



Caregiver Research Study

Summary of Findings Related to Study Goals



Study Goals

- 1 **Interview caregivers** to get a deeper understanding of the stressors of being a caregiver; looking at caregiver quality of life issues and healthcare related issues.
- 2 Explore the **usability of enhanced virtual care**
- 3 Obtain **current perceptions of virtual care**
- 4 Explore if **virtual services** can provide **solutions** to the identified stressors
- 5 Use findings to help develop a **healthcare platform** which will address the self-identified stressors of caregivers.



Goal 1

Interview caregivers to get a deeper understanding of their stressors.



Top Identified Stressors

#1 Mental and Emotional Stress

#2 Frustration accessing and navigating health information and resources, and dealing with government agencies.

#3 Lack of awareness and availability of community resources to support individuals staying in their own home.

#4 Difficulty managing and coordinating the health information of care recipient.

#5 Unsure of disease process or how to manage certain situations

Goal 1

#1 Stressor; Mental and Emotional Stress



- The survey informed us that **78.5%** of our caregivers felt overwhelmed weekly to several times/week!
- Many felt their **life was unpredictable, out of control and not their own.**
- Caregivers expressed: feeling **overwhelmed, exhausted, guilty, worried, isolated, frustrated, fearful, resentful, stressed and anxious.**

*...I gave her a great quality of life,
but it sure impacted mine...*

- Caregiving contributed to **complex family relationships.**
- All relationships were impacted; employer, siblings, spouse and/or their own children.
- Conflicts with **family demands** and **having to balance work and family life.**
- There is a **significant financial burden** associated with caregiving.

Financially exhausting

a HUGE financial burden

- Caregivers recognized the **positive aspects of caregiving** including more supportive relationships, feelings of **appreciation/accomplishment** and **making a difference.**

...wonderful feeling of satisfaction at the end of day....

Goal 1

#2 Stressor;

Frustration accessing and navigating health information and resources, and dealing with government agencies

- Caregivers felt as though they did not have the access to find information that would help provide care.

...this is all new to me and I didn't know what I needed...

- New to the role and not knowing what is needed to make caregiving easier; **needing Information** but **in small useful doses**.

Trial and error and a lot of error

a huge life change

- Lack of access to information, many described needing and wanting a “**Caregiver’s Handbook**”.

Finding information decreases my level of worry

- Identified the need for a “**liaison**” role; someone who works between resources and Caregivers.

Someone who can guide you and answer your questions.

- There is a desire to be among caregiving peers; a safe place

Caregiver support groups are needed and the public need to know they are out there

Goal 1

#2 Stressor;

Frustration accessing and navigating health information and resources, and dealing with government agencies

Many Caregivers expressed frustration when dealing with the healthcare system. Caregivers shared that there is no coordination between the departments and it felt as though none of the departments talk to each other.

They cited frustrations such as:

“Process is hair-pulling”

“Inconsistencies with help from within the departments.”

“Repetitive paperwork requirements from dept to dept; year to year... archaic process”

“...it was a waste of time and hard on my nerves...”



Goal 1

**#3 Stressor;
Lack of awareness
and availability of
community resources
that support
individuals to stay in
their own home.**



Having access to consistent, well matched personal support staff would be helpful.

Having access to more relief care options (adult day programs) and funding for same would be helpful

A central organizing agency for accessing reliable personal support workers would be helpful

Relief care staff and programs in rural areas should be more available so that people can be cared for at home

Virtual care for counselling would be helpful for caregivers

Goal 1

#4 Stressor; Difficulty managing and coordinating the health information of care recipient

Caregivers felt that having access to the health information of the person they cared for (with appropriate permission granted) would be an incredible help to their role.

It's a challenge just to have to do this every day. To coordinate all the care and to assist as a helper.

Good clear communication is important

Too many "hoops" to go through and needing "referrals" to everything



Goal 1

#5 Stressor; Unsure of disease process or how to manage certain situations



Caregivers identified that it would have been valuable to have an objective opinion from someone who could answer their questions and guide them to next steps.

Wishing I could reach out and just call someone.

Caregivers felt it was difficult not knowing what to expect; not having a timeline, not knowing what is available at the right time.

Dementia is unpredictable and doesn't always make sense.

Lack of organization or rushed communications at discharge from hospital resulting in misinformation and slow access to medication changes, required equipment, and/or organized home care workers.

Goal 2

Explore the usability of enhanced virtual care.



Technology acceptance

Caregivers self-identified as being comfortable helping the person they cared for access and implement technology to aid in care.

The simpler, the better

Caregivers shared that information provided must be interactive, specific, and to the point.

Concerns that need to be addressed

Concerns include privacy, internet dependability, cost, and resistance from the person being cared for.

Goal 3

Obtain current perceptions of virtual care.

The majority of the respondents were comfortable with technology and could see the value in it.

Many felt the person they cared for would resist technology because of the cost.

Availability of technical support and user training is a must.



Goal 4

Explore if virtual services can provide solutions to the identified stressors.



Stressors

#1 Mental and Emotional Stress

#2 Confusion and frustration caused by accessing and navigating information and resources related to care requirements and dealing with government agencies.

#3 Lack of awareness and availability of community resources to support individuals staying in their own home.

#4 Difficulty managing and coordinating the health information of care recipient.

#5 Unsure of disease process or how to address certain situations

Virtual Services

Virtual counselling services

Virtual support groups

Virtual access to healthcare appointments which includes a family-centered approach. This module also allows the provider to communicate with other members of the care team.

Healthcare Navigator

Marketplace for technologies, resources, equipment, and educational information.

Standardized personal support worker intake assessment.

Central depot of medical history including medication profile.

Links to 'best practices' resources

Responses to our possible new healthcare app:

It would have made an astronomical difference

It would be a gift to caregivers and could help lift the burden.

It sounds like a dream to me. I hope it becomes a reality, because that would have made a difference- and still could...

That kind of gift would be amazing to caregivers, "big thumbs up"



Goal 5

Use findings to help develop a healthcare platform which will address the self-identified stressors of caregivers.



SEUULO

Healthcare Reimagined

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