Date:	Wednesday, May 8, 2024
Time:	14:00-15:00
Location:	Virtual - ZOOM Meeting

In Attendance	Representing
Michelle van Beusekom	Chair
Denise Sanella	Treasurer
Fred Benedikt	Secretary
Jenny Stewart	GM Director of Care
Kristine Neilson	Resident Advocate / Activity Programs Manager
Benz Tran	Behavioural Supports Ontario Lead
Kelsey Hasckewicz	Guest – University of Regina
Agnes Wolfe	Member
Hank Kuntz	Friend
Catherine Jotautas	Member
Yvonne de Boer	Member
Lisa Stepanic	Member
Gus van Weert	Resident Council Liaison

**Minutes Items** 

### Welcome

### **Old Business**

• Approval of previous April 10, 2024 meeting minutes – moved by Denise and seconded by Lisa

### **New Business**

- Guest Speaker Kelsey Haczkewicz from University of Regina Results of LTC Caregiver's Experience Survey
  - Kelsey is a Masters student in Clinical Psychology whose research interests include caregiver stress and the experiences of physical and mental health in older adults. This past January we were invited to participate in Kelsey's research survey focused on informal LTC caregivers' (i.e. family and friends) experiences of loneliness, social support and caregiver burden in addition to the support needs of these informal caregivers and the potential benefits and components caregivers would forsee being beneficial in a mobile application geared towards providing them with additional support.
  - A copy of Kelsey's presentation is attached (see Appendix A)
  - Kelsey outlined overall context for the study: aging population, growing need for LTC (not everyone will be able to stay at home), and chronic understaffing in LTC sector.
     As a result of this context the role of informal caregivers is very important.
  - Respondents expressed feelings of happiness related to being able to support their

### Minutes Items

loved one but also frequently a sense of loneliness and subjective burden

- Survey had 219 respondents from across Canada. Focused on if a mobile application would be a useful resource to help alleviate the loneliness and subjective burden faced by many informal caregivers.
- Hypothesis was that those without robust social support would find the app most useful. Results contradicted the hypothesis. Those with social supports were most interested in the app. Those who experienced high levels of loneliness and social burden were least interested.
- Overall themes revealed by the survey related to caregiver experience: all consuming nature of caregiving; stress (related to demands on time, interactions with staff, decline of loved one); strain on relationships and ability to participate in social activities; loss of personal time; challenges balancing competing roles (eg. caring for loved one, kids, other responsibilities, etc.); impact on employment (missed days, working less hours, taking early retirement to be able to care for loved one); impacts on physical wellbeing (frequent feelings of exhaustion)
- Overall themes revealed by the survey related to the proposed app: performance expectancy (respondents flagged that an app can't do everything and may be too impersonal); effort expectancy (respondents expressed that if the app is too hard to figure out, people won't use it); facilitating conditions (respondents flagged need to be clear on what technology is needed to use the app)
- Psycho-social outcomes revealed by the survey include: older caregivers and those with additional dependents experienced the highest levels of subjective burden; men experienced slightly higher levels of subjective burden; loneliness was highest amongst older women; loneliness was lowest amongst Substitute Decision Makers; older caregivers and married caregivers had the highest level of social supports; women were generally more accepting of using new technology.
- Key finding: an app needs to be driven by need
- Q+A: Michelle mentioned the private Facebook group for Ontario based caregivers created by the RNAO (Registered Nurses Association of Ontario) during COVID (so that people could share experiences, information and concerns) as a good example of a practical use of technology that corresponded to a need
- Fred expressed surprise at the finding that the people most interested in the app were those who had a solid support network and not those with the least support.

### • GM Resident Activity Kits

• Following up on the presentations made in March and April by Danielle (Alzheimer Society Peel) about how to create meaningful activities for residents at different

### **Minutes Items**

stages of dementia, Michelle asked if members were in favour of using Family Council monies (we have just over \$3K in our account) to create personalized "activity kits" for residents living on each of the Home Units. There were no objections.

 Next steps: Kris Neilson and some members of her Activities Team will attend the June Family Council meeting for a group brainstorm with members on creating a list of items to purchase for the Activity Kits. Discussion will also address the balance between items of general interest (eg. activity boards for general use) and items that would be tailored to an individual resident for their personal use.

### • Update on Grace Manor Resident and Family Experience Action Plan

- The Annual Action Plan is developed in response to the results of the annual satisfaction survey of both residents and families –the survey reveals where Grace Manor is doing well and where it needs to improve.
- Michelle provided a brief recap of the Action Plan process which for the first time included input from Family Council members. In the past this was developed by GM Administration with the residents, shared with Resident Council and then shared with Family Council.
- Jenny presented each of the Action Plan items (See attached Appendix B) and a status update on each item. Highlights include creation of a men's activity group; implementation of the King/Queen for a day program (monthly); reboot of the Resident Spotlight program (monthly); ensuring spice caddies have been replenished and are being offered to residents; enhancing dining experience with music, enhanced décor and greeting of residents as they enter the dining room; increase in sign up of new volunteers for Grace Manor.
- Justine and Judy are finalizing performance measure targets for each section in the Action Plan which will be tied to results (% satisfaction) on the next survey which will be conducted in November.
- Justine will regularly update the "status" column in the plan so we can track which initiatives are underway and the changes we should see when we are on the floor.

### Home Updates

- Ministry of Long Term Care inspectors were at Grace Manor on April 22. Report will be shared with Family Council when available.
- Jenny recapped recent increase in staffing (details in April 10 minutes)
- Benz (new Behavioural Supports Ontario Lead) introduced himself. Benz previously worked as a nurse on the third floor of GM. In his new role, Benz leads on the assessment of and determining appropriate interventions for residents demonstrating "responsive behaviours". In this role his goal is to enhance quality of life by assessing

### **Minutes Items**

behavioural needs. He collaborates with other team members and facilitates monthly education sessions. Benz is a graduate of Sheridan College and did a placement on 2S when he was still a student.

Mebratu Gebru is the new Spiritual Coordinator for Grace and Faith Manor. His role includes leading bible study groups; bible readings; supporting multi-faith activities (in recognition of the diversity of faith amongst the resident population at GM and FM); one to one visits; offering counseling and support to residents when needed (eg. when a friend or floor mate passes away). Mebratu has a standing meeting at the same time as our Family Council meeting so unfortunately was not able to join us and introduce himself personally.

### **FUNDRAISING / PROJECTS**

• No updates.

### CLOSING REMARKS/REMINDERS

- We need your good ideas and observations to help improve the quality of life and care for the residents. Please consider volunteering for a role on the Executive Council.
- Next meeting: Wednesday, June 12 2024 at 2:00PM by Virtual Zoom.
- Send suggestions for new agenda items to: gracemanorbramptonfc@gmail.com

### MEETING ADJOURNMENT

Appendix A – Kelsey Haczkewicz LTC Presentation – informal caregiver support Appendix B – Resident and Family Survey Action Plan (with updates by GM Administration)

**IDENTIFYING THE SUPPORT NEEDS OF THE INFORMAL CAREGIVERS OF LONG-TERM CARE RESIDENTS: THE** POTENTIAL BENEFITS OF A **MOBILE APPLICATION** 

> Kelsey Haczkewicz Email: kmh978@uregina.ca May 8, 2024





# **OVERVIEW**

- Rationale
- Hypotheses



## Methodology • Findings & Discussion



RATIONALE



## **THE USE OF LONG-TERM CARE** FACILITIES

 Canadian population is in a state of rapid growth and is heading towards becoming super-aged

• Canadians prefer to age at home, however this is often not an option for those living with complex medical needs

•As the population grows older, the need for long-term care placement grows proportionately

(Gibbard, 2017; Statistics Canada, 2022, United Nations, 2016)

# THE ROLE OF THE INFORMAL INSTITUTIONAL CAREGIVER

•Older adults living in long-term care facilities are often dependent on staff to fulfill basic needs

•Long-term care facilities tend to be understaffed and resident's informal caregivers tend to have a better knowledge of the resident's needs

Institutional informal caregivers perform tasks such as:
 cheering up the resident ophysical touch
 visiting omnitoring meals

°advocating for the resident

(Gaugler, 2005; Metzelthin et al., 2017; Turner & Findlay, 2015; Schulz et al., 2014, Williams et al., 2012)

## **INFORMAL CAREGIVER OUTCOMES**

- Joy and satisfaction
- •Guilt
- Shame
- Caregiver burden
- Loneliness
- Lack of social support
- Lack of communication with staff

(Barken & Lowndes, 2018; Ericksson et al., 2012; Fu et al., 2021; Lindt et al., 2020; Metzelthin et al., 2017; Williams et al., 2008)

## **CURRENT SUPPORT OPTIONS**

- •Long-term care staff
- Support groups
- Web-based messaging
- Mobile applications

(Barken & Lowndes, 2018; Colvin et al., 2003; Pillemer & Suitor, 1996; Ramo & Lim, 2021)



# PURPOSE

To examine institutional informal caregivers' experiences of loneliness, social support, and subjective burden in addition to the support needs of these informal caregivers and potential benefits of a mobile application.

(Grossman et al., 2018; Lazard et al., 2019; Ramo & Lim, 2021)



# HYPOTHESES





# HYPOTHESES

2

Informal caregivers who endorse higher rates of **loneliness and subjective** burden will be more inclined to endorse using the mobile app

Informal caregivers who experience high levels of perceived social support will be less inclined to endorse using the mobile app



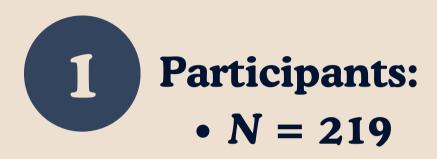


# METHODOLOGY





# **METHODOLOGY**





2

### **Measures:**

- Demographic Information Sheet
- Zarit Burden Interview
- UCLA Lonelines Scale
- Multidimensional Scale of Perceived **Social Support**

**Procedure** 



• Unified Theory of Acceptance and Use of Technology Questionnaire • Technology Readiness Index 2.0 • Mobile Application Questionnaire



# **STATISTICAL ANALYSIS**

- Frequencies were calculated for the demographic variables
- Series of multiple linear regression models were carried out to test Hypotheses I and II
- Directed qualitative content analysis was used for the **Mobile Application Questionnaire**
- Exploratory analyses consisted of one-way ANOVAs and ttests
- Exploratory analysis of frequencies of mobile app features



FINDINGS & DISCUSSION

# PERCEIVED SOCIAL SUPPORT AND INCLINATIONS TO USE THE MOBILE APP

Perceived social support from others was a significant predictor of technology acceptance

Loneliness and subjective burden were not significant predictors of technology acceptance



## Theme 1: The all-consuming nature of caregiving

"I'm constantly thinking about how to organize my life so I can do the things I need to for my mom."



## **Theme 2: Stress**

"Spending time with them [the resident] and watching the decline and family interactions/decisions regarding them has increased my stress level daily."





## Theme 3: Relationships and social activities

"It [caregiving] increased my stress quite a bit, especially when my brother and I disagree about the appropriate care for our father"



## Theme 4: Use of personal time

"Due to visiting twice daily at noon and evening, how is there time for other things?"



## Theme 5: Balancing competing roles

"I'm sandwiched between being a wife, mother, grandmother, and friend."



## **Theme 6: Employment**

" I actually took an early retirement so I could look after my mother."



## Theme 7: Physical well-being

"I am physically exhausted from looking after my parent for years and now my mother in law too. My health is deteriorating and I feel I can't even focus on that because there is always an issues arising with my father."



# **TECHNOLOGY THEMES**

## **Theme 1: Performance Expectancy**

"When I am overwhelmed I need a real person support to take away some of the burden. An app could not do that."





# **UTAUT THEMES**

## **Theme 2: Effort Expectancy**

"Create an intuitive app that can be customized to different situations."



# **UTAUT THEMES**

## **Theme 3: Facilitating Conditions**

"How would you train someone how to use it? Can you do it on a computer instead of a phone?"



## Subjective Burden

- younger caregivers reported significantly lower levels than older caregivers
- SDMs reported significantly greater levels
- those with additional dependents reported significantly greater levels
- men reported insignificantly greater levels than women

(Committee on Family Caregiving for Older Adults, 2016; Cresp et al., 2020; Fu et al., 2021; King et al., 2024; Law et al., 2023; Mason & Falzarano, 2023; Tuttle et al., 2022; Zygouri et al., 2021)





## Loneliness

- older ICCs reported significantly greater levels than younger caregivers
- women were significantly more lonely than men
- SDMs were significantly less lonely than non-SDMs

(Ekwell et al., 2004; Hajek & Kong, 2018; Routasalo et al., 2006; Schuz et al., 2015)



- older ICCs reported significantly greater levels than younger
- ICCs married ICCs reported significantly more support from all sources than single ICCs

(Adamczyck, 2013; Hurlbert & Acock, 1990; Langheit & Poulin, 2022; Soons & Liefbroer, 2008; Ng et al., 2021)



### er levels than younger ly more support from

## **Technology Acceptance and Use**

### • ICCs who identified as female were more accepting than male

(Xiong et al., 2020; Zhang et al., 2014)



## **App Features**

### Feature

Social networking Video chatting Messaging Mental health supports Links to information regarding the resident's diagnosis Communication with LTC facility A calendar/scheduling feature

Note: N = 47



n (%)
6 (12.8)
2 (4.3)
8 (17.0)
8 (17.0)
7 (14.9)
8 (17.0)
7 (14.9)

# **KEY FINDINGS & CONCLUSION**

- Perceived social support from significant others is associated with technology acceptance within the ICC population.
- Several demographic characteristics influence ICCs' psychosocial outcomes, including subjective burden, loneliness, and perceived social support
- ICCs find caregiving to be all-consuming, impacting most aspects of their lives.
- Results may have implications for future interventions:
  - focus on the informal caregiving community's needs

# THANK YOU





### **Grace Manor**

### **2023 Resident Satisfaction Survey**

### **2023 Family Experience Survey**

### **Action Plan**

(Please do not remove. If you need a copy, please see your administrator)

Our Grace Manor Annual Resident Satisfaction and Family Experience Survey was conducted November 5, 2023 with a deadline of December 15 2023. The CQI coordinator tabulated both resident satisfaction and family experience survey results that were then shared February 2024 with both Resident and Family Council. It was decided between both councils that a combined action plan would be the approach this year and thus our temporary action plan working group was formed that included residents, family and staff all together.

The survey sample size was the following; 37of the 44 residents (identified as able to complete) participated in the 2023 survey (breakdown of resident numbers:114 on census, 44 identified as able to complete, 24 new admissions not included and 6 empty beds). The 35 of the 84 families participated in the 2023 survey (breakdown of family numbers:114 on census, 24 new admissions not included and 6 empty beds). Residents participated through volunteer assistance to complete the online monkey survey link if needed and families participated with the online survey monkey link directly. Below is the action plan to be completed in 2024 based on the results of the 2023 Resident Satisfaction and Family Experience Surveys.

• "I would recommend this home", 2023 78% target for 2024 85%.

Areas to Improve	Action Plan (to be carried out in 2024)	Person Responsible	Date Completed
Personal Care and Services • Privacy	<ul> <li>PSW Staff to be re-educated on the Resident Bill of Rights by May 15, 2024. This will be reviewed and discussed in monthly staff meetings.</li> </ul>	DRC, ADRC, Ed Co	Ongoing
<ul> <li>Resident Bonding</li> <li>Respect</li> <li>Daily decisions</li> <li>Personal relationships</li> <li>Comfort</li> <li>Staff Responsiveness</li> <li>Trust</li> </ul>	<ul> <li>Revise outbreak communication to ensure timely communication through clinicconnex, and website information update February 2024.</li> <li>Nursing Staff to be re-educated on effective communication with residents of varying degrees of cognitive decline and customer service approach using the surge learning module by October 31, 2024.</li> </ul>	DRC, ADRC, Ed Co, Tenant Business Services, RA IPAC Lead DRC, ADRC, Education Coordinator	Completed Feb.24
<ul> <li>Communication</li> <li>Visiting Experience</li> </ul>	<ul> <li>Staff to be re-educated on the bathing/grooming/oral care/ toileting routines by April 15, 2024.</li> <li>Re-educate staff by December 15, 2024 on the "who am I" posters and review how to carry out the areas identified by the resident/family. Complete at least 25 demonstrations - 5 on each unit.</li> </ul>	DRC, ADRC DRC, ADRC, Admin, Dept Heads	Completed and ongoing

<ul> <li>Identify 5 staff (1 from each home area) who can become the HCH Champions of Eden in 2024. Enroll these 5 staff in the "tracks" training program to become champions in the Eden Alternative approach (timing will depend on Eden management). Hold monthly meetings with the champions to assist in carrying out the "who am I demonstrations", and other person- centered care initiatives.</li> </ul>	ADMIN, DRC, ADRC, Dept Heads, Education Co	Timeline depending on Eden training Schedule
<ul> <li>Empower the registered staff with leadership training to ensure enhanced PSW interactions with residents to promote informal ex-change and reduce loneliness through Surge Learning by November 15, 2024.</li> </ul>	DRC, ADRC, Education Coordinator	
<ul> <li>Review the lost items protocol during registered and laundry staff meeting by April 2024.</li> </ul>	DRC, ADRC, Laundry Housekeeping Mgr.	Completed, ongoing
<ul> <li>Remind the PSW staff to double check clothing labels before dressing residents as per job description during monthly staff meeting by April 2024.</li> </ul>	DRC, ADRC	Completed and ongoing
Survey result 2023 77% agree target for 2024 85% agree.		

<ul> <li>Programs/Activi ties</li> </ul>	<ul> <li>Create an adhoc men's committee to find out what they would like to do per neighborhood</li> </ul>	RA, Activity Coordinator	Implemented to Mar/Apr
• Spiritual Care	and increase programing specific for men and	Designate Spiritual	calendars and
<ul> <li>Participation</li> </ul>	gather those with similar interests such as baseball, car racing by June 15, 2024.	Coordinator /Pastor Recreation staff	going forward
	<ul> <li>Implement a monthly King or Queen for a day program incorporating "all about me", "who am I" by April 24, 2024.</li> </ul>	Activity Coordinator, Rec staff	Implemented March /April and going
	<ul> <li>Implement independent purposeful engagement activity kits to reduce boredom on each resident home area by May 15, 2024.</li> </ul>	Dir of Programs/Services	forward
	<ul> <li>Enhancing the resident spotlight (Old legacy) program, to be person centered- quarterly - evidence of it on calendar of events by April 15, 2024.</li> </ul>	/Recreation, Admin	and ongoing
	<ul> <li>Hire a Spiritual Care Coordinator to ensure understanding of resident spiritual</li> </ul>	Dir of Programs/Services	Completed started April
	needs/preferences and enhance the overall	/Recreation	10th
	delivery of spiritual programming to meet	staff/residents	
	standards of MHLTC/FLTCA by April 1, 2024.		
	<ul> <li>Change the Resident Advocate role to include/ Activation Program Manager to provide additional over sight to provide meaningful activities to the activity programming by February 20, 2024.</li> </ul>	Dir of Programs/Services /Recreation, RA/PM, Dietary Manager	Completed Feb. 5,2024.
	<ul> <li>Implement opportunities for residents to assist pre and post meal set up by April 15, 2024.</li> </ul>	RA/Activity Coor, Dietary Manager	Completed. Shared with RC April. Will continue to
		1	

	Survey result 2023 46% agree target for 2024 70% agree.		resident engagement.
<ul> <li>Meal Service</li> <li>Snacks</li> <li>Dietitian</li> </ul>	<ul> <li>Re- educate residents on spice caddies through Resident Council and Food Committee Meeting by April 15, 2024.</li> </ul>	Dietary Manager	Completed April 22/24
	<ul> <li>Provide a steak option during BBQ months in summer to increase satisfaction by August 30, 2024.</li> </ul>	Dietary Manager	
	<ul> <li>Enhance the dining experience through improved ambience such as music, decor and greeting residents as they enter by March 15, 2024.</li> </ul>	RA/Activity Coor, Dietary Manager,	Completed through variety of music offered has increase, table decor seasonal improved -
	<ul> <li>Ensure taste caddies are regularly replenished and placed on tables by March 2024.</li> </ul>	Dietary Manager	ongoing Completed and ongoing
	Survey result 2023 58% agree target for 2024 75% agree.		

Accommodation <ul> <li>Housekeeping</li> <li>Laundry</li> </ul>	<ul> <li>Inform residents and families through memo and at admission that the bedside has a top-drawer lock option and key provided by April 30, 2024.</li> <li>Re- train laundry staff to deliver laundry to the correct room through staff meeting by April 30, 2024.</li> <li>No specific questions that fell into this section results came solely from survey comments.</li> </ul>	Laundry HSK MGR	RC informed April 22/24 Completed and on going
Resident Advocate Palliative Care/ End Of life	<ul> <li>Supply Care Plan at every 6-week, post admission care conference, and as requested for annual care conference meetings and at any time to review and ensure Palliative approach to care.</li> <li>Survey result 2023 69% agree target for 2024 75% agree.</li> </ul>	RA/PM, DRC, ADRC	Implemented and ongoing
Medical Services	<ul> <li>At the admission and annual care conferences, families and residents will be reminded of the process to speak with the physician or nurse practitioner.</li> <li>At the quarterly MAC-PAC meeting in February 2024, physicians will be reminded to communicate with residents and families any significant changes to resident's health status (labs, medications, diagnosis).</li> <li>No specific questions that fell into this section results came from survey comments.</li> </ul>	NP NP, Admin.	Implemented ongoing completed

Volunteer	<ul> <li>Enhance volunteer recruitment efforts to increase volunteer base and support resident group activities. (porter to bingo, hymn sing) we had 194 active volunteers in 2023.</li> <li>No specific questions that fell into this section results came solely from survey comments.</li> </ul>	Volunteer coordinator, RA/PM, Director Program Services	Additional 53 volunteers onboarded in 2023 with total volunteers' hours of 1,854.03 or (FTE ratio) 6.54
Environmental, Safe and Secure Maintenance	<ul> <li>Improve call bell alert system through purchase and installation of new Specralink phones on each home area by April 20, 2024.</li> <li>Survey result 2023 65% agree target for 2024 75% agree.</li> </ul>	Director Environmental Services	Completed April 22, 24