

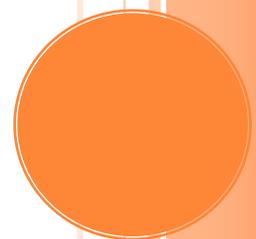
CAREGIVER TELE-GROUP SUPPORT

Evaluation Report

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INTRODUCTION

Caregivers Nova Scotia Association and the Dalhousie School of Occupational Therapy identified a need to develop a pragmatic support program for caregivers who are unable to attend in-person support groups. A literature review was conducted to identify research on the efficacy and protocols for conducting telephone support groups. This led to the creation of the Caregiver Tele-Group Support (CTGS) program – a telephone support group for family/friend caregivers. A one-day training workshop for caregiver support coordinators was created to educate and provide participatory roleplaying opportunities to learn the skills necessary for facilitating a telephone support group. The CTGS was piloted in the fall of 2014 to provide initial data on (1) whether it is an acceptable and appropriate format for caregivers; (2) whether it decreases caregiver stress, social isolation or risk of mental/physical health decline; and, in addition (3) the identification of primary and secondary outcomes and tools for a subsequent effectiveness study.

Background: Prior research indicates there is a higher prevalence of individuals acting as family/friend caregivers in Nova Scotia, compared to other parts of Canada.¹ This higher prevalence translates into a higher probability of more caregivers needing support. If the needs of family/friend caregivers are not addressed, they can suffer from emotional strain, depression, anxiety, and overall decline in wellbeing and quality of life for themselves and their care recipient.²

Peer support groups provide information, feedback, and emotional assistance from individuals who have similar experiential knowledge. Peer support groups for family/friend caregivers have been shown to decrease caregiver burden and loneliness, and to improve caregivers' abilities to cope with stress and take care of their own needs.³ Unfortunately, often the only peer support groups available to caregivers are face-to-face and therefore not accessible to those unable to travel to access these resources.⁴ This presents a significant problem not only to caregivers living rurally but also to those caring for a high-needs family member. Peer support through the telephone can be more convenient for unpaid caregivers who find it hard to leave care recipients or access respite care in order to attend in-person groups.⁵

CTGS Program: For this pilot, six sessions were chosen as a reasonable time period for evaluation because it is similar to the number of sessions delivered in support groups.⁶ Two CTGS groups were formed, each led by different facilitators. One group met weekly and had three participants; the other group met every other week and had five participants. During each session of the CTGS, a caregiver support coordinator facilitated group interactions using an evidence-based protocol developed by the research team. The protocol was flexible so coordinators could tailor the groups to the needs of the participants. The CTGS pilot was delivered over the telephone rather than the internet to decrease any potential stress of using a new technology and also to provide a stable connection as some areas of Nova Scotia do not have high-speed internet connections.

Methods of Evaluation: To evaluate CTGS, the Caregiver Risk Screen (CRS) was administered before and after CTGS participation, and interviews were also conducted with caregivers following their participation. The CRS is a tool developed to detect whether a caregiver is at risk of declining physical and/or mental health. In addition to the information gathered from participants, a debriefing meeting was held with the two facilitators and the executive director of Caregivers Nova Scotia. At this meeting the processes of CTGS were reviewed and suggestions were made relating to aspects of the program that were successful and those that were not. The facilitators also completed logs after each of the CTGS sessions describing what they had done to prepare for and deliver the session. These two pieces of information have been summarized under the section Feedback from Facilitators.

This report provides an executive summary of the findings, then discusses the findings in more detail.

EXECUTIVE SUMMARY OF FINDINGS

The most trustworthy information came from interviews with the caregivers following their participation in the CTGS. Participants provided rich stories about their caregiving situations and provided honest feedback on what they liked or disliked about the program. In summary, they expressed their desire to see CTGS continue even if they personally did not want to continue; they reported major benefits of validation of their feelings about caregiving and a reduction in social isolation. They also made valuable suggestions for improvements to the CTGS program, such as creating tailored groups based on the care recipient's condition.

The quantitative results from the CRS were inconclusive. This was expected given the small number of participants, which made it inappropriate to conduct statistical analysis and difficult to detect any trends in the caregivers' CRS scores before and after the CTGS pilot program. One benefit of using the CRS was the identification of the number of caregivers at high to very high risk of physical and mental health decline. A limitation was the CRS was not sensitive to the benefits participants identified in the interviews.

Information gathered from facilitators confirmed the findings from the caregivers. In addition, they provided valuable feedback on how future group-sessions could be delivered. They consistently reported positive group dynamics and remarked that facilitation was as easy as in-person support groups and became easier over time. Facilitators suggested having the groups every other week would likely be sustainable. At times the lack of caregiver commitment to the group could be challenging.

Recommendations for Future Research

Future research on the CTGS program should have a larger sample size to assess the effectiveness of the intervention. In addition an alternative quantitative tool should be considered that would be capable of reflecting the CTGS benefits identified in the interviews. The caregiver interviews should be continued to enable comparisons between the quantitative tool and the perceived benefits of participants.

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Potential participants should be provided with additional information at recruitment, informing them of the benefits and expectations of the program. This could help recruit caregivers who were likely to benefit and feel prepared to participate in the group. Recruiting caregivers likely to be socially isolated or who are new caregivers would be a good population to target for the next study, for example caregivers of homecare clients.

Finally, offering the CTGS to six participants every other week seems to be the consensus from both caregivers and facilitators as the most appropriate approach. Additional caregivers would need to be initially recruited to allow for dropout in the group. If necessary the facilitator for the group could change, as long as participants are prepared. If there are enough caregivers recruited, tailored CTGS groups should be considered for caregivers with particular needs.

EVALUATION RESULTS

The evaluation results are presented in the following order: I) Caregiver Risk Screen (CRS), II) Caregiver Interview, and III) Feedback from Facilitators.

I) Caregiver Risk Screen Results:

The Caregiver Risk Screen (CRS) measures the caregiver's risk of physical and mental health decline, with scores being categorized as very high (23-30), high (17-22), moderate (11-16), and low (below 11). Prior to the start of the program, two participants were at very high risk, three were high, one was moderate, and two were at low risk. Following CTGS, participants' CRS post-test scores were only marginally different from pre-

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test scores, where seven participants stayed within their initial category of risk and one increased in risk from moderate to high. Caregivers' situations were complex and affected by multiple factors in addition to the care recipient's health, such as family dynamics, the quality of the relationship with the care recipient, and the amount of help

available from others. Any increases in scores were attributable to major changes in their caregiving circumstances such as a sharp decline in the care recipient's health or frustrations from negotiating with the health care

system. It is likely that these circumstances were beyond what the CTGS program could have impacted.

The participant whose CRS score decreased the most (a drop of six) remained in the low risk category. She showed decreases in her CRS score on questions assessing social isolation, relationships with family, and relationship with the care recipient. These decreases aligned with evidence in her interview that she derived significant benefits from the social aspect of CTGS and the practical sharing of information that would have affected her relationships with her family and care recipient. Two other caregivers' CRS scores decreased 4 points, but they stayed at a high level of risk. One described the benefits of sharing her story with people in the group who could appreciate her caregiving situation. She felt her feelings and experiences were validated and came away with a new perspective and fewer feelings of guilt or selfishness. The second caregiver, despite an overall decrease in CRS score, was still struggling with her caregiving situation. She reported benefit from the ability to compare her situation to others in her telegroup, but her stressful circumstances overwhelmed the benefits. The other participants with smaller decreases in their CRS scores showed similar patterns.

II) Caregiver Interview Results:

Comments from the interviews have been grouped into the following themes: 1) Recommendation to continue CTGS, 2) CTGS Benefits, 3) Mismatch leading to lack of validation, 4) Comparing telephone and in-person support groups, and 5) CTGS Logistics.

1) Recommendation to continue CTGS:

All of the caregivers recommended that Caregivers Nova Scotia continue offering the CTGS program. Participants were very thankful to each other and Caregivers Nova Scotia for the opportunity to share in the support group, with several expressing they would like to continue the telegroup in the future. All names used below are pseudonyms.

"[Caregivers] need all the support they can get, so the more of these kind of projects and programs that can come in - man, I think it was great to hear the other women, just really, I felt like they were making use of the time, really. Talking about all the really difficult stuff. A lot of hashing-out went on that I would listen to, for sure. I think it was very valuable. So I hope lots more.... I hope it keeps going. I hope it's just the beginning" (Mona).

“The government should be really rolling this out big time right now. There’s so much need out there. And don’t wait. Like, you know, get your research in. Roll it up, and a recommendation to get it out ASAP because it’s a lifeline... We got a crisis on our hands, and we need help... and it’s pretty cheap to get a facilitator for an hour and a half and roll out some conference calls, just to give people a lifeline”
(Moir).

2) CTGS Benefits:

The most frequently mentioned benefits from CTGS were validation of their feelings, social connections, and knowledge sharing between participants that led to improvements in caregivers’ self-care.

“When you’re speaking with other caregivers there’s almost a level of understanding that comes naturally and you don’t have to explain to them, the way you would to friends or family, sort of the different logistics of your day, or the effect it’s having” (Lucy).

“The big thing for everybody that looks after someone is the isolation that you get, that happens, ‘cause you’re not free to come and go, and go do social things like most people. So really, anyone that’s giving care at any time on their own, ya know, that isolation becomes an issue. [The telegroup] is just a little lifeline you don’t have to leave the house for”
(Mona).

“My situation, I felt like so unique, people are not going to understand much. But they were good, they were supportive” (Elspeth).

“But ‘self’ is – sometimes, it just goes, goes away. There is no self. But when the group came, there was me. That little bit of time, I was on that phone, it was all about me! And that was wonderful. Because the rest of the 23 hours, it’s not about me” (Edith).

“I learned that there are things you can get help from that I hadn’t known about before, and I have a list of all these things now, and if and when I need these things I can utilize them” (Eliza).

The significance of these benefits for some participants cannot be underestimated – for some the CTGS was a lifeline.

*“Ah, I was a basket case before that telephone, and it helped me over a lot of rough spots. Just to be able to look forward to talking with those ladies and listening to them and not always looking at our own life”
(Edith).*

“I knew there was somebody on the end of the line or at the end of an email that would respond in a timely fashion. So that was a lifeline for me. If I did not have that...I would not have anyone. I mean, you can't do that with a doctor. You can't do that with any other professional. And you can only rely on your spouse for so long, ya know. You need someone outside of that family” (Moira).

*“..just knowing that other people understand is huge. And having people to talk to about those problems, because you can't stop people on the street and tell them about the...but you can talk to the other women in your group and that's a beautiful thing. That's a beautiful and valuable thing. It can't even be measured how important that is....The lifeline of the phone is social, and therapeutic, and a lot of things”
(Mona).*

3) Mismatch leading to lack of validation:

Despite the recommendation from everyone to continue the CTGS program, some caregivers felt they did not quite fit into the group. These individuals would have liked the group to be more similar to their caregiving situation, suggesting matching participants by care recipient condition, level of caregiver stress, or particular cultural needs. A suggestion was made that one-to-one support might be better for those with extreme caregiving situations. Those who felt mismatched did not experience validation of their feelings in the group.

“I found myself wishing that there was someone there that I could have connected to on the same level, although the caregiving was the focus – the caregiver was the focus – um, but you don't feel the same way... But, I just, I enjoyed tele-meeting these folks, and appreciated the insight that they offered, and their willingness to share. I think it would have been more beneficial to me if it had been from folks who were in my circumstance” (Ann).

“Ya know, really, the other women I’ve spoke to in this group...their life is so, so, so, so far much harder than mine, that it almost feels irresponsible complaining about it... So rather than finding it a place where I felt comfortable unloading, because my situation is so much better, I didn’t feel that comfortable unloading about my stuff, and I yet I really took on a lot of that other suffering I felt the other women go through” (Mona).

“I’m not too keen [to continue with the telegroup]. ‘Cause I think I take the things in a different direction when I talk. Like I’m talking to you, I’m not talking too much about my mother, I’m talking about my personal life. Right? I kind of need a friend, one-to-one” (Elspeth).

4) Comparing telephone and in-person support groups

Comments regarding the benefits of a telephone-based support group were generally positive, with the most common positive aspect being the lack of travel which made it easier for participants to attend the group. Some caregivers appreciated the fact that they were anonymous, as this helped them to feel more comfortable sharing personal experiences with the group. Another reported benefit of anonymity was the absence of distraction from others’ body language when it was one’s own time to talk. This enabled them to concentrate on their own needs during their turn and also to express emotion privately.

“[At first] I was very reserved, ‘cause I tend to be a face-to-face person... [but] it was amazing. We just clicked. Now, the benefit, was I didn’t have to get dressed, I got all my laundry folded every week for 6 weeks. I had peace. It was just the most structured, delightful experience I’ve ever had...in...my...life... I pretty well got respite in each time, like I moved my respite around so I’d have that time. It was great” (Alexandra).

“Although we know our first names, the telephone provided a certain confidence through anonymity. Sometimes things are easier to say on the telephone than they are in a group setting. I feel like I made four new friends, though I could pass them on the street and not even know who they are” (Ann).

“Everybody seemed to have their own airtime. But sometimes if you’re in a group and you can see the body language, and someone’s breaking down, you just give up your needs and tend to that person’s needs. But on the phone call, it didn’t seem to happen that way (Moira)”.

However a few participants mentioned they missed not being able to see the other caregivers.

“I think [in person,] you can read their facial expressions, because you can reach out and touch their hand. And, um, their eyes, their... you can tell by their eyes. Sometimes when they don’t say anything... you can... I don’t know, I just find it better in person” (Ann).

“Um, I didn’t feel socially that connected, because you don’t see people...But some things I still liked it, talking to somebody” (Elspeth).

5) CTGS Logistics

All of the caregivers were very appreciative of their facilitators, highlighting both their excellent facilitation skills and their generosity. It was also felt that there was enough time during the CTGS sessions to share with others, with most members being very respectful about sharing airtime. Even though the two groups were different sizes, each group was happy with the number of participants in their group. There seemed to be a consensus that the group should not be too large, as it may become difficult to provide enough sharing time for everyone and to make the same connections with a larger number of people.

“There was a lot of time for people to share and you never felt like you were being rushed or, you know, shut out or ignored or anything” (Lucy).

“I mean, some people, depending on their issue might have talked a little bit longer, but all in all we were pretty respectful of one another’s time so that we could all get, you know, some air time” (Moira).

“I think that if there had been six people – I could be wrong – but I think if we had had six people in the group, it might have been too many because everybody wouldn’t get the chance to say what they needed to. It would be harder to keep everyone straight, especially where you’re not seeing their faces. And, I mean, everybody doesn’t connect like everybody. You don’t connect the same with six people as you would with three. I think it allowed us to get closer as a group”
(Eliza).

“Even though we did say ‘Oh this, this is the perfect number’. That’s because, for us, it was. But, I would try anything. Anything at all”
(Alexandra).

The caregivers’ comments on frequency and length of time for the group varied depending on their needs. Those with higher needs wanted it more frequently and those with less needs or busier lives wanted it less frequently. For example, caregivers mentioned that once a week might be appropriate when the care recipient was palliative.

“Yeah, I did find it... a little too frequent, in that there were a couple times when it was just a six day gap.... So maybe every two weeks would be frequent enough, or maybe every three weeks... And that would probably be a factor for me. I probably would prefer it if it was a little less frequent, if I was going to continue” (Lucy).

“I thought it could be once a week instead of once every two weeks. But some people might not have found that. I just thought that the more you could do for these people” (Mona).

III) Feedback from Facilitators

1) Group Dynamics

The facilitators felt that the group dynamics in the CTGS program were positive. In the facilitator logs facilitators indicated 100% of the time the group interactions were very positive. They consistently reported their group members as ‘interacting well’, being attentive and respectful of one another, and encouraging each other to each have time to talk. One reported that “after the first couple of minutes, this format was as comfortable as in-person [support groups]”, while the other facilitator noted that in the absence of visual cues, it was at times hard to know when someone had finished speaking. However, participants seem to be able to recognize the voices of the other participants by the second session.

2) Group Content and Facilitation

During the sessions the two facilitators were able to offer advice or guidance to group members through providing requested information such as disease prognosis, relaxation, healthy diets, etc. They felt having an agenda of discussion topics was helpful, but it was not always necessary. Once the group members became comfortable with each other they were self-propelled, dynamic, and usually respectful of one another. Members started to direct what was discussed and to make suggestions for future sessions. Facilitators stated that gentle facilitation and redirecting the conversation was successful at balancing the competing needs of participants. Facilitating over the phone might be less draining than facilitating in person. In the logs, 92% of the time, the caregiver issues were easily addressed over the phone. A majority of the sessions (75%) required follow-up phone calls or emails.

“This meeting seemed to go very quickly and it was very easy to facilitate. I really just let the ladies go and they needed very little by way of facilitating” (Group Facilitator).

“A wonderful discussion – rich and meaningful. Very easy to facilitate and it seems the more time they spend together, the more unnecessary I become” (Group Facilitator).

The difficulty recruiting caregivers, lack of commitment to the group, and caregiver dropout was at times frustrating for facilitators. As the sessions progressed some of the caregivers forgot to let the facilitators know they would not be calling into the session, they may call into the session late, or leave early. From the logs, 5 of the sessions had 100% attendance, 4 had 80-83% attendance, and 4 sessions had 75% or less attendance. This attendance record occurred despite the fact that facilitators either called or emailed the caregivers before each session to remind them the group was taking place. These reminders became easier for the facilitators over time.

Setting expectations for caregivers was important, but being flexible was considered critical so caregivers would not perceive CTGS as a burden. To prevent some of these frustrations, it was suggested that more information be provided at recruitment regarding the benefits and expectations of the program. This would help target caregivers who were likely to benefit and felt ready to participate.

3) Logistics

Facilitators felt that the telephone system worked well and that it would not matter if caregivers were grouped by location. In this pilot participants came from similar regions, but most did not come from the same communities. Not knowing what people looked like seemed to lessen some of the participants' anxiety that other CTGS members outside the group might recognize them.

The facilitators agreed that delivering the CTGS program every second week was likely to be sustainable, but the optimal number of participants was unclear. There was a suggested maximum of five per group (which coincides well with the participants' suggestions), but recruiting seven would allow for dropout. It was noted that some of the richness of an intimate conversation could be lost if too many people were on the telephone.

Facilitators discussed the challenge of how much and when to share personal information about participants, as some members expressed interest in connecting socially outside of the groups. In the debriefing session it was decided that personal information could be shared at the end of CTGS, but only with the understanding that participants may or may not hear back from other people in the group.

Additional feedback from the facilitators included an expression of comfort with being changeable between groups (if necessary), and a feeling that those caregivers most likely to benefit from the CTGS program are those who lack confidence in their ability to advocate on behalf of their loved one.

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CONCLUSION

In conclusion the CTGS program is a valuable resource for caregivers. Further research will be able to identify caregivers who are most likely to benefit and provide more information on how to assess the effectiveness of the program.

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