why are we here?
- Where did we come from?
- What have we done?
- Who is 'we'?
- Hopeful contributions
- Future directions
- **Launch breast cancer module!**

Why are we here?



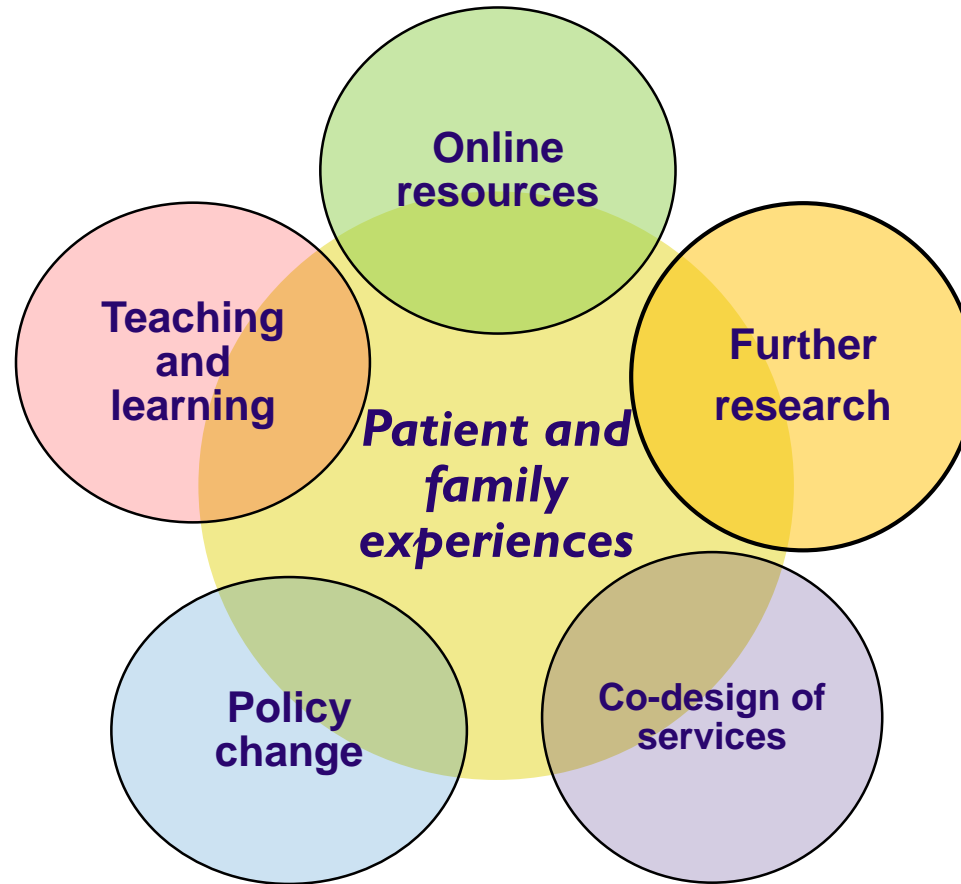
- To celebrate the production and launch of 3 pieces of work that will contribute to evidence-based resources for patients, families and professionals about Canadian's lived experiences of illness:
 - What it's like to be a family caregiver
 - The challenges for immigrants with mental health problems and the professionals who care for them
 - What it's like for women to live with breast cancer
- To thank **EVERYONE** involved

Why are we (really) here?



- Because people could be healthier and health care services could be better ... if had more systematic ways of sharing patient and family stories to
 - Support other patients and families
 - Co-design services
 - Influence policy-making
 - Teach healthcare professionals, and
 - Inform future research

The vision and 'so what'?





Where did we come from?



Healthtalk UK





- Started in 2000 by 2 clinicians (Herxheimer and McPherson) as Database of Individual Patient Experience (DIPEX) working with Health Experiences Research Group (HERG) at University of Oxford and DIPEX Charity to host web site: www.healthtalk.org
- Aims: to identify problems that matter to patients and carers; to provide support for others with similar problems; to promote a balanced encounter between patients and health professionals; to be a learning resource for students in the health professions
- Over 100 topics on health and well-being, including 3500+ individual interviews
- Rigorous qualitative research involving 30-50 individual interviews at home using video/audio recording, maximum variation sample, 2-stage consent, copyright agreement, analysis to determine themes with extracts from interview on web site (about 25 topic pages with 250 illustrative clips per collection)

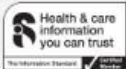
www.healthtalk.org


[Home](#) [People's Experiences](#) [Young People's Experiences](#) [Health Professionals](#) [Learning & Teaching](#)

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 **healthtalk.org**
youthhealthtalk.org







[A-Z](#) [Categories](#) [Young people](#) [Search](#)


[Home](#)

People's experiences of health

Reliable health information from patients, for patients

Related:

- Find out how we can help you
- Friends, family and carers
- NEW: Giving up smoking



Support, encouragement, empathy is best when it comes from someone in the same situation as you.

[PEOPLE'S EXPERIENCES OF HEALTH](#) [DONATE TO HEALTHTALK.ORG](#) [HEALTH PROFESSIONALS](#) [LEARNING & TEACHING](#)

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FUNDING CRISIS APPEAL
DONATE NOW
First £5K of donations
will be DOUBLED*



A-Z

Categories

Young people



Search

● AUTISM

● BONES & JOINTS

● CANCER

● CARERS

● CHRONIC HEALTH ISSUES

● DISABILITY & IMPAIRMENT

● DYING & BEREAVEMENT

● HEART DISEASE

● IMPROVING HEALTH CARE

● INTENSIVE CARE

● LATER LIFE

● MEDICAL RESEARCH

● MEN'S HEALTH

● MENTAL HEALTH

● NERVES & BRAIN

● PREGNANCY & CHILDREN

● ORGAN DONATION & TRANSPLANT

● WOMEN'S HEALTH

It gives us a unique look at what it's like to be on the receiving end.

FUNDING CRISIS APPEAL

YOUNG PEOPLE'S EXPERIENCES

HEALTH PROFESSIONALS

LEARNING & TEACHING



Welcome to healthtalk.org

Find information on a range of illnesses and other health-related issues from seeing and hearing people's real life experiences. Thousands of people have shared their experiences on film to help others understand what it's really like to have a health condition such as breast cancer or arthritis. **Find out more** or select from our list of health conditions above.



healthtalk.org on Twitter

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Tweets

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@healthtalkorg

25m

Have you seen our extensive range of teaching resources and trigger films? bit.ly/1sd5qt7 #meded #ukmeded

Expand

Acceptance in UK

- 2.3 million visitors in 2014
- 60% of videos are watched all the way through
- Voted in top five web sources for reliable health information
- Only source of patient experience evidence listed by UK NICE (National Institute for Health and Clinical Excellence)
- 100+ peer-reviewed published papers by HERG
- 'Health Information for All' designation
- Survey found 80% of medical schools using clips and teaching resources
 - <http://www.healthtalk.org/learning-teaching>





DIPEX International

- 12 current members: UK, Japan, Germany, Australia, South Korea, Netherlands, Israel, Spain, Canada, USA, Czech Republic, Norway



Research question and objectives

Research question:

- *‘What are the experiences, information and support needs of people with **condition x**?’*

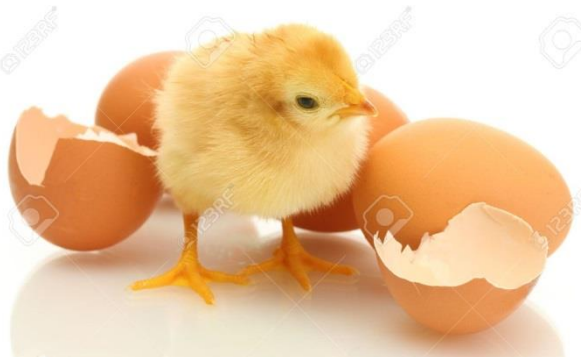
Objectives:

To create collections of personal narratives that are balanced and accurate, using rigorous qualitative methods, so that:

- Information on the web site would represent the full range of experiences that might be connected with a health condition;
- Visitors to the web site would find experiences that they could relate to
- The information provided will help people to make informed decisions about their health, backed by solid evidence

Health Experiences Research Canada

- In 2010-2011, St. Mary's Hospital Foundation provided 'seed' funding for the health experiences initiative for Canada, based at St. Mary's Research Centre (McGill-St. Mary's team)
- Featuring qualitative interviews with people across Canada in their homes using video/audio recording and presentation of results on a web site to inform other patients and professionals
- Based on methods developed at Oxford University HERG for Healthtalk UK (www.healthtalk.org) and part of an international collaboration of research teams in 12 different countries: www.dipexinternational.org





What have we done?



Family Caregiving Module



Research team

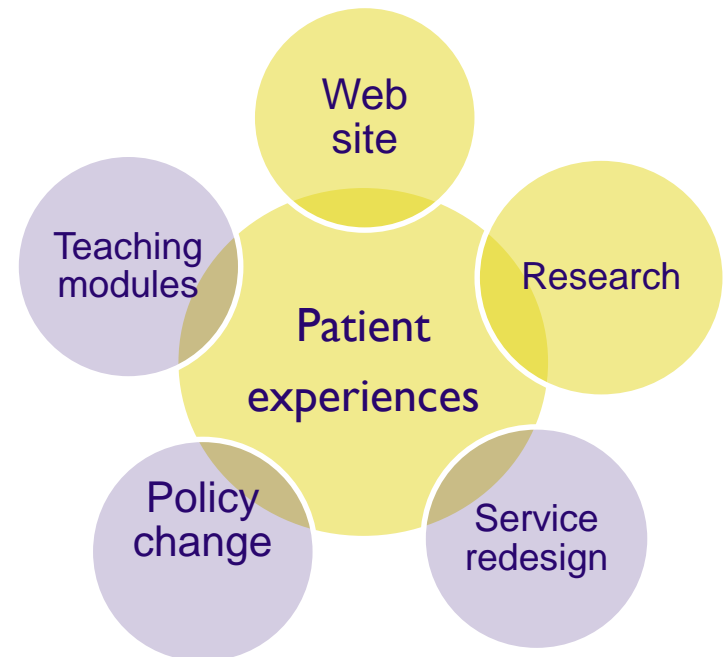
- Susan Law (PI)
- Ilja Ormel (Researcher)
- Brent Hopkins (RA)
- Tabitha Tonsaker (MSc Student)

Results:

- 37 autobiographies
- 29 thematic pages
- 280 video and audio clips
- Resources section

Advisory panel

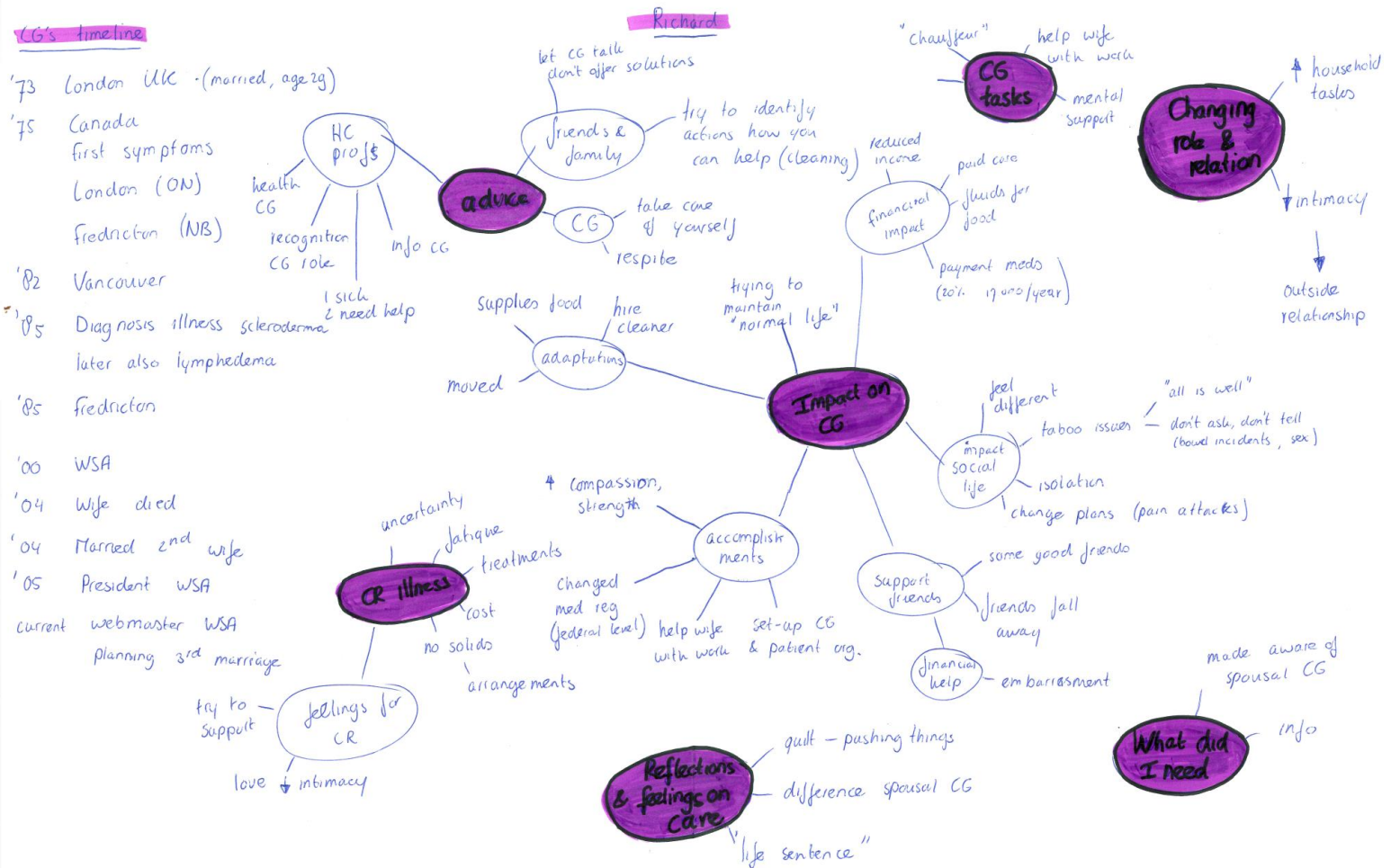
- Mark Yaffe (MD)
- Debbie Josephson (MD)
- Marc St. Cyr (Caregiver)
- Ann Macaulay (MD, PRAM)
- Kerry Kuluski (Researcher)
- Renee Lyons (Chair in LTC)
- Richard Hovey (Researcher)



Recruitment and interviewing



Analysis: OSOP (one sheet of paper)



- thematic analysis with constant comparison – Nvivo 10
- objective: creation of 25 topic pages for website

www.healthexperiences.ca

www.experiencesante.ca



Modules

About Us

Contact



See and hear people's real-life stories

Experience video and audio clips of in-depth interviews with **real people**: Healthexperiences.ca reflects Canadian's experiences of illness and health.

Healthexperiences.ca provides trusted information based on rigorous qualitative research led by experts at McGill University and St. Mary's Hospital Center, in collaboration with the University of Oxford and the UK's award-winning website Healthtalkonline.org



Our Partners:



Feedback

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Caregiving 'montage'

- [insert]

Family caregiving

Caring for a relative or a close friend can have a wide range of impacts on the caregivers. For this module we interviewed 39 people who cared for someone with a chronic physical illness. Some had just started as a caregiver while others had cared for many years. The caregivers told us about their experiences including the good moments along with the challenges they encountered. We would like to invite you to click on any of the links below to see, hear and read about their experiences.



The team thanks...

Topics

Here you will find the various experiences of the people we interviewed. The experiences are summarized in themes such as caring for yourself, impact on health, support from family and friends, and many more. You will be able to read about their experiences and also to see the people we interviewed and to listen to selected parts of their interviews.

[VIEW THE TOPICS](#)

People

Here you can read the personal stories of the caregivers that we interviewed. Where they explain how they became a caregiver, for whom they are caring, and many other interesting things about their experiences.

[SEE THE PEOPLE](#)

Introduction by Dr. Mark Yaffe, Family physician



- ▶ 1. Caregiving in Canada
- ▶ 2. Impact of caregiving
- ▶ 3. Caring for yourself
- ▶ 4. Doctors and caregivers

Information & Links

Here you will find information and links to information pages and resources, such as specialized support groups, around the topic of caregiving.

[VISIT THE SECTION](#)

"If Canada's health care system were a plant, family caregivers would be its roots - fragile, vital and invisible." - Donald Cameron

Topics

The topics are summarized in 5 main groups. Each main group has several topic pages that each discuss a specific theme such as financial impact or providing support etc. You can read more about a theme by clicking on one of the main groups and selecting the theme of your interest. This will bring you to a page with an overview of the experiences of the caregivers relating to this theme. The page is illustrated with relevant video, audio or textual clips of the interview.

1. Being a Caregiver

2. Resources & Professional Services

3. Personal challenges in caregiving

4. Impact on the Caregiver

5. Advice

» Trying to find the right balance

CLICK HERE

» Caring for yourself

CLICK HERE

» Legal issues

CLICK HERE

» Adapting to new roles and key issues for spouses

CLICK HERE

» Challenging emotions and feelings

CLICK HERE

» Effects of the care recipients' behaviour

CLICK HERE

» Travelling, holidays and respite

CLICK HERE

RETURN TO CAREGIVING MODULE

Family Caregiving

< Topics People Information & Links

Related Topics

Becoming a CG



What is it like to be a caregiver



When care changes over time



Support from family and friends



Uncovering why and how caregivers care



Providing support



Society and caregiving



Home » Family Caregiving » Being a Caregiver » Society and caregiving

Society and caregiving

The people we interviewed spoke about being confronted with people's perceptions and attitudes about their role as caregivers. Although some people were sympathetic or empathetic, caregivers had many negative and troubling interactions with other people. They spoke about how people's misconceptions sometimes led them to behave thoughtlessly or to make insensitive comments. These negative encounters made it more challenging for caregivers to live with their situation and to communicate their concerns.

Another major point was the invisibility of caregivers in society. Currently, over two million people in Canada are providing care for a family or friend with an illness or disability. The total economic value of that care is estimated at over \$25 billion dollars per year in Canada. Despite their significant numbers and their value to the healthcare system, many of the people we interviewed felt that caregivers were invisible to the public in general.

Invisibility of caregivers

Caregivers spoke about personal issues and concerns with regards to invisibility. For example, they did not always feel valued or that they received sufficient recognition. But there was also a lack of adequate services and support.



Drew would like the healthcare system to recognize caregivers' contributions.

» WATCH



Rowdyneko has noticed that younger caregivers often have to stop working. There are not enough resources or support for them.

» LISTEN

People

You can view someone's profile by clicking on their link. On the page you will see the caregivers' personal stories. They explain how they became a caregiver, for whom they are caring, and many other interesting things about their experiences. You will also find links to their clips.

Gender

Select



Age

Select



Recipient

Select



Caregiving time

Select

**Rachel***27 yrs old*

Caring for her Mother

[VIEW PROFILE »](#)**Richard***66 yrs old*

Caring for his Wife

[VIEW PROFILE »](#)**Donovan***77 yrs old*

Caring for his Wife

[VIEW PROFILE »](#)**Sheni***56 yrs old*

Caring for her Husband

[VIEW PROFILE »](#)**Christiane***61 yrs old*

Caring for her Husband

[VIEW PROFILE »](#)**Amazing Alyce***47 yrs old*

Caring for her Husband

[VIEW PROFILE »](#)**Lillian and Michael***55 yrs old*

Caring for their Children

[VIEW PROFILE »](#)**Shoshana***54 yrs old*

Caring for her Husband

[VIEW PROFILE »](#)**Rowdyneko***61 yrs old*

Caring for her Husband

[VIEW PROFILE »](#)

Family Caregiving

< Topics People Information & Links

Home » Family Caregiving » People » Jacques

More clips by Jacques

Caring for yourself



Home care and live-in caregivers



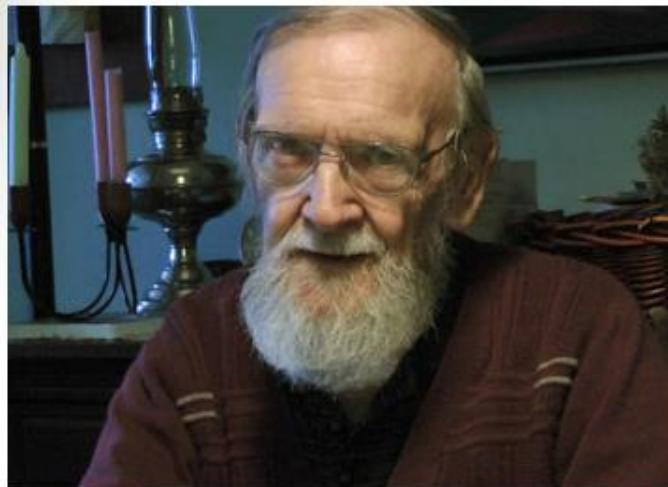
Personal growth and transformation



Social impact and lifestyle changes



Jacques



Age: 88-year-old

Age at start caregiving activities: 31

His background:

Jacques (88 years old) is widowed and lives with his 57 year-old daughter at home. She has been mentally challenged since birth and has epileptic attacks regularly. Jacques' daughter goes to a day care centre four days a week and he provides care for her the rest of the time. Jacques is determined to continue to care for her as long as he has the capacity to do so.

Jacques' daughter attended specialized education programs through most of her childhood. However, at age 14 her school was closed, and it was difficult for Jacques and his wife to find alternatives for her care and education. They did their best to keep her busy with activities at home until she reached the age of 18. During this period, Jacques' wife became ill, and for three years he cared for both his child and wife. Sadly, his wife died following her illness, and Jacques was left alone to care for his daughter. In general, Jacques has always been able to find the services required for his daughter.

Information & Links

Here you will find information and links to information pages and resources, such as specialized support groups, around the topic of caregiving.

National Caregiving
Organizations & Resources

[VIEW NOW](#)

Other National
Organizations

[VIEW NOW](#)

Provincial Caregiving
Organizations & Resources

[VIEW NOW](#)

Selected Tools &
Local Resources

[VIEW NOW](#)

Legal, Ethical &
Other Issues ?

[VIEW NOW](#)

Books And Publications

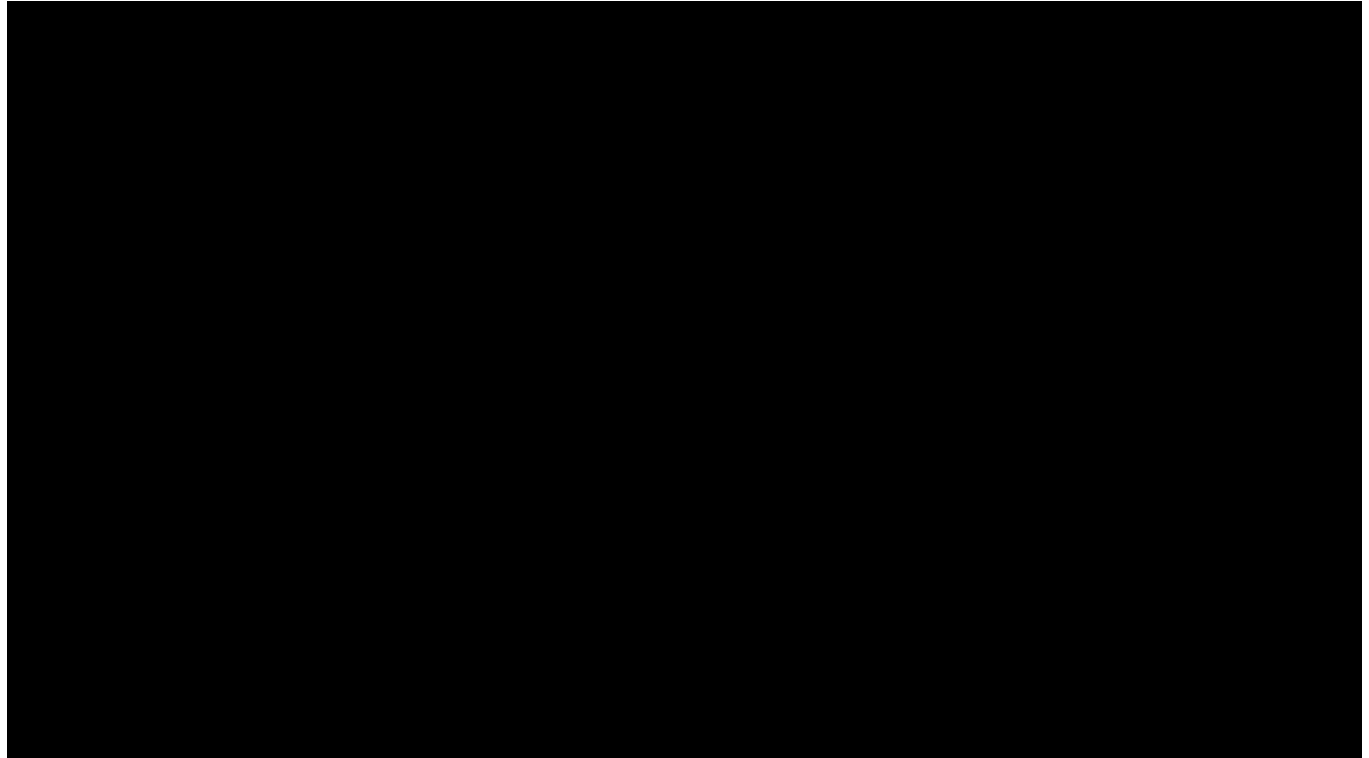
[VIEW NOW](#)



Immigrant mental health

- Another priority health issue
- Bell Canada Community Grant
- Interviews with 6 migrants, 8 immigrants and 8 professionals (health, social/community, and legal) who care for this group
- Developed a 'trigger film' – to raise awareness of these issues and stimulate discussion for change

Introductory 'teaser' film:

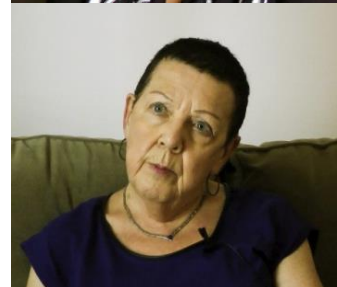


And now?





| Women with breast cancer – participants <i>Consent for:</i> | | Number | |
|--|--|--------|--------|
| Video | | 26 | (72%) |
| Audio | | 7 | (19%) |
| Text | | 2 | (6%) |
| Withdrew | | 1 | (<3 %) |
| Total: | | 36 | |



Policy relevant issues



Young women share how their experiences related to fertility during breast cancer treatment were affected by different provincial health policies

What have we done?

- Talked to 39 family caregivers across Canada ... who said things like ...
- Talked to 36 women with breast cancer across Canada ... who said things like ...
- Talked to xx immigrants and migrants as well as xx people who care for them ... who said things like ...

Who is 'we'?

HERC 'core' team:

- Program Coordinator: Ilja Ormel
Researchers: David Wright, Kathleen Charlebois, Sandra Peleaz, Joel Montanez, Linda Rozmovits, Mary Ellen Macdonald
- Clinical advisors: Drs. Debbie Josephson, Donna Stern, Mark Yaffe, Donna Tataryn, Ellen Rosenberg, Hannah Schwartz
- Research assistants: Ally Moison, Sandhya Baskaran, David Loutfi, Brent Hopkins, Christian Dabrowski, Martina Marien

Patient/family collaborators

- 3-4 per advisory group

Funders:

- St. Mary's Hospital Foundation
- McGill Rossy Cancer Network
- Quebec Breast Cancer Foundation
- Bell Canada Community Grant
- CIHR Banting MSc Fellowship
- CFPC Janus Grant

Community Partners – e.g.:

- DFM, McGill University
- McGill Programs in Whole Person Care
- Centre for Medical Education, McGill
- Local caregiver support organizations
- Hope and Cope Cancer Wellness Centre
- Quebec Breast Cancer Foundation
- Oncology Program, West Island CIUSSS
- School of Nursing, University of Ottawa
- Immigrant and refugee centres, Montreal
- Maison Bleu, Montreal
- St. Mary's Hospital Foundation

Students:

- Tabitha Tonsaker
- Alexandra Dimmer
- Ilja Ormel

Why do we do interviews?

Experience ≠ satisfaction: same patient

Interview:

“The other thing I didn’t raise and I should have done because it does annoy me intensely, the time you have to wait for a bedpanElderly people can’t wait, if we want a bedpan it’s because we need it now. I just said to one of them, ‘I need a bedpan please.’ And it was so long bringing it out it was too late. It’s a very embarrassing subject, although they don’t make anything of it, they just say, ‘Oh well, it can’t be helped if you’re not well.’ And I thought, ‘Well, if only you’d brought the bedpan you wouldn’t have to strip the bed and I wouldn’t be so embarrassed.”

Patient questionnaire:

Overall, did you feel you were treated with respect and dignity while you were in hospital?

“Yes, always”

Overall, how do you rate the care you received?

“Excellent”

With thanks to L Locock

Hopeful contributions?

- Online resource. 7 areas of influence:
 - finding information, feeling supported, maintaining relationships, affecting behavior, experiencing health services, learning to tell the story, and visualizing disease (Ziebland and Wyke, 2012)
- Teaching:
 - McGill IPE curriculum content and design
- Policy
- Future research – breast surgery app!
- Experience-based co-design – SMHC, MUHC

Growing body of evidence re benefits of PFCC:

- Enhanced patient satisfaction
- Better adherence to treatment
- Improved health outcomes
- Reduced overuse and underuse of healthcare
- Contributions to health system goals of efficiency and effectiveness
- e-Patient Dave: *“patients are the most underused resource in healthcare”*
 - http://www.ted.com/talks/dave_debronkart_meet_e_patient_dave

Current and future directions

- Current experience-based projects:
 - Perinatal mental health pilot
 - End-of-life pilot
 - Curriculum for IPE at McGill
 - New 'app' for breast cancer patients
 - Experience-based co-design projects
 - Help with patient-reported outcomes project
- Future modules:
 - Top ten common conditions
 - Conditions that contribute to stigma

See and hear people's real-life stories

and 1.

Healthexperiences.ca provides trusted information based on rigorous qualitative research led by experts at McGill University and St. Mary's Hospital Center, in collaboration with the University of Oxford and the UK's award-winning website [Healthtalkonline.org](#)



Feedback

See and hear people's real-life stories

and audio clips of in-depth interviews with
healthexperiences.ca reflects Canadian's experiences

Healthexperiences.ca provides information based on rigorous
qualitative research led by experts at St. Mary's
Hospital Center, in collaboration with the UK's award-winning website Healthtalkonline.org



Breast Cancer in Women

For this module, we interviewed 35 women across Canada to hear about their experiences with breast cancer. They told us about their experiences including the good moments along with the challenges they encountered. Find out what women said about issues such as diagnosis, family and friends, and body image. We invite you to click on any of the links below to see, hear and read about their experiences. We hope you find the information helpful.



The team thanks...

Introduction by Dr. Donna Stern,
Oncologist



1. Diagnosis and illness pathway
2. Understanding diagnosis and trustworthy information
3. Treatment pathways
4. Reconstruction
5. Preserving fertility
6. After treatment
7. Advice for families

Topics

Here you will find the various experiences of the people we interviewed. The experiences are summarized in themes such as understanding the diagnosis, talking to children, support from family and friends, and many more. You will be able to read about their experiences and also to see the people we interviewed and to listen to selected parts of their interviews.

[VIEW THE TOPICS](#)

People

Here you can read the personal stories of the women that we interviewed. Where they explain how they discovered the first symptoms, the treatments they received, how it had an impact on their lives, and many other interesting things about their experiences.

[SEE THE PEOPLE](#)

Information & Links

Here you will find information and links to information pages and resources, such as specialized support groups, around the topic of breast cancer.

[VISIT THE SECTION](#)

"Before, I was the last person I would think about... it was my family, then work, the dog, the neighbour's dog then me. [Now] I'm up on top and I'm okay with that." - Shelley

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Thank you/merci!

www.healthexperiences.ca

www.experiencessante.ca

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