

Healthy Aging and Care
Innovating Together



Viellissement en santé et soins
Innovons ensemble

Informal Caregivers of New Brunswick Survey Results

St. Thomas University Bachelor of Social Work
Social Action Placement
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Presentation Outline

Participant Demographic Information

Limitations

What Informal Caregivers do

Resources Currently Used/Needed

Informal Caregiver Concerns

Realities of Informal Caregiving

Socioeconomic Costs

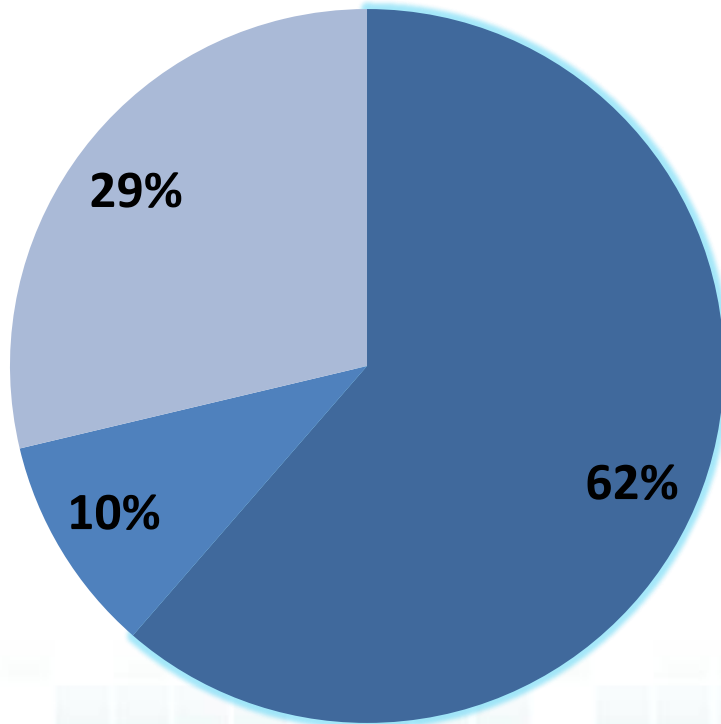
Recommendations

Positive Impact of Caregiving



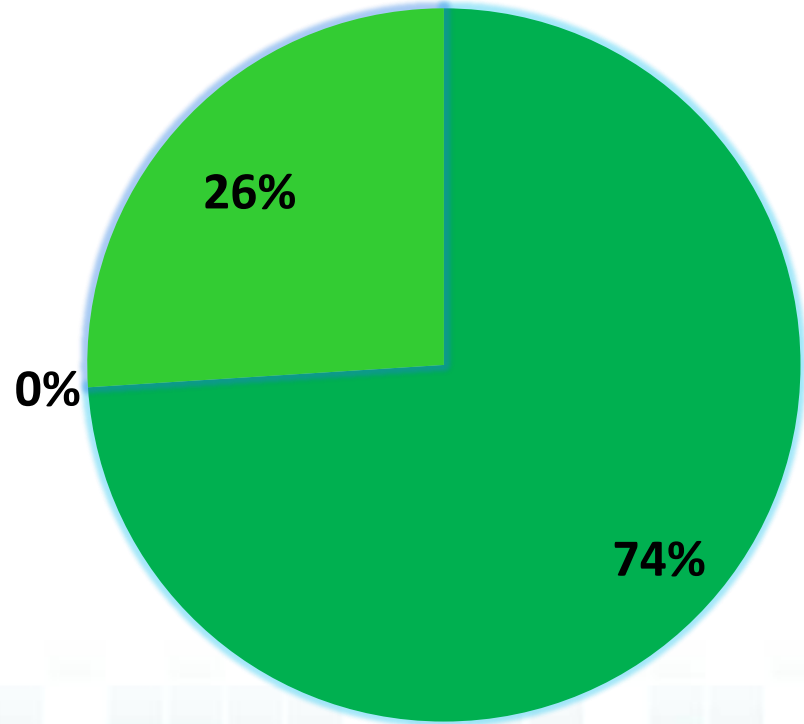
Demographics - Gender

English Responses



- Female
- Male
- Prefer not to say

French Responses

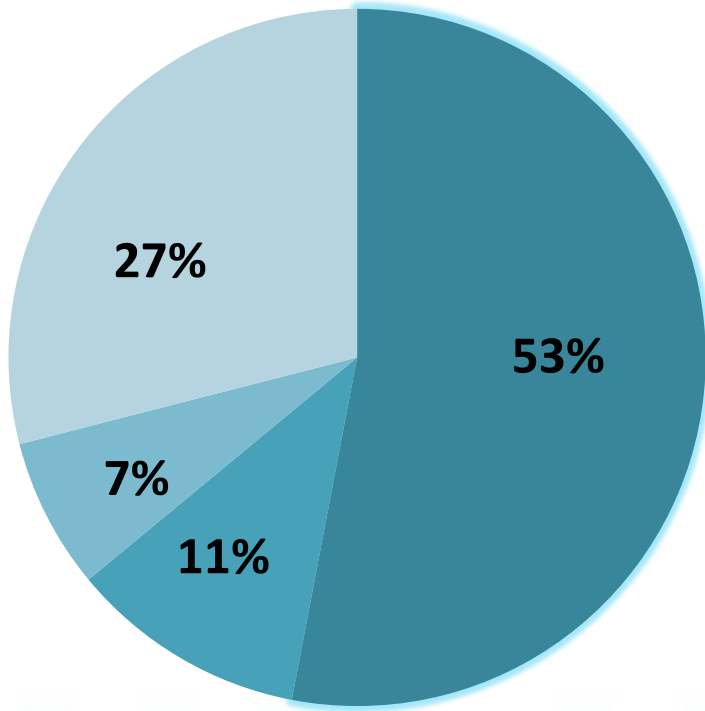


- Female
- Male*
- Prefer not to say



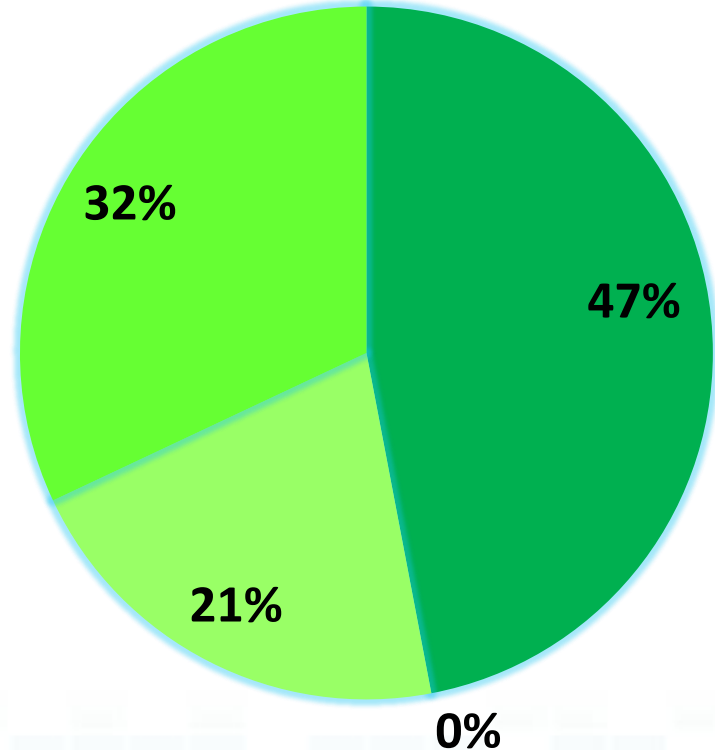
Demographics - Marital Status

English Responses



- Married or living with a partner
- Widowed or divorced
- Single or never married
- Prefer not to say

French Responses

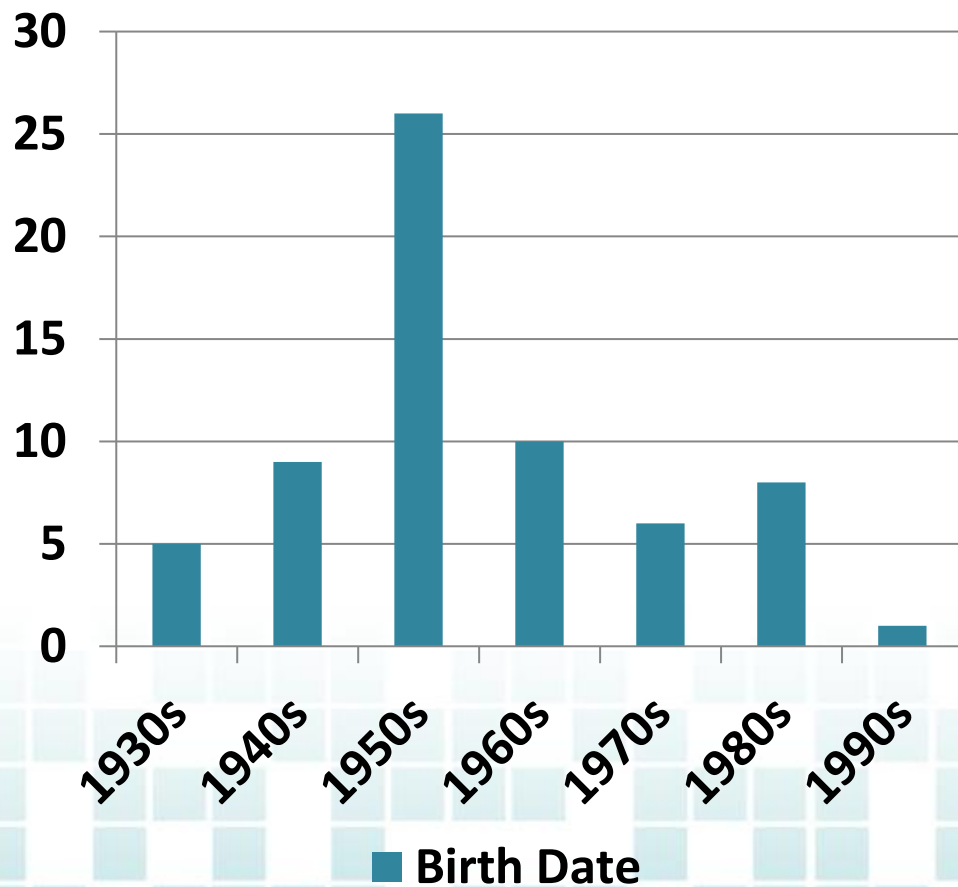


- Married or living with partner
- Widowed or divorced*
- Single or never married
- Prefer not to say



Demographics - Age of Respondents

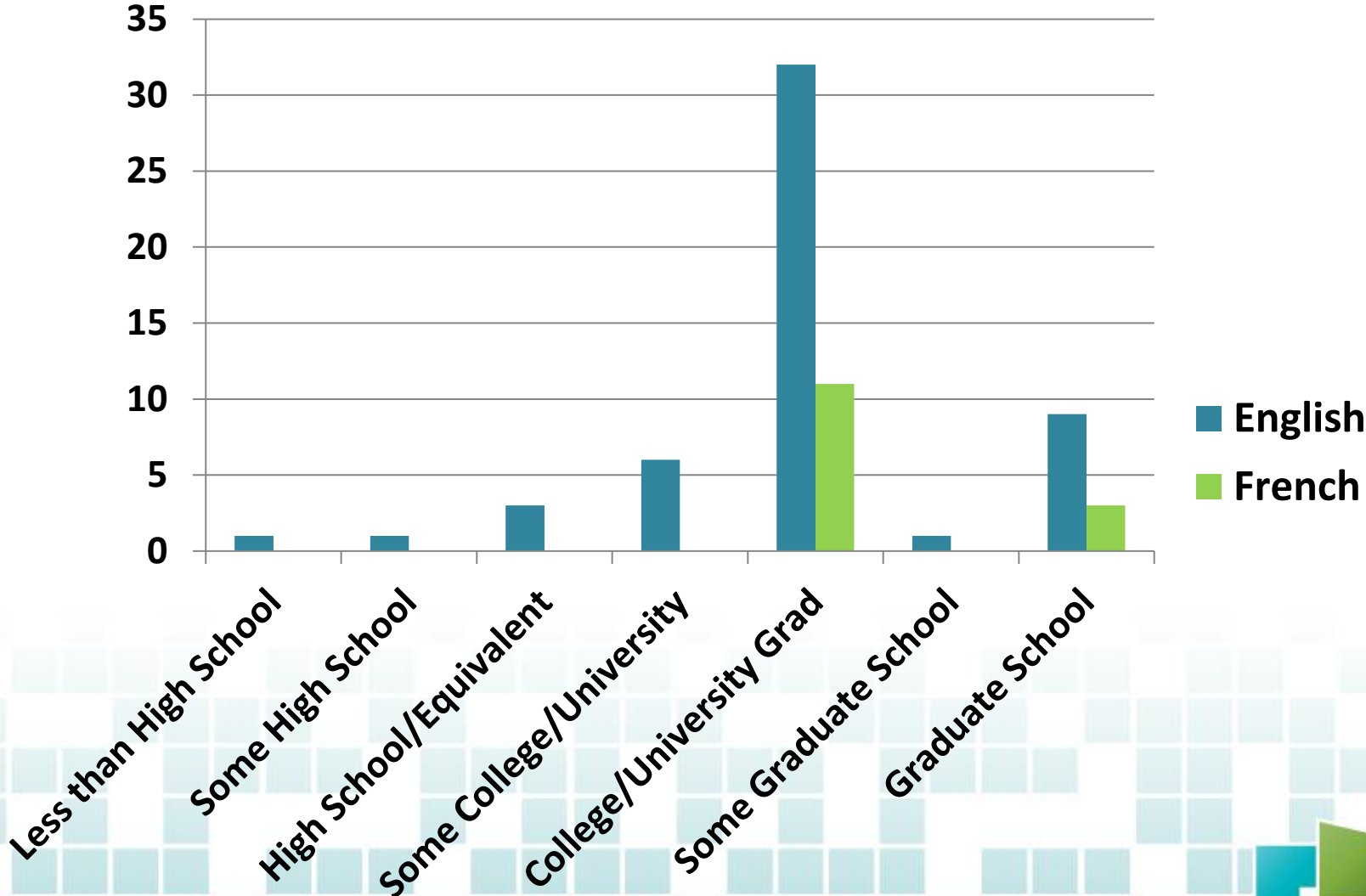
English and French Responses



- Majority of respondents who answered the French survey report being born in the **1980s**
- Majority of respondents who answered the English survey report being born in the **1950s**
- Youngest respondent was born in **1991**
- Oldest respondent was born in **1937**



Demographics - Education



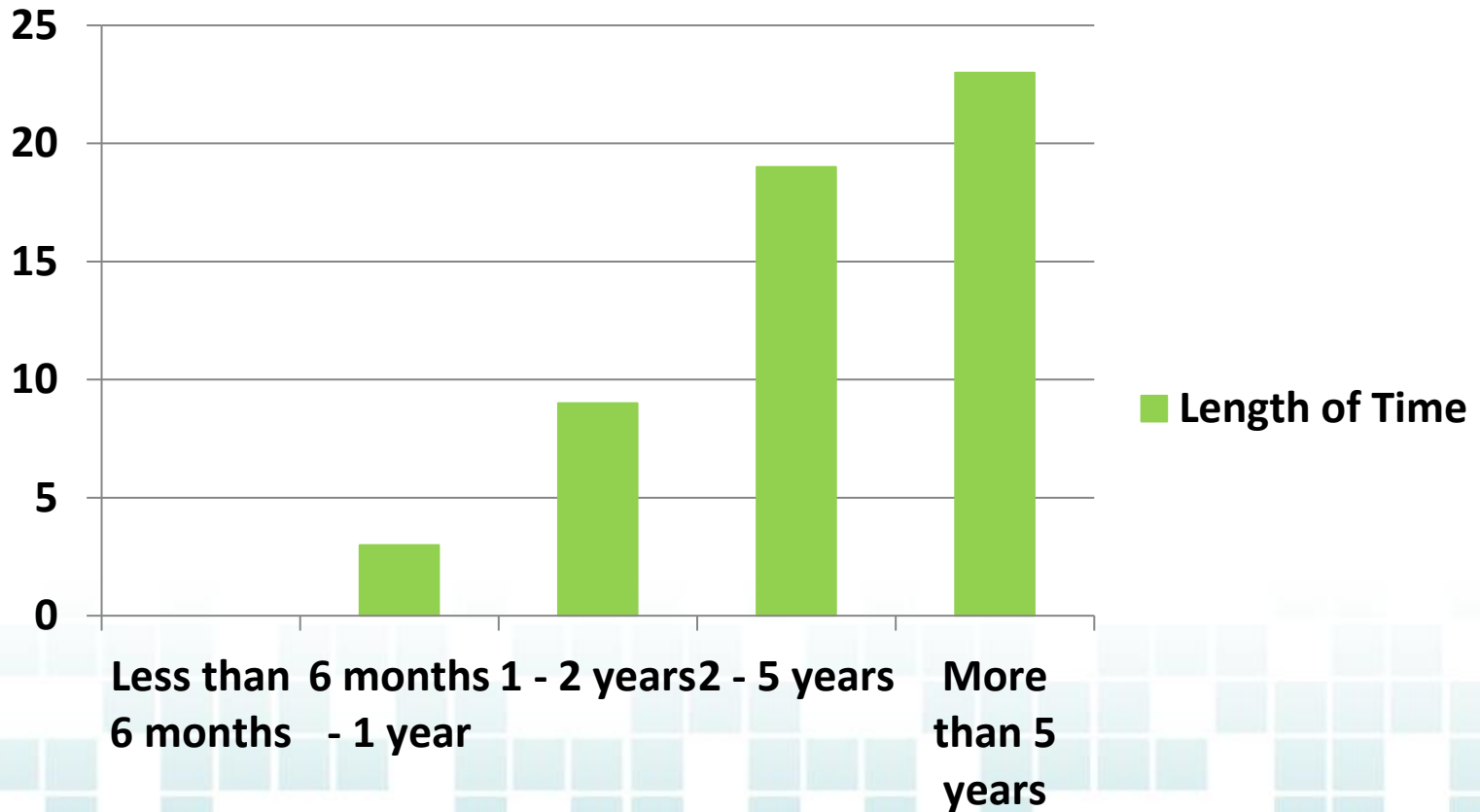
Demographics - Geographic Location

Counties	English and French Responses
Carleton	9
Charlotte	2
Gloucester	4
Kent	1
Madawaska	2
Northumberland	6
Queens	3
Restigouche	4
Saint John	4
Sunbury	3
Victoria	2
Westmorland	7
York	14



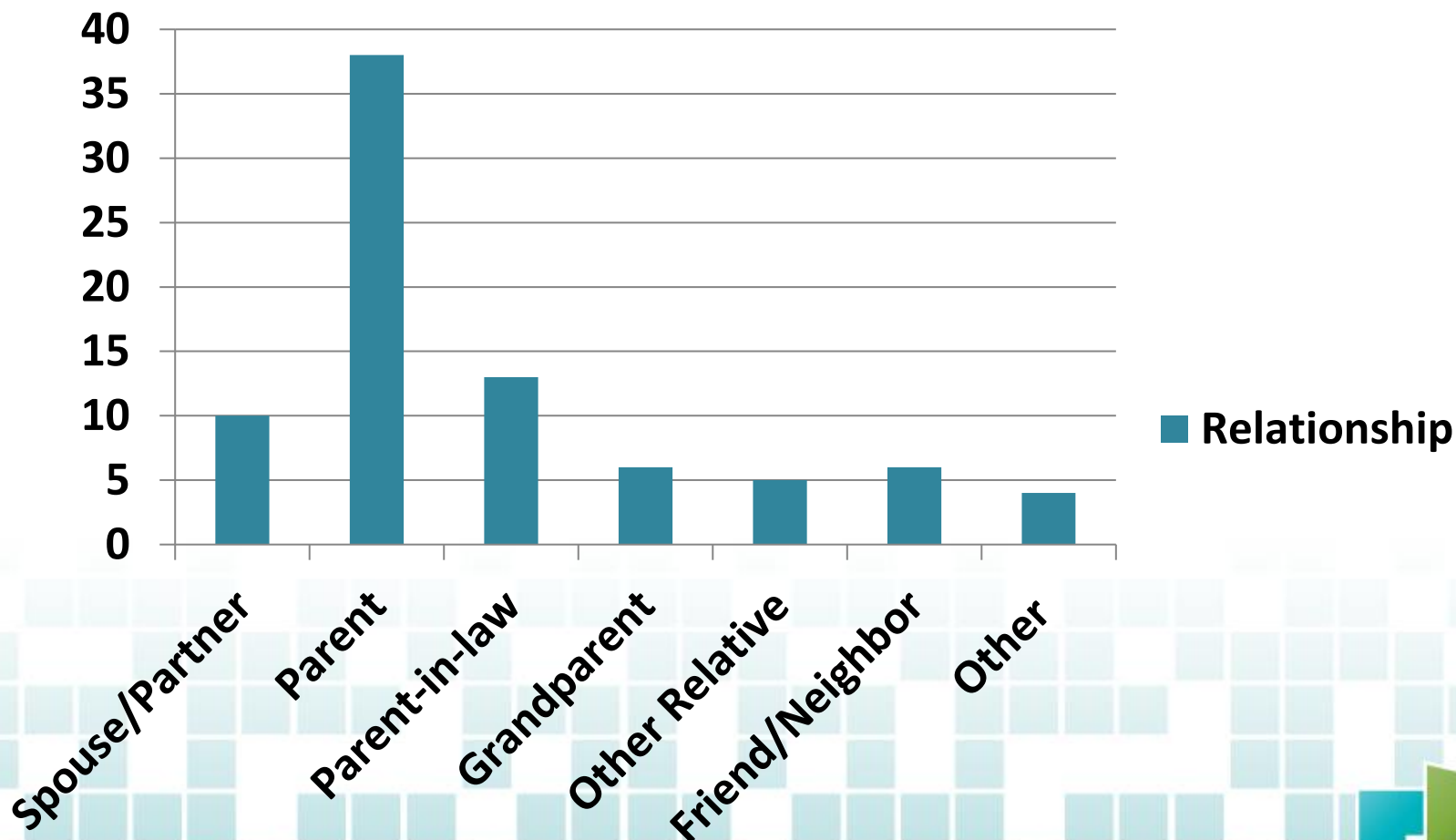
Demographics - Length of time as an Informal Caregiver

English and French Responses



Demographics - Relationship to Care Recipient

English and French Responses



Demographics - Reason for Caregiving

Stroke

Cancer

Osteoporosis

Alzheimer's or Related Dementias

Hearing Loss

COPD

Asthma

Parkinson's

Mental Health Issues

Age-Related Issues

Blindness

Recovering from Surgery

Lung Disease

Multiple Sclerosis

Diabetes

Heart Issues

Hip Injury

Arthritis

Loneliness

Chronic Pain

Meniere's Syndrome



Additional Demographic Information

- 56% of respondents have been an informal caregiver previously in the past.
- 9% of care recipients were veterans.
- 72% of care recipients live in their own home.
- 100% of care recipients receive care in the language of their choice.



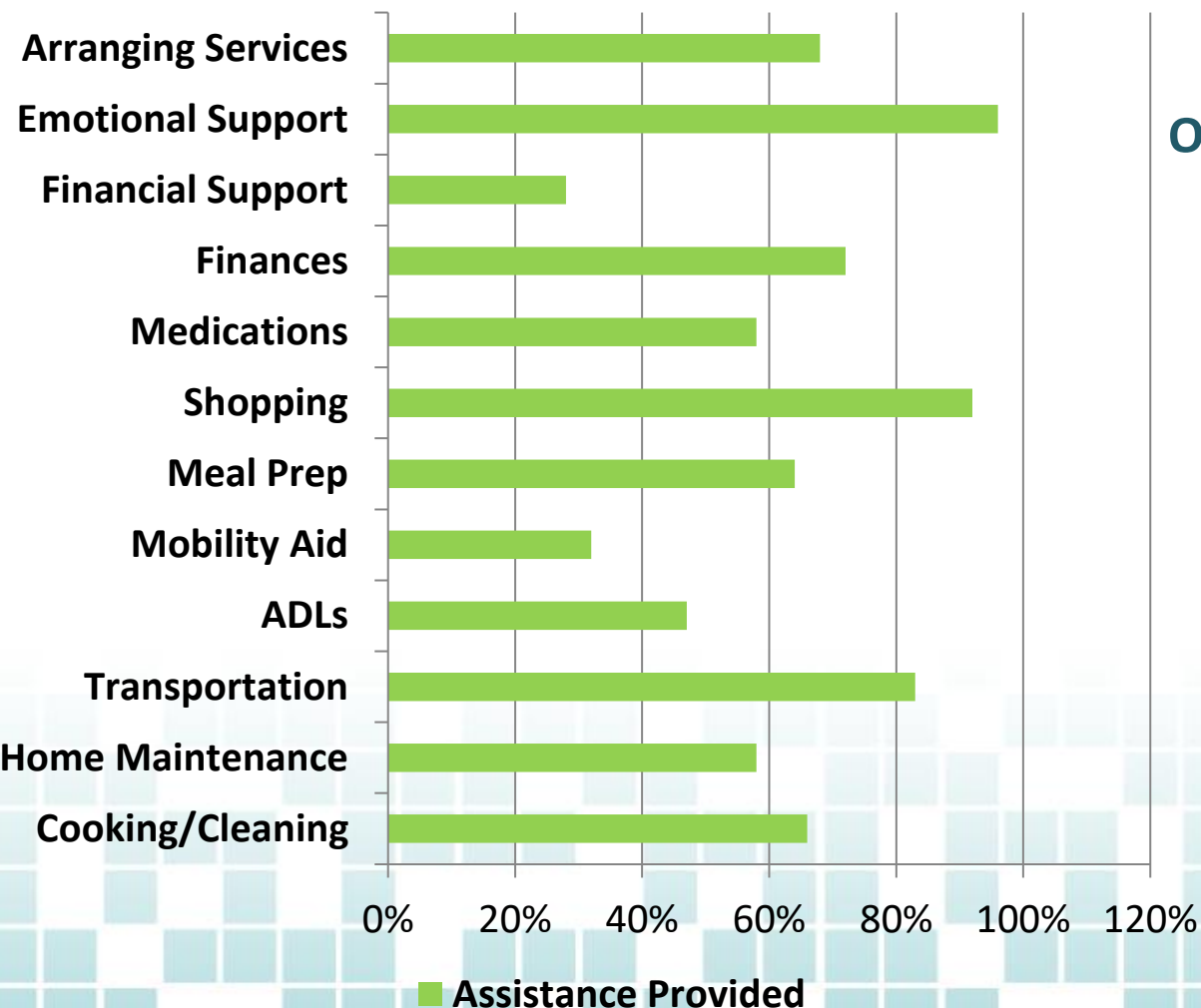
Limitations

- Limited time to collect responses
- Small sample size
 - Of the 73 English responses, only a little over half of participants completely finished the survey
 - Of the 19 French responses, only 1 participant completely finished the survey
- Survey was very lengthy
- Some participants voiced that the online version of the survey was inaccessible
 - Difficult to distribute and collect paper version
- Difficulty in reaching areas of the province outside of Fredericton



What Caregivers Do...

English and French Responses



Other Identified Responsibilities

- Legal Matters
- Therapeutic Activities
- Exercise
- Telephone Support
- Advocating
- Contacting Agencies
- Accompanying to Appointments
- Companionship



Comfort Level with Caregiving Skills

Skill	Very	Somewhat	Not at all
Administering meds (injections, iv use)	41%	21%	38%
Administering meds (eye drops)	61%	30%	9%
Assistance with personal hygiene	38%	38%	24%
Recognizing signs and symptoms of pain	53%	45%	2%
Wound care	28%	33%	40%
Use of incontinence equipment	30%	30%	41%
Using home oxygen	21%	25%	54%
Assisting with physical movement	32%	57%	11%
Use of assistive devices (walkers, wheelchairs)	63%	35%	3%
Use of monitors	42%	42%	17%
Medical equipment (tube feeding, dialysis)	14%	21%	64%



Concerns Associated with Caregiving

Concern	Very	Somewhat	Not at all
Finding trained and reliable homecare providers	56%	34%	10%
Having enough to pay for care	31%	38%	30%
Understanding government programs	32%	62%	6%
Learning about legal options	24%	58%	18%
Getting cooperation and assistance from family	22%	39%	39%
Ensuring care recipients safety	49%	36%	15%
Finding transportation	17%	35%	48%
Communicating with healthcare professionals	33%	42%	25%
Talking with care recipients doctor	23%	34%	43%
Planning end-of-life-care	26%	51%	23%
Balancing other family responsibilities	43%	50%	7%
Dealing with challenging behaviours	26%	57%	17%
Modifying home to meet care needs	14%	38%	48%
Personal Needs	59%	30%	11%

Socioeconomic Impact of Caregiving

57%

experienced changes in
Physical Health

experienced increased
Financial Strain

33%



COST OF CAREGIVING



90%

experienced
**Emotional Strain
and Stress**

sacrificed time typically
spent on
Social Wellness



79%



Physical Costs

- 58% of informal caregivers reported experiencing physical health changes as a result of informal caregiving

“Fatigue”

“Anxiety”

“Lack of exercise”

“Depression”

“High blood pressure”

“Lack of sleep”

“Exhaustion”

“Weight gain – comfort eating”

“Aged 10 years”

“Increased alcohol consumption”

“Stress related physical pain”

“TIA ”

“Being physically hurt”

“Gaul bladder attack”

“Insomnia”



Financial Costs

- 33% of caregivers reported that caregiving has caused them financial strain
- The amount of personal financial cost to the caregiver varies
 - Although the highest response indicated that 41% of caregivers spend more than \$250 per month it should be noted that 6% of caregivers spend more than a \$1000 per month
- 14% of informal caregivers have retired early, and 11% have decreased hours as a result of their caregiving responsibilities
- 15% of informal caregivers have missed 10 or more full or partial work days within the last year as a result of their caregiving responsibilities

“Cant work and do not receive any compensation”

“Not yet...”

“Travel Costs”

“Put off retirement”

“Renovations”

“Little things add up”

“Dealing with frugality of care recipient”



Emotional Costs

- 90% of informal caregivers reported experiencing emotional strain/stress as a result of informal caregiving.

“Sadness, anger, anguish, stress, fatigue..”

“Panic attacks, depression”

“Emotional trauma”

“Difficulty making decisions.. Who goes before who?”

“Emotionally draining”

Stress, high blood pressure, anxiety, worry..”

“Long goodbye – prolonged grief”

“Cannot sleep, cannot concentrate.”

“Heartbreaking to watch someone deteriorate”

“Increased responsibility/pressure”

“Loss of control..”

“Less emotionally available for others who need me”



Social Costs

- 79% of informal caregivers have had to give up social time as a result of their informal caregiving responsibilities
- 69% of informal caregivers have experienced changes in personal relationships
- 34% of caregivers spend more than 30 hours per week caregiving

“Less time for... church, travel, extra curricular activities, volunteering, spending time with other family members”

“Forced to decline social invites – time is consumed by care”

“Missing out on typical undergraduate student experience”

“Lack of freedom”

“Strain on marriage”

“People not understanding the realities of caregiving.”

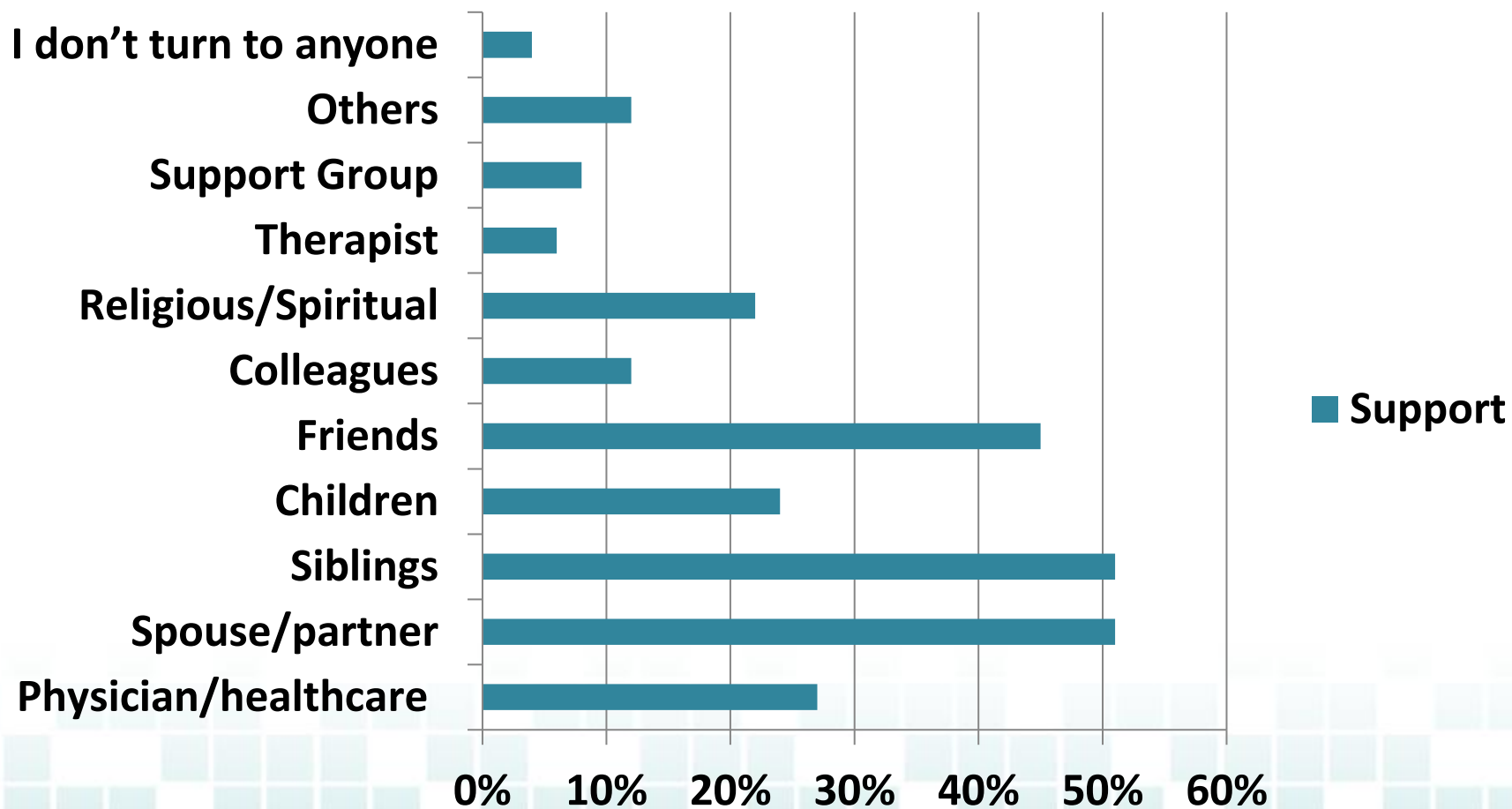
“Feeling alienated from peers.”

“Friends are uncomfortable around the person who needs care”

“No time to socialize”



Who do Caregivers Turn to?

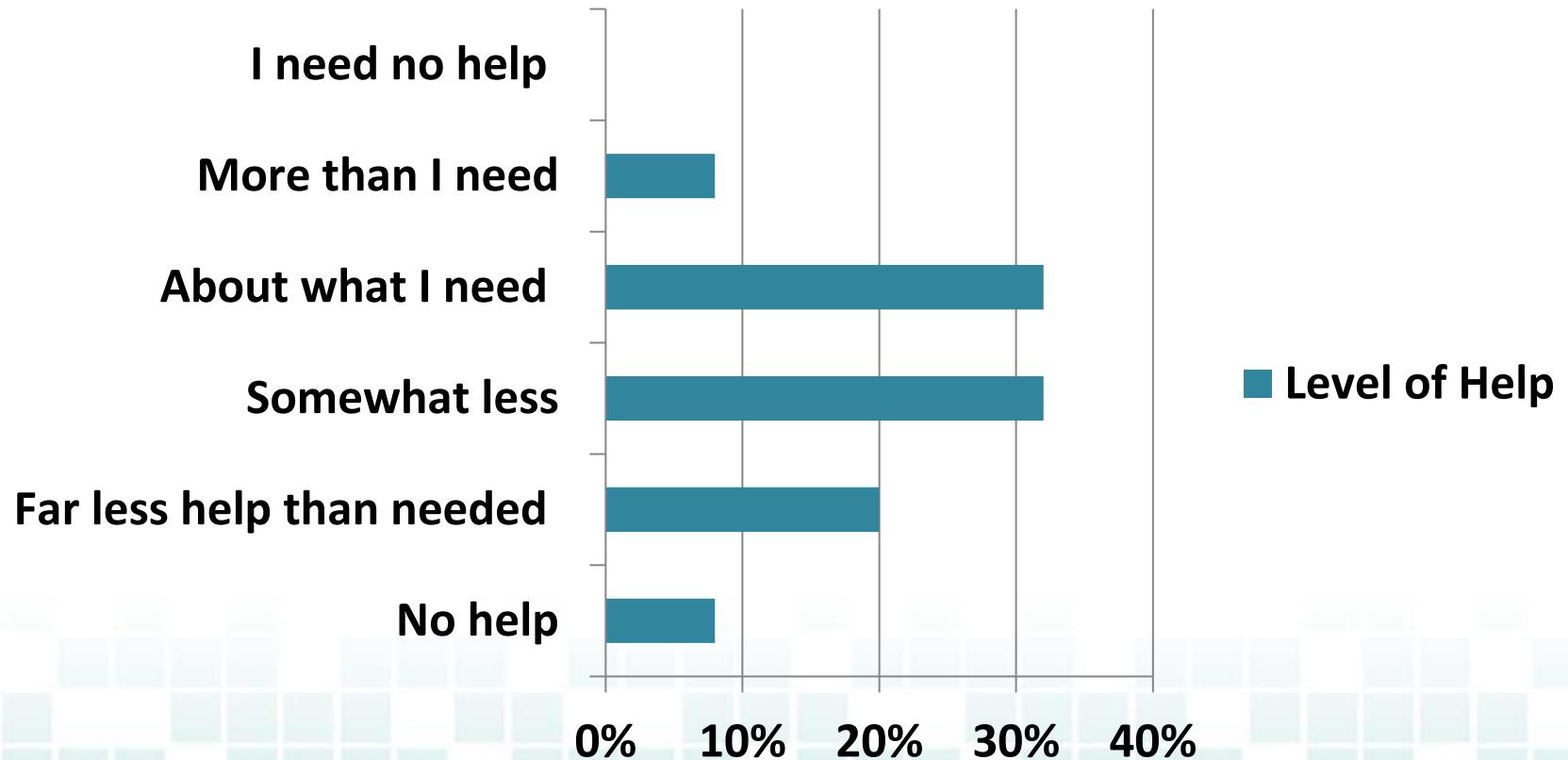


Support Systems

- 32% of informal caregivers reported that they do not take time off for relaxation when they are feeling overwhelmed
 - Top 3 reasons:
 - No one is able to take care of care recipient
 - Do not feel comfortable asking someone else
 - Feeling as though they need to take on full responsibility
- If they do take time off, who looks after the care recipient?
 - Able to take care of themselves
 - Other family members/friends
 - Hired nurse or home health aid
 - LTC Respite Beds



Level of Help Received from Family



Recommendations

- Increased respite services
- Caregiver support groups/Workshop seminars on self-care
- Services required in rural areas
 - e.g. Meals on Wheels, Adult day programs
- Home care courses for caregivers
- Platform to assist in locating/identifying care services
- Internet references on caregiving
- Support for caregivers following the death of the care recipient
- Creating a “Culture of Help”



Positive Impact of Caregiving – Themes

- Growing closer to the loved one
- Personal growth, inner strength
- Feeling “guilt free” when they pass
- Spending quality time with the person that you otherwise would not have spent
- Satisfaction in caring for them, increase positive self-feelings, feeling “needed”
- Feeling good about one’s priorities, gaining appreciation for life
- Making new friends and connections
- Strengthening existing connections to friends and family



Positive Impact of Caregiving – Personal Narratives

- “Much joy also came from caregiving and a unique and beautiful relationship between my husband and I over the years. I learned Alzheimer’s language even though he couldn’t verbally express himself for many years. I learned to read his eyes and soul. I also met many wonderful friends during the process as well as medical professionals. I learned the value of good friends, the ones who stick by you. I learned about strength within myself because of love”
- “It is a very growing experience to be a part of the last days of your parents life”
- “I developed strong relationships with my immediate family members. I learned a lot of coping skills, and how to juggle multiple demands on my time”



Positive Impact of Caregiving – Personal Narratives

- “My mother is fiercely independent, as her daughter, it is an honour to be able to keep her dignity intact, and for the first time in her life she needs me.”
- “I felt privileged to be able to help”
- “Heartwarming to care for loved ones who have loved and cared for me. Setting a good example for the generation following me and watching”
- “the family is now closer and we communicate more with my mother”
- “ ... brings home how fragile we humans are and why we should be appreciative of our capacities”



Thank You!