

**“It’s Better than Telephone, and it’s Better than Driving to Thunder Bay!”:
Clients' Perceptions of Experiences in Participating in a Group-based
Stroke Self-Management Program Using Videoconference Technology**

Denise M. Taylor, PT, BScPT

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Abstract

PURPOSE: Videoconference is used in rural and remote areas to improve access to healthcare, including individual clinical assessments and the delivery of group education. Moving On after Stroke (MOST[®]) is a group-based, self-management program for stroke survivors and their caregivers, which consists of information sharing, facilitated discussion, goal-setting, and exercise. The program was delivered simultaneously to local participants onsite and distant participants using videoconferencing (MOST-Telehealth Remote). This research was designed to learn about the experiences of the remote participants, their perceptions regarding perceived enablers and barriers to videoconference participation, and suggestions for improvement.

METHODS: Semi-structured interviews were conducted in person with nineteen rural MOST-Telehealth Remote (MOST-TR) participants within one year post-program. The interviews were transcribed and coded using NVivo 2.0. Data were analyzed for common categories using qualitative descriptive methods.

FINDINGS: All participants valued accessible programming without having to travel long distances. Many reported “feeling as if they were in the same room” but also acknowledged that there were technical limitations when participating via videoconference. They recognized a loss of subtleties in communication. Factors facilitating engagement and participation were similar to factors in face-to-face groups and included: program content; having a skilled group leader; and having a connection to another group member, rather than the videoconference environment itself. The importance of onsite coordinators, volunteers, and the presence of other local participants were highlighted. Suggestions for improved group cohesion and participation included having a preliminary face-to-face meeting, implementing technical strategies, and having onsite support.

CONCLUSION: For MOST-TR participants, the benefits of videoconference participation outweighed the shortcomings. Addressing the limitations of videoconference connection and providing local support may improve the experience for rural participants in small-group, videoconferenced, support programs.

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Chapter 1: Introduction

Stroke is a chronic disabling disease and the leading cause of adult disability that often permanently changes the lives of its victims.^{1,2} Many individuals who survive a stroke have difficulty resuming a satisfying life.³ Within Canada, over 50,000 people are diagnosed with stroke each year. The Heart and Stroke Foundation estimates that there are currently 350,000 people in Canada and about 50,000 people in Ontario living with the sequelae of stroke.⁴ The prevalence of stroke within Northwestern Ontario (NWO) is 1.5%, significantly higher than the provincial rate of 1.1%.⁵

NWO spans 526,355 km² and has a population of 234,770 people; the area encompasses more than 50% of Ontario's landmass but has only 2% of the provincial population.⁶ The region is sparsely populated, with 50% of the NWO population living in the rural and regional areas outside of the city of Thunder Bay.⁶ On account of the sparse population and vast distances, access to healthcare is much more challenging than in more populated areas. Healthcare human resources are limited and professionals often serve clients spanning the entire continuum of care. Support groups are also limited in the north. They are impacted by small numbers and the limited healthcare human resources to support their development and sustainability. The videoconference delivery of MOST[®] provided accessibility to a supervised, community-based, self-management program with both group exercise and peer-support.

Stroke often results in long term impairments, leading to limitations in activity and social participation. Many people living with the consequences of stroke have difficulties with activities necessary for community participation, such as fulfilling family roles, completing household chores, socializing, accessing transportation, and shopping.⁷ Long-term community reintegration outcomes for stroke survivors and their caregivers are often poor, even when their observable impairments are mild.^{8,1, 9-12} This reflects that factors other than physical impairments

alone contribute to successful activity, social participation, and reintegration levels post-stroke. Furthermore, caregivers report reduced participation in their own social and recreational activities, as well as decreased health status.^{13, 14}

For stroke survivors living in sparsely-populated rural and remote areas such as NWO, these problems are exacerbated by a lack of programming, limited healthcare resources, and inadequate peer-support.¹⁵ The small numbers of stroke survivors in these areas limit opportunities for peer-support, and cost-efficient delivery of local group programs.¹⁶ As a result, innovative approaches to the delivery of community programs in rural and remote communities are needed.¹⁵ In an attempt to deliver post-stroke services, Moving On after STroke (MOST[®]) developed an innovative telehealth approach to the delivery of programs in rural and remote communities.

Telehealth is an all-inclusive term for the provision of health services using information and communication technology. Videoconference delivery is one form of telehealth whereby a synchronous, two-way connection is made between two or more sites. Videoconference connections can be either “voice-activated” or “continuous presence”. During a voice-activated connection, multiple sites can be connected but only the last audible site is viewed on the full screen. Continuous presence connection has the advantage of an ongoing view of all connecting sites simultaneously, but the viewing screen is divided into two, four, or nine sub screens etc. to accommodate the number of sites connected. Although videoconference has been found to positively impact rapport when compared with an audio-only connection, it is not equivalent to live interaction.¹⁷

Videoconferenced, continuous presence connection, has improved considerably since its inception when there were long audio delays. An audio lag still existed during the study and the lag increased as the traffic on the telehealth network neared its bandwidth capacity and/or with

inclement weather. The present day audio lag can be described as similar to a poor international long distance telephone connection.

Telehealth has been used successfully for patient consultations,¹⁸ healthcare provider education,^{19,20} and recently for client group education and self-management programs.²¹⁻²³ A key recommendation by the Romanow Commission was to expand telehealth to improve access to care and to reduce the discrepancy in services to rural and remote Canadians.¹⁵ Most studies suggest that patients are satisfied with videoconference delivery, however, preliminary review indicates there are still many knowledge gaps regarding the telehealth experience.²⁴

Videoconference dissemination appears to provide an opportunity to equalize people's access to the services of healthcare professionals. However, this thesis is premised upon the concern that professionals, policy makers, administrators, and the general public may have too quickly "jumped on the telehealth bandwagon," excited to offer services to people in their home community using videoconference, taking a positive experience with one situation and extrapolating it to another situation, making assumptions that it is sufficient, effective, and cost efficient, with limited rigorous studies investigating its full impact.²⁴⁻²⁶

Moving On after STroke (MOST[®]) is a group-based, self-management program for stroke survivors and their caregivers living in the community.²⁷ The program provides information about stroke-related topics and facilitates discussion, problem solving, goal-setting and self-management skills in a supportive environment.²⁸ It is comprised of both discussion and a group exercise program. Participation in MOST is associated with improved community reintegration and positive health behaviour changes in stroke survivors.²⁷ MOST is presently offered in NWO using videoconference technology. Facilitators and Thunder Bay participants at one site are connected via videoconference to stroke survivors from rural NWO at two other remote videoconference sites.

Peer-support is a critical component of the MOST program; therefore, the development of group cohesion and participant involvement is crucial to success. This thesis examines the perceptions of experiences of remote MOST participants in order to explore factors influencing their participation and involvement in the group. Every Canadian has the right to participate in evidence-based healthcare programs and reap the benefits of participating in events that otherwise would not be available due to geographical location. Yet, there are challenges associated with offering healthcare via videoconference. The first step in addressing these challenges is to identify them in order to improve the group videoconference experience.

The interviews conducted for this research explored the supports required for group cohesion and the barriers that the videoconference aspect of this program presents to group cohesion. In person interviews with nineteen participants were completed and analyzed using qualitative research methods. The study findings can be used to guide and improve future applications of videoconference for group programs, including group exercise programs.

Chapter 2: Literature Review

2.1 Telehealth and the Context of Northwestern Ontario

Canada is known for its vast landscape, diverse weather patterns, sparsely populated regions, and uneven distribution of healthcare providers.²⁹ Furthermore, equitable access to timely, quality care is a Canadian commitment and a public expectation regardless of geographic, social, economic, or cultural contexts. In 2002, the Honourable Ray Romanow was commissioned to investigate the future of healthcare in Canada and make recommendations for its ongoing sustainability. As a result of this investigation, one of the three key recommendations concerning rural and remote healthcare by the Romanow Commission was to expand telehealth to improve access to care and to reduce the discrepancy in services.¹⁵

Within NWO, the Ministry of Health and Long-term Care commissioned the Closson group in 2005 to investigate the integration of health services within NWO, to preserve the universal, equitable access to timely, quality care, as per the pillars of the Canada Health Act.^{30, 31} One of the key recommendations of the NWO Closson Report was the need to provide healthcare closer to home and to enhance the integration of health services within NWO.³⁰ In response, the Northwest Local Health Integration Network (NW LHIN) has prioritized the provision of service closer to home in its Integrated Service Plan.³² Telehealth is one strategy which can be used to deliver health services over large distances.

Numerous benefits of videoconferencing have been described, including improved access to health services, timely and appropriate healthcare intervention, cost-effectiveness, elimination of the need for client or clinician travel, enhanced educational opportunities, improved health outcomes, better quality of care, better quality of life, reduced rural isolation, and enhanced social support.^{25, 33, 34} Gagnon et al.³³ report that healthcare providers and the public alike perceive

videoconferencing as a tool to improve healthcare services for populations living in remote areas with the potential to facilitate access to services that would otherwise be difficult to obtain. Specific to rural and remote healthcare, videoconferencing is reported to be perceived by provider, public, and private sectors as an opportunity to bring new health services to rural areas, build health human resource capacity in rural areas, allow patients to stay in their home communities when receiving care, decrease both travel time and cost to access healthcare services, and improve continuity of care.³⁴ For two decades, videoconferencing has been used successfully for individual patient consultations,^{18, 35} client education,^{35, 36} health professional lectures,^{19, 35, 37} and small group learning.²⁰ More recently, videoconferencing has been used for caregiver support programs,³⁸⁻⁴⁰ and self-management programs for people with chronic illnesses^{21, 23} and stroke.^{38, 41} Some telehealth programs include an exercise component.^{41, 42}

Within Ontario, the Ontario Telemedicine Network (OTN) is an established broadband Internet Protocol (IP) network connecting over 100 sites.⁴³ Although OTN boasts the busiest videoconference network in Canada, similar broadband IP networks exist in other provinces such as Alberta, British Columbia, Nova Scotia, and Quebec. Videoconference technology is widely used within NWO for continuing education for healthcare professionals,³⁷ administrative meetings, physician and rehabilitation client consultations, client education,⁴⁴ a multiple sclerosis support group,⁴⁴ and more recently for delivering both a multi-centre cardiac rehabilitation program and the MOST group stroke self-management program. The extensive videoconferencing infrastructure in the NWO region, supported by telehealth coordinators, and the public's demand for healthcare improvements, have made NWO "telehealth ready," and prepared for success.⁴⁵

Previous studies investigating videoconference user satisfaction have focused mainly on the technical component using mostly quantitative survey methodology and occasionally including some qualitative methods within surveys.^{18-20, 36} Research with healthcare professionals

has described both benefits and challenges of videoconferencing.^{33,35} Reported benefits include improved rapport with patients, improved access, improved productivity, improved quality of care, and improved coordination of care. Improved access and quality of care have included both the ability to access services at home or close to home, as well as increased frequency of patient contact, and quicker response. Reported barriers include the technology itself with poor visual representation and audio lags, the preference for in-person care, and the need for dedicated videoconference human resources. A study investigating the use of videoconferencing for physician residency training in Alberta found differing degrees of satisfaction between the remote audience and the local audience.¹⁹ The distant audience expressed high satisfaction with the convenience of the videoconference and was satisfied with the education itself; whereas, the local audience, or live audience, expressed dissatisfaction with the education itself and found that the distant audience negatively impacted the delivery of the education.

Although videoconferencing has been found to better allow the immediate establishment of rapport compared with telephone interactions, and videoconferencing allows participants to more easily maintain this rapport, videoconferencing is still not equivalent to live interaction.¹⁷ An onsite local coordinator is necessary at each connecting site for initial set up and troubleshooting^{17,36} and despite technological advances, technological problems remain. An audio lag is often noted, similar to a poor long-distance telephone connection, leading to the perception of smooth conversation transitions at one site, but awkward transitions at other sites.^{20,}
⁴⁴ This issue continues to improve over time. One strategy to improve audio lag is to use the mute function of the voice system. When this strategy is used, only the site where someone is speaking can be heard by the connecting sites.⁴⁶ This is especially useful during presentations that involve connecting large numbers of sites; however, it has been noted that using the mute function appears to be counterproductive in small group discussions. Using the mute function has actually been reported to negatively affect participation and discussion as participants need to

make an additional action to un-mute the voice system to participate in the conversation. This additional step has been reported to hinder participation in the group discussion.²⁰

Within telepsychiatry, Mielonen et al.⁴⁷ found that videoconference had shortcomings related to the lack of face-to-face presence such as: shaking hands, touching, and not being able to sense smell. They reported the necessity of an in person, pre-initiation meeting, especially for first-time patients. Technically, they identified that participants found the adjustability of the camera important, including the ability to switch the picture between pre-set camera positions and zooming in for close-ups. They also appreciated the remote control and the view of the outgoing screen.

The importance of the facilitator role during videoconference groups has also been reported.^{20,40} In addition to the facilitator's usual role as educator, the social role is impacted by videoconference, and a technical role is added in the videoconference environment.²⁰ In one study, qualitative interviews were done with both service providers and caregivers who participated in information and support sessions.⁴⁰ The study found that videoconference delivery was well accepted and for some participants was preferable to face-to-face interaction. The critical element identified in the program was that local services were enhanced by a skilled facilitator, not available locally.

A systematic review of telehealth concluded that telemedicine is currently advocated as a mode of healthcare delivery because of its potential to reduce inequalities in service provision and to improve access to care.²⁴ Studies of interactive tele-consultations have been performed in a variety of diverse settings throughout the world and most suggest that patients are satisfied with this mode of delivery. However, a recent review by the Cochrane Collaboration reported that telehealth provision of patient care is feasible, but reported very little evidence of clinical benefit compared to standard face-to-face healthcare, and no analyzable data about cost effectiveness.²⁵ The group cautioned healthcare providers that telehealth may require different clinical skills,

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specifically related to communication and the sharing of information, and warned that telehealth may alter the nature of both the clinical encounter and the relationship between patient and provider. The Collaboration pointed out that the emphasis in previous studies has focused on the service perspective, with investigation of the patient perspective limited to satisfaction levels. Although similar perceptions, opportunities, benefits, and challenges to using videoconferencing have been reported, few qualitative studies have explored the clients' perceptions of their videoconference experience. This lack of a client view on the understanding of social effects of videoconferencing was identified by Jennett et al. in 2003.²⁶ A preliminary review of literature about videoconferencing indicates there are still many knowledge gaps in relation to factors impacting patient experiences and satisfaction with videoconferencing.^{24, 26}

2.2 Self Management

With regard to health, self management has been defined as “learning and practising the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition.”⁴⁸ Self management addresses the three types of activities required of people living with chronic illness described by Corbin and Strauss: the work to care for the disease, such as taking medications, visiting physicians, exercising or maintaining a special diet, making changes to live healthier and to reduce the risk of further complications; the work to maintain a normal life, such as doing chores, maintaining social contacts and hobbies; and the emotional effort to deal with feelings, such as frustration, anger or depression.⁴⁹ While clients are ultimately responsible for managing their condition, guidance and support from peers and health professionals can greatly facilitate this process and assist the client.

Self-management interventions have been shown to be efficacious across a variety of conditions.⁴⁹⁻⁵¹ Self management is considered the key component of both chronic disease management and health promotion activities.⁵⁰ The most comprehensive foundation for self-

management interventions is Social Cognitive Theory.⁵¹ This theory specifies the determining influences on health-related behaviour changes and is useful in guiding interventions.⁵² The core concepts of Social Cognitive Theory include: 1) the knowledge of the risks and benefits of different health practices; 2) perceived self efficacy, or the confidence that one can exercise control over one's health behaviours; 3) outcome expectations about the expected costs and benefits for different health behaviours; 4) health goals people set for themselves, the concrete plans and strategies for realizing them; and 5) the perceived supporting factors and obstacles to the behaviour changes one is aiming for.

Perceived self efficacy and outcome expectancies are key predictors of the effectiveness of self-management programs. Perceived self efficacy refers to the confidence to perform a particular activity, such as making a change.⁴⁹ This confidence influences what people choose to do, how much effort they make, and how long they will persevere in the face of real or perceived obstacles. The four sources of self efficacy for behaviour change are listed as: skill mastery; vicarious experiences gained through comparison of others in a similar situation and modeling of positive behaviours by others; verbal persuasion from peers, healthcare professionals, or family members; and physiological feedback of one's own physical or mental state.⁵³ Outcome expectancies are beliefs about how much the identified behaviour will produce favorable or unfavourable outcomes.⁵² People are more likely to act when they believe their actions will produce beneficial outcomes; however, they are also unlikely to change their behaviour if they believe their environment will not accept these new behaviours. Consequently, self-management interventions need to enhance both self efficacy and outcome expectancies.

With the chronic disease self-management model, participants are encouraged to take charge of their lives by making informed choices, adopting new perspectives or strategies, acquiring problem-solving and coping skills, utilizing appropriate resources, initiating behavioural change such as exercise, and maintaining or regaining emotional stability.²⁸ Social

support is viewed as a critical factor in this process.⁵⁴ Existing social support may facilitate self efficacy, and may also have a direct impact on well-being. Group self-management programs can strengthen and expand social networks by bringing together people with similar concerns, by providing opportunities for group problem solving and support, and by facilitating linkages to ongoing community resources.⁵⁶⁻⁵⁸ The self-management approach has been the foundation in the development of MOST, a group self-management program specific to stroke survivors, and their caregivers.

2.3 Moving On after Stroke®

The Moving On after Stroke (MOST®)²⁷ program is based on self-management principles. It is a multi-modal, psycho-educational, and exercise program for stroke survivors and their caregivers living in the community.⁵⁵ The objectives of the MOST program are to provide information and facilitate problem-solving and self-management skills in a supportive environment. It is a group program delivered over nine weeks, with two sessions per week. Each group is comprised of eight to twelve stroke survivors and their caregivers, and is facilitated by two MOST-trained healthcare professionals. Each session consists of one hour of discussion, followed by one hour of exercise. Participants have a chance to discuss stroke-related topics with peers, and learn and practice problem-solving and goal-setting skills within the group. Each group of eight to twelve stroke survivors is constant, or closed, over the entire set of 18 sessions. New members do not join the group. Consequently, at the sessions, the group members get to know one another and may become more comfortable sharing with one another. MOST is associated with improved community reintegration and positive changes in health behaviours in stroke survivors.²⁷

In recognition of the needs for community stroke programming in rural and remote communities, MOST has been modified for videoconference delivery. An initial pilot study

evaluated the feasibility of videoconference delivery with one of the two facilitators, in Toronto, connected via videoconference to the host site. The second facilitator, the stroke survivors and their caregivers, were at the host site in Thunder Bay.⁵⁶ Program delivery relied upon the Ontario Telemedicine Network (OTN). This pilot phase demonstrated that remote facilitation using videoconferencing is a practical and efficient delivery and training mechanism for the program.⁵⁶

⁵⁷ Focus groups conducted as part of the evaluation of this pilot phase project identified that the participants were much less intimidated by the videoconference technology than the investigators had expected. Even with one of the facilitators at a distance, the participants showed positive outcomes, and reported benefits from the program including a decrease in their sense of isolation.

Subsequently, a large, randomized controlled trial was initiated to evaluate the videoconference dissemination of the MOST program to more isolated rural communities: MOST-Telehealth Remote (MOST-TR). In this program a group of up to twelve stroke survivors from all across NWO were connected via videoconference. The local group of participants and both facilitators were in Thunder Bay. Two additional rural and remote sites were connected using videoconference allowing an additional six stroke survivors and their caregivers to join the Thunder Bay group. Participating sites included: Sandy Lake, Fort Frances, Kenora, Dryden, Sioux Lookout, Geraldton, Marathon, Terrace Bay, and Manitouwadge (Figure 1). Distances spanned as far as 600 kilometers to the northwest of Thunder Bay, and as far as 450 kilometers to the northeast. For many stroke survivors and their caregivers, the MOST-TR intervention via videoconference was the only feasible means of participating in the MOST program, twice a week, for nine weeks.

In addition to facilitating the group through discussion and program content, the MOST facilitators monitor the well being of the members of the group which was anticipated to be more difficult across videoconference. As such, prior to the actual program implementation, site coordinators were arranged at each of the remote sites to assist with local recruitment and assist

with participant orientation and safety. The site coordinators posted signs for participants to locate the telehealth room, arranged the room, set up the walking route, and ensured safety and comfort of the participants for the first two sessions. During the remaining sessions, the site coordinators also provided assistance during a fire drill and updated the participants on information and procedures for local issues.

The physical safety of participants is a concern when delivering an exercise program across videoconference. The stroke client population has numerous potential safety risks during exercise: balance deficits causing falls, people with diabetes adding a risk for glucose level abnormalities during exercise, and perceptual and cognitive issues making exercises difficult to follow. There is limited videoconference research involving group exercise with some of the participants being unsupervised and distant from the majority of the group. The literature includes studies in which a distant group of exercise participants are connected to a physiotherapist using videoconference, but are additionally supervised by a local community fitness leader.⁴¹ Using prudence, an in person assessment, including a balance and walking component, was done with each participant prior to his or her participation in the program. Assessments were performed at the local rural hospital by a trained registered healthcare professional, other than one of the facilitators. Caregivers or volunteers were asked to assist with the exercise program as required and hip protectors were provided for any rural participant at high risk of falling. There were no safety issues or any adverse events during the entire trial and participants found that exercising with one another in the group was still possible and beneficial across videoconference.

During program delivery, MOST-TR used synchronous audio and video feed videoconference connection, internet protocol (IP), broadband width, over OTN's secure network. Continuous presence connection was used, allowing visual display of all sites at all times. Microphones were not muted during any of the conversations, at any of the sites to

promote optimum participation during the discussion from all participants at all sites. This decision not to use the mute button was made to reduce any hesitation of the participants within the group to speak. Table microphones were placed at the centre of each table at all sites to improve sound quality. Because there were three sites, the connection was “bridged” by OTN staff in Toronto. The video camera could be controlled at each site, locally, with the use of a remote control. Camera angles were preset to rapidly focus on the speaker. A document camera, which transmits text directly through the video screens, replaced flip charts.

As is standard for MOST, refreshments were provided during two of the MOST-TR sessions. The same refreshments were provided at each of the sites, catered by the local hospital with the exception of one health center. There, the site coordinator had to pick up a fruit tray from the local store.

This large, wait-list control, randomized trial examined the feasibility and effectiveness of the videoconference delivery of MOST, a group self-management program, to improve community reintegration and health-related quality of life in stroke survivors and their caregivers, in rural/remote areas in Northwestern Ontario.

2.4 Theories of Group Development

MOST is delivered in a group format to promote and encourage information sharing, peer support and connection among participants. These are important factors in promoting participants’ self efficacy in goal-setting and health behaviour changes. The phenomenon of a group has been variously described.⁵⁸ Some feel the group is a collection of individuals, a sum of its parts; others feel that by coming together, the group of individuals is no longer a sum of its parts, but a complete entity in and of itself.⁵⁸ Some argue that although individuals in a group do not remain individuals, they do not lose themselves entirely to the group either. People join groups for a variety of reasons: they like the activity or purpose of the group; they like the others

in the group; they want to experience the feeling of belonging; or they find they can only accomplish a personal goal by participating with others.⁵⁸ The dynamics and benefits of the group itself play a part in group members' ongoing participation. The decision to continue participation in a group, such as the MOST-TR program, and the quality of this participation is impacted by additional factors.

The critical components of self-management are learning information, sharing experiences, and practicing self-management skills; doing so in a group environment with peers, rather than individually with a healthcare provider, adds further beneficial therapeutic effects. Groups were initially implemented to save time in educating patients, but it was soon recognized that there was therapeutic value within a group format due to the interactions among group members.⁵⁸ Kurt Lewin, a social psychologist, investigated the dynamics of groups and observed that it is usually easier to change the behaviours of individuals within a group, than to change the behaviours of each of the individuals separately.⁵⁸

The psychological benefits and therapeutic factors of groups have been well defined.⁵⁹ These benefits assist the individual to make personal changes but are additionally impacted by the group's cohesion. Yalom defined group cohesiveness as the product of three factors: the individual's perception of the value of the group; his perception of belonging to the group; and his perception of being valued by the group.⁵⁹ It is important that members of a group feel they are making a contribution to the group. The facilitator's ability to guide and encourage the discussion among the group is important to each member's participation, his ability to make positive changes, and his ultimate independence of the leader.^{58,60} Members who drop out of a group are usually those who feel the least sense of cohesion. Within a highly cohesive group, members will try harder to influence one another and be more willing to listen to and accept suggestions from others.

In addition to the skill of the group's leaders, the purpose of the group, the duration and number of sessions of the group, and the setting of the group affects group development and cohesion.^{58, 59} This last factor, setting, is of key interest within the context of MOST-TR, one group, in three geographically separate sites, connected via videoconference. Sub-grouping, or splitting off into smaller units, has been identified as one potential barrier to strong group development and cohesion.⁶¹ Although sub-grouping is often described as a barrier to the group's cohesion, it can be perceived as either helpful or harmful to individuals within the group. In some instances, sub-grouping may permit a more connected interaction with a smaller portion of the group. At other times, sub-grouping can result in an 'us versus them' situation.⁶¹ This sub-grouping phenomenon is of particular interest when imposing the videoconference environment onto a group, as there is a high potential for each geographical videoconference site to form a sub-group.

There is a high correlation between group cohesion and the participant's perception of his or her ability to make behaviour changes. The impact of delivering MOST-TR via videoconference, to three geographically separate sub-groups of participants, on the group's development and cohesion and ultimately the participant's goal of behaviour change must be considered.

2.5 Videoconference Impact on Groups

The impact of videoconferencing on the development and cohesion of a group is of utmost interest since these elements are critical to the success of the group as a whole and to individual behaviour changes. Meier has extensively examined the interactions between two groups using videoconferencing in a business context.⁶¹ In Meier's research, the two groups were well known to one another as members of a standing committee which met weekly for approximately four hours with the expectation that group discussion would lead to a group

decision. The members agreed to use live, synchronous, two-way videoconferencing to conduct these meetings. Group interactions during one videoconference meeting were analysed to explore the group processes, the social context of turn-taking, communication styles, group dynamics, and meeting content. Communication was observed between individuals within a site and across sites, as well as across the group as a whole. Findings revealed some impact on the group meeting due to the audio and visual limitations of the videoconference technology. The audio lag affected the smoothness of the conversation, especially turn-taking. Turn-taking at one site appeared smooth, but overlapped at the other location. Visually, the inability to make direct eye contact and the inadequate ability to interpret subtle facial actions made it difficult for the group to monitor the activities at the other site. Findings of the study showed that laughter and having fun did not appear to transmit well between sites. As found in other research, gaze, gesture, and body language lost much of their power for coordinating interaction in video-mediated encounters.⁶² Considering that it is postulated that only 7% of our communication is transmitted by the words themselves, with 38% being transmitted by tone of voice and an astounding 55% being transmitted by body language, it is important to appreciate the communicative limitations of videoconferencing technology.⁶³ Heath and Luff⁶² describe how people are relatively insensitive to what they see on camera. They report that the visual feedback is helpful and even necessary for appropriate turn taking in conversations and the flow of a meeting, just not enough to simulate an in person experience.

Overall, Meier's study showed that a local solidarity dynamic emerged, meaning that members of the local onsite group felt a bond, but not the group as a whole. In conclusion, Meier found that videoconference environment in this business context was a particularly difficult environment for establishing a sense of "groupness." The technology impacted the group by producing uncoordinated turn-taking transitions and there were difficulties with hearing if the

conversation was not directed to the entire group. As a result, the ability to achieve the focus of attention in the videoconference environment was fragile.

In a different context, Van Ast and Larson⁴⁰ used videoconferencing to offer a caregiver support group. Based in Perth, Australia, two healthcare facilitators connected with multiple sites throughout rural Australia. Membership in the support group fluctuated depending on the needs of the caregivers. The support group met for two hours each month. The group found great satisfaction with videoconference interaction.⁴⁰ Several participants commented that it was like having the presenter in the room. In fact, this caregiver group even reported a preference for the videoconference connection as compared to face-to-face interactions. They reported finding it easier to speak and have group discussions without the immediacy of a face-to-face connection. Participants reported that any dissatisfaction which occurred when connecting with multiple sites was improved by simply switching to a continuous presence connection. The main factor contributing to the success of the Australian group was reported to be the facilitator's interaction and connection with all participants of the group, regardless of the site from which they participated. The group of Australian caregivers felt that the ability to share with one another was the most valuable part of the videoconference connection.

The findings of this support group study contrast with the findings of Meier's business context study. Whereas Meier reported videoconference to be a difficult environment to establish group cohesion and connection, the caregiver group reported great satisfaction with the technology and even a preference for videoconference interaction over an in-person experience. It is important to note that the expectations of the business meeting participants were likely to have been quite different from the expectations of the support group participants. The business group expected to have the same high level of interpersonal understanding that is possible in face-to-face meetings where one has access to facial expressions and body language clues in order to make group decisions, and found the videoconference environment limited this. The caregiver

group was unconcerned with making collective decisions and was likely participating to decrease his or her sense of isolation and loneliness. In this situation, it was important to be able to talk to others in a similar situation who would not judge each other or have expectations about his or her performance. Consequently, they actually preferred being at some distance from those to whom they were talking, lessening the likelihood of being judged negatively. Satisfaction with videoconferenced meetings appears to depend on the purpose of the meeting, and it needs to be recognized that not every participant is going to understand that purpose the same meeting in the exact same way.

Many studies to date have limited their investigation of videoconference experiences to provider perspectives.²⁵ Studies exploring client experiences have typically studied client satisfaction using survey methods and have focused on the technological component.^{18-20, 25} The feasibility and effectiveness of the videoconference delivery of MOST-TR, a stroke self-management program, was evaluated in a larger randomized controlled trial; however, the larger study did not specifically examine the rural participants' perceptions of their participation in the MOST-TR program. Even though rural stroke survivors are motivated to participate in the MOST-TR program, it is unclear whether and how their experiences and perceived benefits differ from those who are in the same room as the facilitator and the majority of group participants. Peer-support is a critical component of MOST and group development and participant involvement is crucial for the success of the program.²⁷

The use of videoconference technology in a self-management group delivery warrants further investigation. Therefore, individual in-person interviews were conducted with remote participants to explore their experience as participants of the videoconferenced MOST-TR program.

Chapter 3: Methods

Qualitative research is a process of exploring social human problems using inquiry methods in a natural setting. It is able to provide both an overall picture and a detailed report from the perspectives of its informants.^{64, 65}

The objectives of this research were:

1. To learn about factors which enabled participation and involvement in the Moving On after Stroke Telehealth Remote (MOST-TR) program;
2. To learn about barriers to participation and involvement in the MOST-TR program;
3. To learn about participants' overall satisfaction with the MOST-TR group intervention;
and
4. To learn about participants' perspectives regarding what technological, educational and/or interpersonal strategies may enhance the delivery of videoconference-based group programs.

A program evaluation design using qualitative, semi-structured interviews was used. This methodology is well suited for answering these research questions, because qualitative methods allow the researcher to learn about human experience, the social world, and the interaction between the two. Qualitative research can generate qualitative description, rather than quantification or numerical categorization of the world.⁶⁶

3.1 Reflexivity

The interactive nature of the relationship between the researcher and the participant is recognized as one key feature of qualitative research. The data are shaped by the attitudes, values, and experiences of both the participant and the researcher, the relationship between the

researcher and the participant, and the situation, or context of the interview itself.⁶⁴ As Rossman and Rallis⁶⁴ (p. 5) discuss, the researcher is the means through which the study is conducted. The researcher can never be truly objective or unbiased.^{66,67} The researcher's previous experiences, attitudes, relationship with the participants, and beliefs all affect the gathering of the data. For these reasons, the researcher needs to be aware of her own personal attitudes, values, and experiences as they relate to the research question and the data collection.

Reflexivity refers to the notion of the researcher being aware of her own identity while seeking to critically examine and iteratively analyze how this affects the research process: the design of the research, data collection, interpretation, and narration of the findings.⁶⁸ A discussion of reflexivity is a strategy to add credibility to qualitative methodology. This involves the researcher disclosing information, values, and assumptions about herself, so that she and others can be aware of how the research is influenced by her social location.

This research is fundamentally shaped by the fact that I am a physiotherapist. I consider healthcare and rehabilitation to be positive influences for people following stroke. In fact, I regard timely healthcare as not only a positive, but critically necessary for well-being. I believe appropriate rehabilitation should be an expectation of every Canadian who has experienced a stroke, regardless of their geographic location, socio-economic status, age, or race. I am also aware that due to the vast geographic distances and the population distribution differences within Canada, equal access to healthcare is a tall order and may not look exactly the same at all locations.

Although I have never been the recipient of videoconferenced healthcare services, I provide physiotherapy rehabilitation services and community reintegration programming via videoconference as a healthcare professional. I am a trained MOST facilitator and have facilitated 15 MOST groups over six years. I have witnessed many participants of the MOST program resume work, travel independently, become active participants in a relationship, resume

household duties, and take responsibility for their own personal health and well-being. Many MOST participants, both stroke survivors and their caregivers, have reported benefits from the information, the exercise, and the ability to practice the skills of setting goals and seeking resources; but mostly, they have indicated experiencing a sense of relief to discover there are others in a similar situation and they felt supported by these others. For these reasons, I am biased towards believing that it is important for a program such as MOST to be offered by videoconference so that stroke survivors in remote locations can benefit.

I have experienced differences in my own participation and learning during educational sessions delivered via videoconference. These experiences have led me to wonder about the perceptions of participants in the videoconferenced MOST sessions.

My comfort with videoconference technology influences my research quest for perceptions, barriers, strategies, and solutions. My comfort with this technology has given me the ability to deliver the MOST program using videoconference technology with some success. Without considering it a panacea, I embrace the technology because of the positive outcomes I have experienced. I imagine that my enthusiasm for the technology is obvious to research participants, and I can only hope that they trust me enough to feel comfortable telling me about their fears, challenges, and barriers to participation due to the technology.

3.2 Research Design

Rossmann and Rallis⁶⁴ (p.182) describe interviewing as: “a crucial way to get rich, detailed data about how people view their worlds.” I felt that this was the best method to gather experiential evidence for the purpose of understanding the participants’ experiences.^{64, 69}

To learn about the experiences of the remote MOST-TR participants, I conducted in person, semi-structured interviews.^{64, 69} Semi-structured interviews are based on an interview guide, but permit and encourage flexibility in order to allow for the impromptu exploration and

elaboration of participant experiences.⁶⁷ Categories or topics are introduced in the form of broad, open-ended questions to encourage participants to share their experiences from their own perspectives.⁶⁴ Clarifying or probing questions can be used to encourage participants to provide more detail. In a semi-structured interview, the researcher needs to be active in her listening and be open to new information that may at first seem less relevant to the research question. Rossman and Rallis⁶⁴ say it well: “Keep the questions open-ended to foster exploration and discovery” (p.131). The balance of talking should always favour the participant.⁶⁴

I designed an exploratory interview guide (Appendix A) intended to elicit a narrative of the experience of participating in a group self-management program via videoconference. The interview guide focused on four areas: previous experiences with groups or videoconferencing; participation in the discussion portion of the MOST group session using videoconference; participation in the exercise portion of the MOST group session via videoconference; and factors enabling or limiting participation in the group.

After developing the interview guide, I piloted it with two local participants. I made revisions based on feedback from the pilot participants. This draft guide was then discussed and further revised with input from my thesis supervisors and then used during the interviews. During each interview, I used a method of constant comparison. This involved continuously comparing new information with previously collected data and modifying the interview questions accordingly for ongoing data collection.⁷⁰ After each interview, the data were reviewed and summarized with the participant so that each could confirm or refute what was said and clarifications were made as required. As well, immediate reflections by myself were noted with the identification of possible new patterns. Data were transcribed, coded and analyzed and compared with existing data. The interview guide was modified to reflect any new patterns or emerging data. As such, this iterative pattern of constant comparison intertwined the data collection and data analysis processes. In order to prepare for each subsequent interview, this

process of data collection, interview review with the participant, immediate reflections, data transcription and formal coding, and thematic analysis or labeled categorization was repeated.

After the third reading of the first four interview transcriptions, I realized it would be useful to add additional questions to my interview guide for all subsequent interviews. These new questions included asking about perceptions of the role of local volunteers and a planned face-to-face meeting which had been suggested by other participants during data collection. Although this meant that some questions were asked of some participants but not all participants, this practice is condoned and even encouraged within the flexible semi-structured interview style of qualitative research, and subsequently adds to the richness of the data.⁷⁰

3.3 Ethical Approval

Ethical approval was sought either as an amendment to the larger MOST-TR study, or as a separate study, depending on the particular ethics review board's guidelines. Ethics approval was received from all participating sites: Lakehead University, St. Joseph's Care Group in Thunder Bay, Thunder Bay Regional Health Sciences Centre, Baycrest in Toronto, Lake of the Woods in Kenora, Sandy Lake First Nation Chief and Band Council, Dryden Regional Health Centre, Riverside Healthcare Facilities in Fort Frances, Meno Ya Win Health Centre in Sioux Lookout, Wilson Memorial Hospital in Marathon, and Manitouwadge District Hospital (Appendix B). Each participant was given a small token of thanks for participating in the study such as coffee or a jar of jam.

3.4 Participant Recruitment

So that I could learn about a diversity of experiences and perceptions, I originally sought to recruit participants from four of the remote sites that were part of the MOST-TR program. I sought community-dwelling participants who were either stroke survivors between three to

eighteen months post-stroke or their caregivers, and had completed inpatient or outpatient rehabilitation programs. As well, I sought only those participants who had completed the MOST-TR program and had had some time to reflect upon their experience, but it was also important that their participation had been recent enough that they would be able to remember vivid details of the experiences.

To achieve the optimum range and variability of experiences, I selected participants using purposive sampling.^{66, 69, 71} Beyond my interest in sampling participants from different sites, I was especially interested in sampling from sites where more than one stroke survivor participated as well as sites where a participant was alone. My sampling frame included women and men, younger and older participants, quieter and more active participants, stroke survivors and caregivers. In addition, I took care to select participants who appeared to have had both positive and negative experiences with the program as well as some who dropped out before completing the program. To keep the research manageable, I decided I would recruit a maximum of 10 participants.

In March 2007, I drafted an initial list of potential participants from the four participating sites. Hoping to recruit 10, I sent a letter to 15 potential participants in May, 2007, inviting them to participate in the research (Appendix C). I wrote the letter using Lakehead University letterhead to differentiate the study from MOST-TR and to highlight my role as a graduate student conducting research. Once the participant indicated interest in the study, I telephoned to set up an interview date, time and place. Of the 15 people invited, eight agreed to participate from three of the four sites. As the agreed-upon date approached, I also telephoned to remind them about the interview.

During the summer of 2007, two new remote sites were added to the MOST-TR program, and I wanted to include participants from these sites as well. During the fall of 2007, I invited all

eight people from the new sites to participate in my research and followed the same contact protocol described above. Seven of these individuals agreed to participate.

In the spring of 2008, the addition of more sites participating in the MOST-TR program meant that I had the opportunity to recruit more participants which provided an even more diverse sample than I had originally anticipated. One of the new sites, for example, was a remote First Nation community. After I conducted a preliminary analysis of data collected from the first 15 participants, I concluded that the addition of a few more participants might allow me to reach data saturation. Following the same contact protocol described above, I sent invitations to all four participants from the new sites, and all agreed to take part. The inclusion of these last four participants allowed me to reach data saturation.

3.5 Participant Characteristics

Of the nineteen people participating in this study from across six sites within NWO, 12 people were stroke survivors and seven were caregivers. All of the caregivers were spouses of the stroke survivor. There were nine women (three stroke survivors and six caregivers) and 10 men (nine stroke survivors and one caregiver). Their mean age was 66.2 years, 67.3 years for stroke survivors (age range 48-84) and 64.4 years for caregivers (age range 48-76). Fifteen appeared to be of Caucasian background, and four were apparently of First Nations background. Appendix D provides a brief description of each participant. The average time between the interview and the onset of the stroke was 19 months (SD 7.15), ranging between 7 and 34 months. The average time between the interview and the completion of MOST-TR was 3.2 months, ranging from less than one month to 15 months.

Of the research participants, three were the sole participant at their remote site, three people participated in a local group of two, four people participated in a local group of three, two people participated in a local group of four, and six participated in a local group of seven. The

nineteenth participant was a caregiver who participated infrequently in the actual sessions. Unfortunately, the two people specifically invited to participate in the study because they chose to discontinue the MOST-TR program prior to completion, did not agree to participate in this study.

3.6 Interview Process

After gaining informed consent, (Appendix C), I conducted interviews throughout the summer and fall of 2007 and spring of 2008. All but four interviews were completed at the participants' homes. For reasons of mutual convenience, one was held at my workplace in Thunder Bay and three were at the remote videoconference site.

I offered to conduct the interviews at the participants' home if they were agreeable to that. I felt that it was important that the interview be in person and in their community. For many people in NWO, services are often only available in Thunder Bay and I wanted to show some consideration and genuine interest by coming to the participants and experiencing their community.

Rossmann and Rallis⁶⁴ (p.152) state: "The more familiar the participants are with the researcher, the more they trust him [*sic*] and are willing to share their feelings and knowledge." I had already established rapport with all the participants interviewed as a result of our relationship in MOST-TR. Throughout the eighteen MOST-TR sessions, I felt that I got to know them quite well, but I had not met most of the rural participants in person. There were a few exceptions of participants who I had met in person prior to the interview. These exceptions are noted in the participant descriptions in Appendix D. The rapport developed throughout our MOST-TR videoconference relationship carried over into the planning and the beginning of the interview. I felt this familiarity and sense of trust had a positive impact on the interview, but I was also cognizant of an inevitable perceived power differential during the interview.

The interviews lasted between 30 and 60 minutes. Most of the interviews took place mid-morning or early afternoon. Interview times were selected to accommodate my traveling to the community, with particular interest in scheduling multiple interviews over a period of one or two days. Two communities required air travel. On one occasion, the interview took place in the early evening.

Upon arriving for the majority of the interviews, conversations with participants started with a jovial re-acquaintance or overjoyed expression to see one another in person for the first time. Participants were very open and reflective during the interviews. They often felt comfortable enough to share both strengths and barriers of the videoconferenced program and made suggestions to improve the ongoing delivery of the program.

During each interview, I trusted that my audio recorder would capture the dialogue successfully and I took very minimal notes in order to fully focus on the conversation. I focused on the answers the participants provided and the flow of the questions that I had asked, whether to probe further, explore a new concept, or shift to the next line of questions from the guide. A detailed description of the interview process from my first interview is attached as Appendix E.

3.7 Approach to Data Analysis

After each interview, or pair of interviews, I sat in a comfortable, quiet place, downloaded the audio files, wrote notes about my personal reflections on the interviews, and captured my overall thoughts about the interview content. Throughout the process of data collection and analysis, I kept a folder and a notebook to write my thoughts and reflections about the topic.

Interviews were subsequently transcribed verbatim by a professional transcriptionist. I then reviewed each transcript, corrected inaccuracies, and re-read the corrected transcript to absorb the data.

After that, I then began a qualitative description analysis^{64, 71, 72} with the outcome being “a descriptive summary of the informational contents of the data organized in a way that best fits the data” (p.339).⁷¹ To facilitate analysis, I first created summary sheets for categories of supports, barriers, group experience, stroke experience, and videoconference experience, manually inputting summary sentences and quotes from the data. When this process became too cumbersome, I switched to using the qualitative data management program NVivo⁷³ to assist with category creation and coding, and coded the data using preliminary categories from the interview guide.⁶⁴ I created new categories as required.

Segments of text were organized by codes across all interviews and immediate notes following the interview.⁷⁴ Data were retrieved by code and each code was read for patterns in the data.⁷⁴ I then reviewed categories and grouped them based on common features and patterns emerging from the data to summarize the contents of the data. This process can also be referred to as labeled categorization.⁶⁶ During this review, I wrote summaries of each code and highlighted “good quotes.” Patterns were categorized and described, sorted and resorted until the findings were grouped in an organized manner. Although this process is described in a linear fashion, in actuality, the process of analysis and reading and re-reading of the data was very reflective and iterative in nature. Once the analysis was complete, I reviewed the coded transcripts to ensure that the categories reflected the original data. A final review of the original transcriptions was done to make sure that all pertinent information was included.

3.8 Limitations

It is important to recognize the limitations of this study. Firstly, there is an inevitable power differential between the participants and myself as a healthcare professional. This affected who agreed to participate in the study. Indeed, this study included only participants who had completed the program and had positive experiences.

I had already established a certain rapport with potential participants on account of having worked with them as one of the MOST-TR facilitators. Those with whom I had established a positive rapport may have been more likely to participate in this study than those who did not feel a personal connection with me. It is also possible that some felt obligated to participate because of the power differential, even though all potential participants were assured that they were not obligated to participate. By the same token, those who did not complete the MOST-TR program, although invited, chose not to participate in this study. Due to limited contact, I was unable to establish a pre-existing rapport with these “drop-outs” and this may explain why they showed no interest in participating in the present study. This is unfortunate, because it is possible that those who dropped out of the program were particularly dissatisfied with the videoconference environment. As the literature confirms, ongoing participation is correlated with a sense of belonging to the group and group cohesion.^{58, 60} As such, the participants in this research are not representative of all potential participants. The findings therefore reflect a positive bias of satisfaction with the videoconference connection, group connection, and successful participation in the program.

In addition, the power differential between the participants and me as a healthcare professional affected how participants responded to the questions asked of them and additionally how I interpreted the data. Because participants had first met me in my role as their physiotherapist and MOST-TR facilitator, they may have been reluctant to fully explore the role of the facilitator as a factor in their engagement and participation. Indeed, I felt during the interviews that participants related to me as a healthcare provider. Consequently, there was the possibility that the participants felt the need to please me as the MOST-TR facilitator and interacted with me as a physiotherapist, and so may have found it difficult to critically evaluate my facilitation skills or other aspects of the program.

Lastly, it is not possible to generalize the findings beyond the study participants; although the findings may nevertheless be suggestive of issues for people participating in group-based videoconference programs. While the data reflect the thoughts of a diverse group of people, they were ultimately a non-representative sample of MOST-TR participants. The findings cannot be extrapolated beyond this context.

It is important to note that the focus of the interviews was to understand the impact of the videoconference delivery of the MOST-TR program for the remote participants, connected with the face-to-face group in Thunder Bay using videoconference technology.

3.9 Conclusion

Qualitative methods are well suited for this study as they are best able to describe human experiences and the social world. These methods are able to capture or explore the essence of a perspective or an experience in ways that survey methods or numerical categorization just cannot do.

Nineteen stroke survivors and caregivers participated in in-person, semi-structured interviews exploring their perceptions of the MOST-TR group experience. All had completed the MOST-TR program, and all had developed a positive rapport with me as a result of their participation in the program. Participants explored their satisfaction with, and barriers and strengths to their videoconference participation in MOST and made suggestions for improvements to group delivery of programs using videoconference technology. Interviews were transcribed verbatim and subsequently analyzed using qualitative descriptive analysis.^{64, 71, 72} Throughout the process, I strived to be reflexive, flexible, and non-judgmental to all perceptions. Participants were very open and thoughtful during the interview process and provided both positive and negative perceptions of the experience while at the same time providing valuable suggestions for ongoing group videoconference programming.

The following chapter is my representation of the data as presented by the participants during the interviews.

Chapter 4: Findings

In general, the participants offered both positive and negative comments regarding their perceptions about the videoconferenced group experience. Categories emerging from the data included: accessibility and distance; experiences of videoconference participation in a group; experiences of group involvement across videoconference; and supporting strategies and future suggestions. Table 1 provides a summary of the findings.

None of the participants reported previously being involved in a support group of any kind. Seven participants reported using telehealth previously: one for distance education; five for physician consultation; and one used a webcam to communicate with his grandchildren. Twelve of the participants had never used telehealth or participated in a videoconferenced meeting prior to the MOST-TR program.

In order to ensure anonymity, the names of all participants are referred to by pseudonyms. Further information about the participants is available in Appendix D, where they are listed alphabetically, however, to further ensure participant anonymity, composite descriptions of the participants were constructed, using the following strategies: age and location changes, ascribing details that belong to one case to another, deleting some biographical data, and fabricating inessential details. In excerpts from the interviews, “Denise” refers to me, the interviewer.

As discussed in the methods section, the general atmosphere of these interviews was positive and friendly, and most were conducted in the participants’ homes. Participants were very open and reflective during the interviews. An in depth description of the context of the first interview is included in Appendix E.

4.1 Accessibility and Distance

The participants indicated that due to their geographic location, they had come to expect that access to healthcare services required them to travel long distances, and to sometimes face delayed services.

Jennifer I think you have to do it [travel] when you're in remote areas. The videoconferencing is much better than the traveling to Thunder Bay.

Rosemary Well the cancer doctor was supposed to come last, last month, but it was so foggy that day, you couldn't even see the lakeshore. So it was cancelled now 'til November.

The advantages of using videoconference delivery were discussed with each of the participants. Not surprisingly, participants commented favourably on the ability to access the program without having to travel long distances. All participants appreciated the ability to participate in the MOST-TR program and recognized that due to the nature and length of the program, their participation was only possible because it was delivered using videoconference technology.

Martha It's better than telephone, and it's better than driving to Thunder Bay.

Laura Certainly for me it's wonderful. You don't have to travel, four and half hours, to go. I mean we'd never be able to do it.

For these people living in rural NWO, telehealth and videoconferencing improves their ability to access health services.

4.2 Reflections on how Videoconferencing Affects Participation

Participants reflected on their experiences in participating in a group across videoconference and the enablers and barriers regarding their participation. This overarching category has been broken down into three sub-categories: the influence of the technology; the

impact of videoconferencing on participation in the discussion; and the impact of videoconferencing on participation in the group exercise.

The Influence of Technology

The ability to both visually and audibly connect with others via videoconference was noted by participants as a supporting factor to their participation. Participants commented on the advantages of having an ongoing, live video connection compared with the telephone:

- Denise So you could relate with the people?
Tim Oh yeah.
Jennifer By seeing them.
Denise By seeing them? That made a big difference as opposed to just a phone call?
Tim Oh, I guess phone call would be, would help but it's not the same. Like you know, when you're talking to somebody person to person, that's better than talking to a person on the phone.

One participant actually had the opportunity to participate in three different ways: regularly via videoconference, once in person, and on two occasions with telephone connection only because the local videoconference system was out of service.

- Denise What was best?
Paul Well, live, then on TV. But the worst part was on the phone, you can't hear. Can't really hear anybody because of all the background noise.
...
 The other people I could, I could relate to. The background. They were trying to talk. As long as they said their name.
Denise Okay. So, on the phone it was better if they said their name first.
Paul Yeah.
Denise But when we were on videoconference, did you think that they needed to say their name first or you could see who it was?
Paul I could see who it was.

Although all participants reported the ability to see the room and the participants on the video screen, the quality of the video output was not comparable to an in person experience. Even with the videoconference system's high resolution of 384kb, facial details and subtle facial expressions were difficult to discern. One example of this limitation was discussed during the interviews. During one session, one of the distant site participants had an obvious red rash over

his entire face due to an allergic reaction with the sun. At one point during that session, there was a local discussion about his inability to walk outdoors because of the allergy to sunlight. The facilitators, however, could not see his rash using the videoconferencing technology.

The visual limitations of videoconferencing were also evident when meeting someone for the first time across videoconference, rather than in person. It seemed that when there was a preliminary face-to-face interaction, visual memory of the person made up for the limitations of the technology. This was not the case when the initial meeting took place via videoconference. This became evident when I interviewed a couple whom I had not previously met in person.

Tim ...In Thunder Bay, you only saw half the people I think and we never have a close up.
Jennifer If we were ever in Thunder Bay, we would never meet them... like even you, when you came in, I would never have recognized you off the TV, in person ...
Denise No I agree with you!

From my notes immediately following the interview:

I was comfortable with them [Tim and Jennifer] but not as much as I had thought I would be. They did look slightly different than I had envisioned them on the videoconference and they also commented that they wouldn't have recognized me from the videoconference itself. Very interesting!!

The visual representation of the group was also limited by the size of the television monitor. All sites had 34" television screens at a minimum. Some sites had two television monitors permitting a view of the far sites on one monitor and the local site on the other monitor. Sites with only one monitor saw the far sites in full with a small inset of the local view. At the Thunder Bay site, there were two monitors, a widescreen 42" size monitor showing the far sites, and a 20" size monitor showing the local site. Simon commented on the better visual representation with the larger sized monitor when he was visiting Thunder Bay:

Simon But it was such a difference when we came to your site and we could see the people in [location of distant site], and they looked like real people, not just midgets on a TV screen.
Denise ... that is really disappointing.
Simon So that's technology. Yeah Well.

Based on participants' feedback during the program, the facilitators started to adjust the camera to zoom in on participants when they were speaking. Unfortunately, the facilitators were not able to zoom in to focus on each distant site participant in the same way, as the technology is not capable of controlling the far cameras when connecting with multiple sites. Unless one of the participants at the distant site was comfortable and competent using the camera remote control, the view of the far site was of the whole group. Consequently, the participants at the Thunder Bay site were unable to get an accurate, close-up visual representation of each rural participant. Although some participants were comfortable controlling their site camera, it was not an expectation. Some participants acknowledged that they felt "a bit overwhelmed" by the technology.

Even with the use of camera pre-sets, the videoconference camera limited the visual connection with the whole group and participants' ability to read subtle facial expressions, body language, and gesture. Henry talked about being frustrated that he could not look where he wanted to, in the distant rooms. He felt that a live situation would be more dynamic, permitting his eyes to wander around the room focusing on other participants in the group rather than always the speaker. Within the videoconference environment, however, he could not do that because the camera chose his focus:

Henry The interaction was, you know right there. And yeah, you can look at the videos. However when you're looking at the TV screen, you're not really seeing the people in your group. And, and at times I, I wasn't, I would catch myself just looking, because when I'm at a meeting, I don't look just at the speaker, I look at the people...

Even with the limitations expressed, participants were asked if they ever had the feeling of being in the same room with the group, even though they were at a remote site. Ten participants said they felt as though they were in the same room at one point during the program. One participant explained:

Rosemary I had no problems with being in a remote area, and being away from the core group.
Denise Okay. You didn't feel that there was a difference at all?
Rosemary Oh, I felt like I was right there with you's [pause]. It was good. It was just like we were there. It was just like we were there. I was amazed.

For David, who participated alone at a rural site, the feeling of being in the same room was more sporadic and fleeting:

David Well actually, there was a couple of times I felt like it was really close, you know, it was really close, That big huge television set and obviously... it takes you back to reality. But no, there were a couple of times where that barrier felt like it was kind of not there ...

For others, that feeling of being in the same room never occurred. Rather, they felt that there was always a distance between the sites, although this did not impact their ability to communicate with those at other sites.

Denise Did you ever feel at any point that you felt like we were all in the same room?

Martha Well that never entered my head, because I knew we weren't. ...
But uh, that didn't make a difference.... I mean we could talk to you, we could talk to her.

Denise Did you ever feel like you were in the same room with us?

Tim I never thought of it that way.

Denise No? Did you ever forget that there was the TV and just feel like we were all together?

Tim I can't say, that I [laughter]

Jennifer I can't either. I, I think that we were, well no, I can't say that we were in the same room, because there'd be talking going on in Thunder Bay, that we didn't know anything about. So you know, we weren't part of, and [pause] you never did feel that you were in the same room.

Jennifer Yeah, you could tell the difference. You know, eh, I mean there is a distance feeling through telehealth. But, I mean I don't know if it would make a major thing, but I, I do think that things are really better when you're just around the table.

Some of the participants had an unexpected opportunity to participate in a MOST-TR session in person in Thunder Bay, when they were in the city for personal travel. One participant talked about his positive experience meeting the Thunder Bay group in person for the first time:

Vic Even when we, me and [my wife], went there, like I didn't feel any [pause]. Like everyone looked the same eh, pretty well, like. It wasn't bizarre. It wasn't like you were meeting us for the first time.

Similarly, another participant explained feeling as though she had already met the group in person:

Denise How was that ...when you came and met us all in person?
Leila Well it was like I already knew you's very..
Denise Okay.
Leila That's the way I felt, when I walked in, I just felt, like, we were old friends.
Denise Okay.
Leila We had spent the last how many months together.

And Simon commented on a similar experience:

... like I'm telling you first names of people, that yeah, I did meet them once because I happened to be down there. But since I saw them every week, I felt they were almost like friends.

In summary, side conversations and informal socializing at the other sites contributed to feelings from some participants that they were not in the same room, regardless of the visual and audio synchronicity. Participants reported that videoconference technology was superior to a voice-only telephone connection but had limitations when compared to a live, in person, group experience. Those participants that did have the opportunity to meet in person noted that the rapport established within the group via videoconference was transferable to the in-person experience of meeting the group. They reported that it did not feel as though they were meeting the group for the first time, when in fact it was the first time in person.

Although participants spoke positively about their overall experience with the program and appreciated that the program could be accessed via videoconference, they agreed unanimously that if possible, they would rather have participated in the MOST program in person, delivered locally, rather than across videoconference.

Denise One of the things that I, I think we can strongly say is videoconference is a wonderful technology and it certainly increases a lot of opportunity, it certainly is never going to replace face-to-face.

Simon No. We do a video cams with our grandchildren, but it's not going to replace that fun. Having fun with them.
Denise You can't give a hug across video cam.
Simon No, you cannot.

Impact of Videoconferencing on Participation in the Discussion

Most people said that although they were able to participate in the discussion portion of the session, they would have participated slightly differently had they all been in the same room with one another. As Leila put it:

...probably we would have felt, I would have felt, more at ease with the talking [if I was in the same room with everyone].

Paul talked about his own limitations in participation across videoconference, having the time to talk and share his thoughts without feeling like he was interrupting another participant:

Denise What about on the videoconference, on the TV, did you find that you didn't talk quite as much?
Paul No, not as much. Not as much as I wanted to.
Denise Not as much you wanted to. What made you not talk as much as you wanted to?
Paul Well there's a, there was other groups that I wanted to listen to.
Denise So, did you feel like it was hard to jump in and be in the conversation?
Paul Yeah, like, like when I talked to them, that conversation stopped, and I didn't want to do that to them.
Denise You didn't want to. So you didn't want to say something because it, you might cut off what they were saying?
Paul Yeah.
Denise And you were being polite.
Paul Just a, just to hear there what they have to say.
Denise But if you were physically in the room, say you were down in Thunder Bay, you think that you would have done more talking?
Paul Yeah.
Denise That's really interesting too. Do you think there's anything that Elizabeth and I [facilitators] could have done to make sure that you had that chance to talk?
Paul No well, not really.
Denise Did we invite you to talk enough?
Paul Not as much.
Denise Not as much. So maybe if we could have done that that would have been a little bit better?
Paul Yeah.

Other participants felt they were given plenty of opportunity to discuss things with the group and their personality, more so than the videoconference technology, impacted their participation, or lack thereof, in the group discussion

Most of the participants reported that their participation in discussions was negatively affected in some way by being at a remote site, although they had no means of making a comparison with a face-to-face session. However, one participant, Donada, was able to attend a session in person in Thunder Bay. She compared that experience to her usual experience of participating via videoconference. Unlike her husband Paul, or Leila, Donada felt it was easier to talk across the videoconference and found she actually talked less in person.

- Denise Like the day that you came [in person], did you find yourself that you talked more or less, or the same?
- Donada Less.
- Denise Less. You actually talked less when you were in person?
- Donada Yeah.
- Denise Really!
- Donada I talked less than on the video.
- Denise On the videoconference.
- Donada Yeah
- Denise Okay. So you're it's easier to talk when you're not in person?
- Donada Yeah, yeah.
- Denise Why do you think that is?
- Donada Don't know.

Arianna talked about wishing that she had seen the group in person rather than only via videoconference, and she felt that would have made a difference to her participation:

- Denise Why do you think it's easier to talk to people when we're all in one space?
- Arianna Well, it's more better like a... I find it's funny if I'm here and if you're way out there and someplace, you know, TV and all that. And you can't see, eh, you could see on TV, but you can't... Feels funny talking to, you know a TV?
- Denise It does. It still, feels a little bit funny.
- Arianna Yeah, talk to the TV and you wish you were there sitting, with all the, seeing everybody.

Most participants said that participating via videoconference limited their ability to participate in discussions. It was reported that participants felt they always needed to talk

through the facilitators, rather than directly to one another. One person, however, said that using the videoconferencing technology made it easier for her to participate in the discussion.

Impact of Videoconferencing on Participation in Group Exercise

The facilitators led the exercise portion of each session using both verbal descriptions and demonstrations and provided feedback to participants as required. The participants were asked to share their experiences and perceptions of the impact of videoconferencing on their exercise participation. Participants reported they were comfortable with the exercise experience:

Simon Safety? No because uh, with our group anyway, you focused on yourself, and illustrated it very well... I think you or Kathryn [facilitators] illustrated it well... So no, I don't think there was a safety issue, and I, and I think you, you illustrated it well enough, that it eh it, it works.

Participants talked about being motivated by the group, and appreciated the exercise direction:

Vic I just, I'd just like [pause] being like told stuff, uh, I would never have done all those exercises.
Denise On your own.
Vic On my own, right.
Denise So even though we weren't in the room, we were still able to be that person that says okay, we're all going to do this now, even though it was across videoconference.
Vic It's the same thing.

Another participant commented on the benefits of camaraderie during exercise:

Judy It was always more pleasant when you're in a group.
Denise It's more fun.
Judy Definitely.
Denise And did you feel that it was more pleasant because you were in that group even though the group was across videoconference?
Judy Oh yeah.
Denise So, we got that group benefit. You knew that it was okay to exercise because you had to meet with us and we were all going to do this painful exercise together.
Judy Yeah, yeah, yeah.

The exercise component was well received and most participants found it equivalent to participating in person. However, two participants reported negative experiences with the

exercises across videoconference. Both Doug and his wife Martha talked about frustration with the exercises and the difficulties he had following the instructions and keeping up with the group:

- Doug No that was funny, that exercise thing. I couldn't seem to keep up. And then that, that was what, I was all the time trying to keep up with what the exercises that were going on and I felt 'what's the matter with you? Why, why don't you? Is it you're not interested? Or you don't think it's doing any good?' or all these kind of things were going through my mind. And uh, that was the main thing, that I thought, somehow I'm not being able to catch up. That was one thing that really irritated me was, not [pause]. It was my fault, because I couldn't catch up, couldn't keep up. I was watching it sometimes and thinking and let's see, that so and so, and by the time I thought that out, [laughter] something's, eh, something else was going on.
- Denise Could you see us okay?
- Doug Oh yeah. No problem.
- Denise You could see us okay, eh? It was, just it was difficult.
- Doug And, and could hear of course. Oh yeah, no problem.
- Denise So, it's very interesting I didn't get that feeling that you were having a tough time catching up at all. So then I didn't address it. I didn't know it was an issue.
- Doug Well, I thought it was, that I was having a tough time. Yeah, I always felt that I was trying to catch up.

From Martha's perspective, a significant level of frustration was also noted:

- Denise What about for the exercise part? Do you think it would have been different or participated differently if we have all been in the room?
- Martha Might have been for him 'cause he had a hard time with the exercising. Couldn't keep up.
- Denise Maybe it was a, a little bit easier to follow if we were physically in the room?
- Martha I don't know, everybody else was doing it. Yeah, 'cause that's what was so frustrating! That he couldn't keep up, and then he would leave and he'd be in a bad temper and I'd be in a bad temper.

It is quite possible that Doug may have had similar difficulties keeping up with the exercise even in a face-to-face environment. However, across the videoconference, his level of difficulty and associated frustration with the difficulties were not evident to the facilitators and therefore not addressed. This is one example of a barrier of the videoconference delivery which negatively impacted the experiences of these individuals. Despite the ongoing attention of the

facilitators while they monitored the ongoing quality and safety of the exercises for the participants, the ability to accurately perceive the level of difficulty of the exercises was limited.

Summary

A videoconferenced connection permitted participation in both the group discussion and exercise, although there were subtle differences in participation when compared with in person group experiences. For those who were lucky enough to have a face-to-face experience with the group, all but one agreed that it was easier to talk with the group when in the same room as everyone else.

4.3 The Impact of Videoconferencing on Group Experience

The concepts of group belonging, group cohesion, and the therapeutic factors of groups were explored with participants in order to identify any impact of the videoconference environment on these concepts. Participants were asked to reflect on what initially motivated them to participate in the program: what allowed them to maintain their motivation to continue; whether they felt part of the group; and how the experience compared to an in person group interaction.

Similar to in person MOST groups, distant participants said they were initially motivated to participate in the program to learn more information, to be able to connect with peers, and to have the chance to meet others in a similar situation.

Leila I really thought that it would help us. I thought it would be something, Denise, that might help him through this whole thing. Cause he had sort of gone into a depression on me, although he wasn't saying that. And he wasn't admitting that, but I knew, and I had no where to turn. So, I thought that this might be a help for me, if not for him.

The reasons for ongoing participation for many were reported as the ongoing need for information, the benefits derived from the previous sessions, and the social connection with others. Participants also identified the goal setting and exercise as reasons for ongoing participation. Two of the participants reported their ongoing participation was due to their commitment. They reported this as a personal outlook and core value they have with many activities. For many other participants, the program was providing ongoing information which they were looking for. For one participant, it was primarily the information which maintained her ongoing participation in the program; but upon further reflection, support from the group also played an important role:

Denise What kept you coming back?
 Laura The information. Yeah, just, the information, the support.
Denise The people?
 Laura Yeah. No, it's not like I picked up the phone and you know we called them, the people in the group, we didn't do that. But, whenever we saw them on the street or wherever, there was that connection. You know we could still sit and talk and...

For Rosemary, a caregiver, the support from the other participants was just as important as the information. She even suggested that a lack of social support was likely the reason that another participant in her group did not attend more regularly:

Denise Do you think that that made a difference, that you had other people around the table?
Rosemary That you weren't alone?
 Denise Yeah. Compare it to if you, if it was just you and Glen across videoconference, or like David, he was just there by himself.
Rosemary I think that's why he didn't come most of the time, because he was alone.
 Denise You do eh?
Rosemary And there we're able to, to talk to one another too. And I think that's why.
 Denise So did you have little conversations before, and after?
Rosemary Oh yeah, we talk a little bit, and yeah,
 Denise And did that make a difference for you for coming back then? You just said I think that's why he didn't come so often, did it, is that part of the reason that you did come, because you knew that you'd be seeing Simon?
Rosemary I, I think I would have gone anyway. I would have 'cause I know I needed help. I know I needed help.
 ...

Rosemary I think it made me feel well ‘Gee whiz, I’m not alone, and I guess there’s others going through it.’

None of the participants identified videoconferencing as a facilitator or barrier to their ongoing participation. Similar to in person groups, it was generally the information or content of the discussion and support from the group itself, either locally or across the entire group, or a personal attribute of commitment that positively affected ongoing participation.⁵⁸

Group Connection

For many participants, the MOST-TR videoconference experience allowed them to feel as though they were part of the larger group and they were able to reap the benefits of group membership. Most participants reported feeling a connection with the group despite the geographical separation:

Simon So as far as the program, as far as the people ... whether it be [participant in Thunder Bay], with his walker, or [another Thunder Bay participant] with his cane, or [another participant] and his outlandish comments or whatever, as I say, eh, I think we were part of that group, even though we weren’t in the same room. So I think that worked well.

They felt they could learn information from one another, share information with one another, and receive support from the group:

Leila Well the knowledge, as well as being able to talk to others, and that’s what I found most fantastic, with the, with the MOST group. I thought, you know, there’s other people out there that are going through the same thing as I’m going through and, I wasn’t alone in this thing. ‘Cause I had nobody here that I could talk to, that would understand...

Laura I mean I think, like we, we came kind of a, a close little knit community of people there. Even with the difference in ages. ... But there was still that connection. You know we could still eh, relate to one another and talk about things, and, and I think too for the spouses, being involved, that was very helpful.

They expressed feelings of being connected to others in the group and empathy for other group members:

- Simon We spoke up from our end, 'cause we've, some of us felt connected enough. Rosemary would make a comment, like, you know, so that's why I say, it was almost like being in the room, but not quite.
- Denise Yeah.
- Simon And, we, we thought, you know, that we could make a comment, and I think we did at times.
- Denise Yeah.
- Simon And uh, and when that one guy came in, about the, uh, he sat between [another participant] and, and the, the older lady, uh, what was his name?
- Denise [participant name].
- Simon Yes. Who couldn't get in to the Fifty-Five Club, or whatever.
- Denise Right, yeah, because he's not fifty-five.
- Simon Remember that? And uh, my heart just broke for him. For, for all the, all he wanted was some interaction or, you know and the, and they, they wouldn't let him in the Fifty-Five Club because he wasn't 55? And yet, you know, my heart broke for him, you know, and, and we all did, we said 'that's not right is it?' ... So I was connected with, with him.

There was a definite emotional connection and ongoing concern for each other. During each interview, many of the participants asked about the well-being of other participants in the group.

One particular participant felt he was never able to get to know the group well enough to really be able to participate and engage as much as he would have liked to. It is quite possible that he would not have felt differently in person; although in a face-to-face environment a facilitator may have been able to identify this more easily and have more informal opportunities outside the group to pursue this with him to promote a more positive experience:

- Doug I wanted to get up and say, 'Look, why don't you try this.' Eh, ah, not in the sense that I'm a hell of a lot better than them, that's not the point. But I find that this works, or that works. What about that idea? What about this idea? Or don't feel that you have to be like that. Do it this way.
- ...
- Denise So, what prevented you from just jumping up and saying that?
- Doug I felt all the time they wouldn't understand what I was talking about. I thought that I have no really, no right to get up and talk to them. Uh, and what little experience I have, what have I got that I can show them?

Even as the program progressed, his rapport with the rest of the group remained poor. He felt that he really did not have the right to tell the other members of the group about his experiences, or offer his suggestions regarding the issues they were discussing, in the same way

that he would not share opinions with a new acquaintance but would with a longstanding or intimate friend:

- Denise Did you feel like you could relate to anyone else in the group?
Doug Not very much.
Denise Okay.
Doug Yeah. You know, I've been thinking about it, eh ah, since, and, and ever since it uh, because um, yeah, ah eh, there wasn't a rapport between myself and them, I didn't feel so.
...
Denise The one thing that you've clarified is that you were sitting back and analyzing, and whether that's because you didn't really have, you didn't feel like you had this big connection, you didn't really relate with other people in the group.
Doug Yeah, right.
Denise So you kind of felt distanced and removed.
Doug Right.
Denise From the rest of the group.
Doug hm hm hm hm.
Denise But then,
Doug And, and a bit helpless too. I didn't feel I could join.
Denise And a bit helpless.
Doug Join in and help them at all.

He talked about his limited connection to the other members of the group. As a group, the only connection they had was the experience of having a stroke which was very different for each member:

- Doug I remember looking at them, and thinking, immediately, gosh I've gone through all kinds of experiences as a person. These people have never experienced some of those things. How the heck can I sit there and talk to them? Because they haven't done this, or they haven't done that.

Participants identified that even across videoconference they were able to gain hope from one another, and were motivated by the group:

- Henry Um, the woman that was going to knit, you know, her aim was to start her knitting again. And you could see that she was quite pleased with herself. Like quite pleased. But that, that, hm, I, ah, consider that as a, a motivation for the group. Because they hey, you know, that's really positive.
Denise Yeah, as a group.
Henry I can, I can feed on that. Good things are happening in my group ... It, it, it builds confidence I guess. I don't know.

Videoconference was not seen as a barrier to participants' ability to help the other group members by sharing their own experiences and ideas:

Henry The other, other component, like I thought it would be more helpful for you if I were there. Like it was one more person with input. So, part of the dynamics for me, was, maybe, because of my involvement it could help others.

Denise ...
So you think about how, and that's the beauty of groups is that you get something from it, but you also know that you're giving back to other people in the group, at the same time.

Henry Exactly. Exactly.

Henry also commented on the mutuality of the group:

Henry Um, but I thought, as again, the two sided coin, I would get something and the group may pick up something that: "Oh geez, I felt that. I didn't know somebody else did." And that's a very comforting thought. I mean, if it's an emotional high, or a low or somewhere in between. You know, a moment shared I guess is, can be a treasure.

In addition to the connection to the group and empathy for others in the group, many of the members compared themselves to other members of the group, relating to their similar circumstances and in some cases, this provided a therapeutic value: 'I am not as bad as them'.^{58, 59}

Henry Did I learn things from the group? I think I gained a deeper understanding of where people were, uh, in the sense that some of their conditions and dealing with them were parallel to mine and other people in the group.

Tim And you know, when you talk to other people, you're, you uh, you see how, what they, how they handle their problems. Yeah, compared to yourself. So it helps to have somebody that's in the same, hm, category as you.

Martha He's very slow, but I mean that's nothing, compared to what some of the people in Thunder Bay were going through, with the physical disabilities.

The group therapeutic factors and support for one another were evident and seemed to occur on more than one level: the group as a whole, and the local group at each site. This was reported both by distant participants attending with others at their site and by those who participated alone at their site by their reported lack of local support.

The videoconferenced connection was appreciated, satisfactory, and sufficient to allow them to establish a rapport with the group. However, the videoconferenced connection itself did not satisfy the desire to meet one another in person. One of the caregivers explained that the videoconferenced connection limited her ability to bond to the group and this limited her participation. Donada said that the day she participated with her husband in Thunder Bay, it all came together. That was what she needed. That was the day she felt she got to know everyone. She felt that she needed a face-to-face experience to feel bonded:

Denise	Did you feel like you got to know everyone?
Donada	Yeah, when I was in Thunder Bay, that was really different. ... Finally to meet people that were in the same program with Paul. You know, that's what I needed. Just seeing them I guess, knowing them.

As evident above, for Donada she was unable to really “know” the other participants until she had met them in person. This concept is similar to the desire for the rural participants to have a chance to meet the group in person at least once. Donada was able to do that, and said that it was a positive, grounding, experience for her.

Summary

The participants discussed feelings of group belonging, group cohesion, and therapeutic factors of groups within the group videoconferenced environment. Their initial motivation and continued motivation to participate in the videoconferenced group were similar to a face-to-face experience. Participants reflected that although the group experience was similar to a face-to-face, the videoconference interaction was not sufficient in satisfying their desire to meet one another in person.

4.4 Suggestions and Strategies for Successful Videoconference Participation

The program facilitators used various strategies to maximize the participation of the remote site participants and their connection with the group. The participants were asked to comment on the effectiveness of these strategies and make further suggestions.

Face-to-face connection

During the fourth interview, a participant suggested that it would be helpful to have an in person, or face-to-face meeting with other members of the group:

Jennifer Don't you think that with videoconference, you should meet first, and then telehealth?

From that point forward, each participant was asked for his or her opinion about this suggestion of meeting in person and the feasibility of such a prospect, considering the long distances to travel, time, and costs that would be incurred. Even with the logistical concerns of travel, inclement weather, and cost, all but three participants agreed that meeting the entire group in person, early on in the sessions, would have been of great benefit. Many participants commented on their desire for an opportunity to talk in person, informally, outside of the session, without the facilitation of the leaders, as a chance to get to know one another on a more personal and social level. Judy, who participated alone at a small rural hospital, agreed emphatically with the suggestion of having at least one in-person session:

Denise And a face-to-face meeting, if we all brought you together one time at the beginning that would have really been helpful?

Judy That I would have liked!

Denise Yeah?

Judy That I would have liked!

Denise Would you have been willing to do that Judy? Would you have been willing to take the bus and submit a travel grant to do that?

Judy I sure would have.

And Leila also commented:

Denise One of the other suggestions that someone um, suggested and I just want to know what you think about that, she said, it would be really neat to have

the first group, where we are all in person. And then you could actually get to know them a little bit. Be there all together, and then we go off and do it, and uh, she, she thought that, that might make a better connection. What do you think about that?

- Leila Yeah, I think that would be a good idea, too.
Denise Now is that feasible?
Leila Or even if it was the second session. Like after you got, you know were introduced, Denise, and then got together. 'Cause then maybe you'd feel more, comfortable talking then.
Denise Yeah, yeah, get over some of those first initial humps.
Leila Yeah, yeah. 'Cause I mean you put people that don't know each other into a room; you know they're not going to talk very much the first time.
Denise Yeah.
Leila So if you have the teleconferencing the first time, and then put them together.

Subsequent interviews explored the benefits of a face-to-face meeting, the timing of a face-to-face meeting, and the feasibility of a face-to-face meeting. Consensus was not reached for the exact timing of a potential face-to-face meeting but the importance of considering adverse weather conditions for driving was mentioned and most people agreed it needed to happen within the first few sessions:

- David Well I kind of, like I'd kind of see it as, like get the first, first few anyway. I mean you know, if, if there's a drop-out rate or whatever like that, you want to get the, you know the thing kind of solved anyway and see what the core group is going to be and then, and then, then two or three meetings whatever down the road, have everybody come in to town.

Paul also suggested another face-to-face session at the end of the program:

- Paul Just to, once at the beginning and then ah really at the end.
Denise At the end?
Paul To be with everybody, yeah.
Denise Okay, so not at the beginning, but at the end for you.
Paul Yeah. That way, that way uh, when you have uh, when you're done with the teleconference you get to know everyone. Yeah. And then we can have a big celebration that everyone had accomplished their goals and you knew that we got to meet. And it kind of is like a party at the end.

Not everyone was in agreement with the suggestion to meet in person. Three people felt that the videoconference connection was satisfactory and that traveling to meet the group in person would not have significantly added to the overall experience.

Laura I don't think in the long run, at the end, the end of the scheme, I don't think it would make any difference at all. I mean it's sure, it's nice to always to have contact in the beginning.

In thinking about a face-to-face meeting, Ellen said that she felt it would be important to have at least one of the facilitators do an in person assessment, rather than someone at the local hospital. This would provide an in person connection and visual representation for both the facilitator and the program participant:

Ellen I think it would be better if uh, you came here.
Denise Okay.
Ellen It would be cheaper.
Denise Yeah.
Ellen 'Cause uh, we've got a gas guzzler.
Denise Yeah, yeah. So meeting the facilitators you think would make a difference?
Ellen Um, well, it worked out okay, the way it was. Yeah, if you were to come here, that would be great.

Videoconference-specific Facilitation Strategies

The participants had no further comments on the strategy to keep an open microphone and not use the mute button to reduce any hesitation in their participation. They felt that this strategy worked well. They commented that background noise from other sites did not disrupt the conversation. As facilitators, the outcome of not using the mute function in order to maximize inclusiveness and participation was effective. It permitted the facilitators to be aware of side conversations and limit these at individual sites. Strategies to limit side conversations included occasional reminders and sometimes humour to cue the participants that the microphones were very sensitive and everyone was able to hear all the conversations in all the rooms.

Another comment made by both Paul and Frank was the need to have more directed questions to individuals, rather than posing a question to the group as a whole. In general, the questions asked by the facilitators during the discussion portion were directed to the entire group to facilitate conversation, sharing, and problem solving among the participants. Occasionally, participants were asked questions or comments directly, as a strategy to encourage individual

participation. The facilitators were also respectfully cognizant that some people may be uncomfortable with this and did not wish to participate more actively in the discussion.

The participants had no further comments or suggestions about the provision of similar refreshments at all sites and felt the strategies were utilized well.

Local Site Coordinators and Volunteers

The use of local site coordinators and local volunteers were strategies used to maximize the videoconference experience of the remote participants. All participants agreed that these strategies were important. Some felt that the presence of the site coordinators at only two sessions was enough; whereas, others wished there had been a site coordinator present for more sessions.

Henry	I, I think it is important to have a support person there to start out.
Denise	To start out, yeah.
Henry	Yeah, like what do we do here, how you handle what eh, how do where you're going to take these. Okay you're going to record that I, eh, to get the mechanics ironed out and then [pause].
Denise	So was the two sessions with Lynda [site coordinator] enough?
Henry	I was comfortable.

Vic was unable to attend the first two scheduled sessions and as a result did not have a site coordinator available for any of his sessions. On the first session he attended, he was welcomed to the telehealth room, provided with a quick overview of how the videoconference system and remote control worked, was given a number to call in case of trouble, and was left alone in the room to attend the session via videoconference. He found this very disconcerting and said that he would have been more comfortable had someone been there with him for his entire first session.

Some participants commented that it would have been nice to have someone attend locally with them more often. Aware of the need for efficient use of limited healthcare resources, they suggested that a volunteer might attend regularly, even just to set up the room and be there for the

first ten minutes of the discussion. A volunteer, for instance, could assist with finding required supplies.

Simon You need a physical being there for the first ten minutes at least. After that, you know, you're part of the group ... I think, to have a warm body there for the first ten minutes... a warm welcoming, communicative, interpersonal kind of person would be helpful.

Those who had a volunteer at their site appreciated the assistance with exercise and walking safety. Participants with no volunteers at their site were concerned about confidentiality and noted that the benefit of a volunteer would depend on who the volunteer was. In small towns, participants were concerned that having a volunteer with whom they were not comfortable might limit their willingness to discuss personal issues, which are therapeutically important to the program. Some comments about this were:

Judy Hmm, a help volunteer and uh, oh yeah it would be eh, probably. All depends who it would be. In a small town, I'd rather be alone maybe.

Denise So, you don't think it's important for us to make sure that ah, we had a volunteer or something in the room all the time?

Paul Not ah, all the time.

Denise No but, for the exercise part yes?

Paul Yes.

 ...

Denise You liked having, you were okay with having a volunteer for the exercise, but you don't want them here for the discussion because it's too small of a community, right?

Paul Yeah.

Regardless of whether it might be a healthcare professional staff site coordinator or a local volunteer, it was suggested that the role and expectations of both need to be clearly outlined. The person would need to be introduced to the group, and provided with an orientation to the program.

Local Participants

For many of the participants across videoconference, it was important to also feel connected to others in the same room with them. Those who participated in small numbers

suggested that it would have been nice to have had a larger number of people in their local group for social support, informal social discussion outside of the session topic, and ongoing local connection. For example:

Henry I would have liked more interplay. I found, that, I would have liked more people in our group.

Leila Yeah, I, I was sort of wishing there was more people in [participating site]'s group, that we could have talked out of the conference.

Martha The only thing, like I say that perhaps there could have been more people, far away, and not where you were.

The importance of having as many people as possible at each site at one time, with a minimum of two, was suggested by all three participants interviewed that participated alone at their videoconference site.

Denise Is there anything that we could have done differently to make it even seem less like a barrier so it was almost all the time that you felt like you were in that same room?

David Well if, cause, cause for me, like if we go back to this, if there would have been another person or two with me, at my meetings.

Denise Yeah, okay..

David Then, it would have been more of a shared experience I think. It's you know, a little bit more personal from that side yeah.

One of the caregivers talked about the videoconference format limiting her ability to make more of a connection with other caregivers. Although she did not participate alone at her rural site, she was the only caregiver at that site. She felt that this local, in person connection with others in a similar situation was still important:

Denise Do you think that you would have participated any differently, if you were in Thunder Bay with us?

Leila I wouldn't think so. I may have gotten to know that the other caregivers a little bit more. Because I enjoyed the time I did have to talk to a few of them.

Other Suggestions

One suggestion made was to investigate other options for walking. At one hospital, the walking track was set up in a narrow hallway with administrative offices. The walking portion of

the sessions coincided with times that people were coming in and out of the offices regularly and the participants felt that their activities were intrusive for the staff. Being connected across videoconference, the facilitators were not completely aware of the exercise loop at that facility and did not realize the discomfort the participants were feeling. Therefore, they did not even make the suggestion to walk outside when the weather was nice, which would have been possible for this particular couple.

4.5 Summary

This chapter has reviewed what participants had to say regarding their experiences with participating via videoconference in the MOST-TR program. The findings of this study corroborate much of the existing literature with regard to the overall satisfaction with videoconferencing and the perceived benefit of increased accessibility without having to travel long distances. For the most part, they also had the feeling of being in the same room with those connected at different sites during the sessions. Videoconference participation satisfied the participants' needs for support and information and was able to connect the group and provided many therapeutic group benefits. All participants reported feeling safe during the exercise regardless of the instructors/facilitators being at a distance. Reported limitations to videoconference included the audio lag, decreased ability to recognize subtle facial expressions and body language, a less than "in person" quality video representation, and an altered ability to participate. Suggestions included a face-to-face meeting at the beginning of the program and possibly again at the end, the continued use of site coordinators, and potentially expanding the use of volunteers to meet in-person needs. These findings also echo limitations in the audio and visual connection of the videoconference and the importance of having local, onsite support. Participants suggested that if logistically possible, more than one participant at each site would be optimal and should be considered when scheduling the program at each rural site. Although

participants expressed overall satisfaction and appreciation for the program, all reported a preference for the program to be delivered locally and in person if circumstances could make this possible. Videoconference technology can provide a wonderful bridge to services, but it is obviously not the same as being in the same room face-to-face.

Chapter 5: Discussion and Conclusion

This study used semi-structured interviews to learn in detail the perspectives of the nineteen participants regarding their experiences in participating in a group stroke self-management program, MOST-TR, across videoconference. Although the sample consisted solely of those who completed the MOST-TR program, a number of findings emerged which will be useful to consider in future planning of programming via videoconference. Key findings included: perceptions of the factors enabling their participation and group belonging; perceptions of the barriers of participation and group involvement; and suggestions for strategies to enhance the delivery of videoconference-based group programs.

In this chapter, I discuss the findings of the study in further detail in order to further understand the implications of participating across videoconference in this group environment and suggest strategies to consider in order to enhance group cohesion and participation within the videoconference environment. This chapter also compares and contrasts the findings from my own research with the existing literature on videoconferenced programs done in groups. In general, my own study found similar patterns regarding the satisfaction and limitations reported about participating across videoconference. This study adds further details from a client perspective, rather than a healthcare provider perspective, and adds new information about the limitations in the subtleties in communication, the connection to one another in a group experience, and the experience of participating in a group exercise program across videoconference.

5.1 Accessibility and Distance

Participants appreciated the ability to participate via videoconference as it allowed them access to a program that would otherwise only be offered in Thunder Bay or Toronto, requiring

long distances to travel for eighteen sessions. The participants reported satisfaction in the videoconferenced delivery of MOST and confirmed all five of the perceived benefits of telehealth as described by Jennett et al.³⁴ These benefits included: allowing patients to stay in their home communities to access healthcare services and information; decreased travel time and costs to access healthcare services; increased healthcare options; access to health information; and continuity of care. It is important to note, that if given the opportunity, all of the participants would have rather participated in person, in their local setting. The possibilities of connecting to existing group programs using videoconference technology greatly increases accessibility for people living in rural areas where sufficient numbers of participants and providers are not always available.

5.2 Videoconference Experience –Group Connection

Based on studies of other videoconferenced meetings, it appears that the satisfaction of a videoconference connection is largely dependent on the general purpose of the group and the individual group members' expectations of the group. Motivation to attend MOST-TR was driven by the opportunity to gain information and support, the same whether across videoconference or in person.

When Meier⁶¹ investigated the 'groupness', or connection between the group members of a business meeting, he found many examples of successful 'groupness' that were also found in the MOST-TR project. His analysis found examples of individuals addressing the whole group as well as addressing the local group only. However, Meier also noted that laughter and having fun did not seem to carry over into other locales easily. This was not the case in the MOST-TR project. While it is possible that some humour was not transmitted across videoconference due to the differences outlined above, such as the audio delay and diminished ability to perceive body language, participants at all MOST-TR locations described many incidents of laughter and

humour shared with the group across all sites. Similar findings were noted by Finalyson and Holberg²², who reported surprise at the extent of the group cohesion in the telehealth environment. It is most likely that the purpose of the group interaction influences the style of the group's communication and 'groupness' and consequently alters the transmission of laughter and having fun.

Meier⁶¹ and Kroeker¹⁹ also reported a local cohesion emerging above that of the whole group, but this was not found in the MOST-TR sessions. It is possible that the facilitation techniques did not encourage equal interaction between both sites. This contrast is also potentially due to the unequal number of participants at the rural sites compared with the central site. It is most likely that the contrast in findings is due to the purpose and context of the group with MOST-TR being a supportive, therapeutic, self-management program rather than a competitive business or medical resident training context.

5.3 Videoconference Experience –Participation

These findings indicate that an individual's level of participation is dependent on his or her sense of internal motivation and his or her personal level of connection with the group. The participants reported that the addition of video connection improved their ability to visualize the group, permitted a feeling of being in the same room, and therefore improved their ability to connect with the group. Most participants found they were able to share their experiences and to benefit from the information and peer support the program offered; although, their participation in the discussion portion of the program was altered by the videoconference connection when compared to an in-person experience.

Both Meier⁶¹ and Heath and Luff⁶² talked about the difficulty in discerning subtle facial actions and unreliable body language and gaze when using videoconference which could be misinterpreted. The loss in communication subtleties such as direct eye contact, gaze, gesture,

and emotions was reported by the participants. Participants echoed the findings reported by Finlayson and Holberg²² that they would have enjoyed more time for discussion but they found it difficult to join into the conversation for fear of “cutting off” the conversation in the room. It is noted that the videoconference connection is more formal than an in-person experience. Participants also reported their desire for more time to socialize informally, to share stories, or just talk with one another to get to know each other. Although the rural participants did not comment, from the perspective of a facilitator, there is an added formality to be inclusive of all the participants, especially those off site. The necessity of additional pauses due to the audio delay and rechecking if the offsite participants have anything to add, also changes the flow of the meeting. In addition, videoconference changes the focus of a room. The television becomes a central focus, attracting more attention than other participants in the room, and conversations in the room do stop and shift focus to the participants transmitted on the monitor rather than potentially just adding a small amount of information. The audio delay also accentuates this. As in most videoconference literature, the participants reported that a shorter audio delay would be beneficial and as reported by Meier,⁶¹ they acknowledged that this audio delay occasionally impacted the smooth transition between speakers. Although, unlike other reports in the literature, the participants did not feel the audio delay limited their satisfaction of the sessions.^{19, 61}

The findings identified that one participant required a higher level of rapport and group connection in order to feel comfortable sharing information or suggestions with the other group members. For this person, the videoconference environment alone did not satisfy the rapport-building opportunities and therefore he struggled with feeling he was not part of the group and this limited his desired level of participation. Another participant reported feeling more at ease sharing information and participating across videoconference. This is not surprising when considering that the videoconference connection allows a more removed experience whereby one may feel less threatened by others judging them, given a physical distance between themselves

and others. These types of experiences with videoconferencing have also been reported in education sessions and other caregiver experiences.⁴⁰ Most participants did not appear to be threatened by an in person experience when they did attend in person.

Similar to the MOST-TR study, a small group of caregivers in Australia participated in two-hour sessions with professional healthcare facilitators to learn new information and support one another.⁴⁰ As with the MOST-TR group, this group reported overall satisfaction with the videoconference participation and several of the Australian participants commented it was like having the presenter in the room. This caregiver group also noted an experience similar to Donada in that they felt more comfortable and better able to participate with the videoconference connection moreso than a face-to-face interaction. Also, the group of Australian caregivers felt the ability to share with one another was a valuable part of the videoconference connection.

The majority of the MOST-TR participants expressed no difference in their participation and felt that they were able to participate at the same level as if they were there in person. It is possible that the participants' need and desire for support from others in a similar situation was satisfied with the videoconference connection and thus outweighed their desire for a more intimate in-person experience.

For others in the MOST-TR group, their expectations and desire to be more connected to others in a similar situation and be a part of the group socially for more ongoing informal support was not completely met via videoconferencing. Therefore, their satisfaction with the MOST-TR group experience was limited by the videoconference environment and by having only a small group in person at their site. The participants who were alone at their distant site suggested that if possible, they would have preferred at least one other person participating locally, even if that meant they had to wait until the next program. These participants suggested that the group should only be offered when at least two participants can be situated at each remote site, even if that meant that the timing of the program might not be optimal for them personally. Although

information and support was delivered successfully using videoconference, the in-person connection and ability to connect outside the sessions was limited. The timing of the MOST experience, the local support, and the personality of the participant should all be considered when arranging the groups at each of the distant sites.

The videoconference connection allowed participants to be comfortable and feel safe while participating in a group exercise program. This would not have been possible across telephone without any visual connection. The videoconference also permitted group members to be motivated by one another in the group atmosphere. This finding is valuable and has not been previously identified in the literature. The literature reports group exercise facilitated by a physiotherapist but always supervised locally by a community fitness instructor. The findings from this study introduce the possibility of safely delivering a group exercise class, to a group across multiple sites connected by videoconference, without trained, local supervision. This affords new opportunities for safe group exercise programs in isolated areas.

Through the process of learning about the remote MOST-TR participants' perceptions of the program, it also became evident that videoconference offers additional challenges to the facilitator. The videoconference environment makes it more difficult to identify negative or challenging experiences for the participants through subtle facial expressions and body language. In this study experiences were shared by participants that identified difficulties connecting with others in the group and participating in the exercises. These types of negative experiences could certainly occur in an in-person experience; however, it would be more likely that the facilitator would become aware of this and make an attempt to address the situation. This is congruent with Meier's⁶¹ finding that the videoconference environment can make it difficult to monitor the activities at the other site. The benefits of exercising in a group, the camaraderie, and motivation of one another were evident as reported by the participants. However, this study revealed

situations in which the videoconference environment makes it challenging to assess the level of difficulty of an exercise across videoconference.

Facilitators using videoconference delivery need to be aware of the limitations in identifying negative and challenging experiences through subtle body language and facial expressions that we rely on during face-to-face group experiences. Some participants also identified they found it difficult to really see and get to know the other participants and feel the 'vibe' in the room. The videoconference environment also limits opportunities to check in with members on an individual, informal basis.

5.4 Suggestions for Enhanced Participation across Videoconference

Birden and Page¹⁷ give many strategies for teaching multiple sites within the videoconference environment. They discuss the necessity of having local site coordinators to provide physical assistance for the local group. In addition to our study, a local site coordinator was also used in Lai et al.⁴¹'s telehealth self-management program. The MOST-TR participants certainly confirmed that a local site coordinator was beneficial and some even advocated that ongoing support, even if provided by a local volunteer, would be an asset. Other participants felt that the two sessions with a local site coordinator were sufficient and ongoing support was unnecessary. While some participants acknowledged the benefit of using volunteers and enjoyed the support they provided, other participants felt that the presence of the volunteer had a negative impact on their participation. These participants were concerned about their privacy and the maintenance of confidentiality, especially in small centres. These comments must be carefully considered when delivering programs in rural areas. It is interesting to note that the participants who felt no need for ongoing support had some previous experience with telehealth and videoconferencing, were comfortable with technology in general such as email, and had post-

secondary education. It is possible that the need for local support is dependent on past technological experiences and the education level of the participants at the remote site.

Birden and Page also reiterate the necessity of having technical support throughout the interaction. Both Moehr et al.³⁴ and Gagnon et al.³² stated that the success of telehealth needs dedicated resources and clinician input. The MOST-TR project benefited from the well established OTN network including a 24-7 help desk accessed using either the phone or videoconference, and local telehealth coordinators at each site.

Participants suggested continuing the use of the open microphone and close-up camera angle strategies to control the flow of the discussion, and get a better visual perspective of all the participants. For some clients, this use of the remote control was extremely daunting, and the facilitators certainly cannot expect this task to be the responsibility of the participants. At this time, controlling the far site camera is only possible if there are a maximum of two sites connected with one another. Proposed changes to control all the far cameras from the host site have been suggested to the OTN technical staff; however, at this time the capacity of the technology does not make this an option. One possible solution is to have the telehealth coordinator at each site set some pre-set camera angles and then orient the local participants to the pre-set positions.

Participants suggested continuing to provide similar refreshments at all sites to encourage a feeling of equality among the group members.¹⁷

This study also confirmed the visual restrictions of videoconference as reported in the literature.^{18, 19, 65, 66} When meeting other participants in person, some participants felt as if they had met before and reported a sense of already knowing one another; others felt that the videoconference limited the visual representation and this was disconcerting when actually meeting in person. Participants suggested that one of the early sessions be hosted in person for all group members which would allow for both an in-person visual connection as well as an

informal opportunity for the group to get to know one another on a more personal level outside of the class. Potentially, an initial face-to-face meeting of the group may assist with group cohesion and decrease the number of dropouts. A preliminary face-to-face meeting supports similar suggestions by other videoconference experiences, such as Mielonen et al.'s study in telepsychiatry.⁴⁷ They reported that with client work, the participants should be known to one another beforehand.⁴⁷ This idea of a face-to-face meeting is very encouraging in that it suggests that the participants felt enough connection with the group to invest additional time, regardless of the logistical and economic barriers. Ellen shared that she felt that it would be at least important to have one of the facilitators do an in-person assessment rather than someone at the local hospital. As it has been identified that an in-person assessment is recommended for visual accuracy, rapport building, sense of smell, and prudent for safety in the group exercise, the group's suggestion of one in-person session, or at least Ellen's suggestion of the facilitator meeting each member in person, are important recommendations. It is also possible that this assessment could be done by local staff rather than by the MOST program staff. Although the local assessment would provide an opportunity for increased buy-in and support from local staff and institution, this would not satisfy the in-person connection and visual representation for either the facilitator or the program participant.

Other than offering an in-person experience, participants suggested the continued use of close-up visuals of each member while he/she was speaking. This also mimics the focus of attention on the person speaking when participating in person. Again, this supports our need for a visual connection with one another to further develop the group connection. The facilitator needs to become technically able to focus and readjust the camera to different pre-set positions while continuing to deliver and facilitate the content of the program. It is helpful to co-facilitate in these situations in order to be able to handle these additional roles. These suggestions are useful for future group programming across videoconference.

5.5 Conclusion

Overall, factors influencing engagement and participation in the videoconferenced MOST-TR sessions were similar to those in face-to-face groups of similar context rather than the videoconference environment itself. These factors included: program content, group leaders, and a connection to another group member. The participants in this study were satisfied with their MOST-TR videoconference group experience.

Similar to what was found by Lai et al.⁴¹ and Chan et al.²¹ regarding videoconferenced, self-management groups, MOST-TR group members felt that the program increased their knowledge about their condition, assisted them with putting that knowledge into practice, and helped them to develop a wider social network and create bonds with those in a similar situation. They reported being able to connect with the group and benefit from this connection. None of the participants identified the videoconference technology as a factor impacting their ongoing participation. However, it is important to consider that the videoconference environment may have been a factor for those participants who dropped out of the program or did not take part in this study.

The videoconference technology altered participation in the discussion portion for some participants, some negatively, and some positively. The videoconference environment limited opportunities for the group members to connect with one another in informal discussions outside of the sessions, and for the facilitators to check in with members informally. Successful strategies were suggested, including having an initial in-person meeting with the entire group, camera pre-sets of close-up visuals of each member, local site coordinators and volunteers, and having at least two participants at each site.

This study supports findings from published literature in the areas of videoconference, telehealth success, client and caregiver support programs, and telehealth self-management

programs. It adds to this body of literature by presenting findings from a therapeutic group videoconference environment, to identify the benefits and challenges of offering a post-stroke self-management program via videoconference.

The Northwest Local Health Integration Network has identified the priorities which support the use of videoconference technology including: provision of healthcare services close to home, provision of community support services, timely access to healthcare, use of videoconference to access health professionals in rural and remote areas, reducing distance using innovation focusing on the client, family, caregiver and professional, and wellness and disease prevention models of healthcare. Videoconference technology has the potential to meet the need for community-based ongoing education for individuals living in rural and remote areas. The results of this study may guide future videoconference use for successful group interventions. Future programs can encourage the use of supportive factors and explore solutions to overcome identified barriers to group videoconference implementation. This may increase access to group interventions, including social support programs and exercise programs, for many small rural areas where both patient numbers and healthcare resources are scarce.

A recent Cochrane review on the effectiveness of offering healthcare services via telehealth concluded that telehealth services are not merely the replication of services as they are given face-to-face, but rather offer care which is fundamentally different.²⁴ Both facilitators and participants need to recognize that there are differences between participating via videoconference and participating in person. The connection of the group across telehealth is very real, almost like being in the same room for some people, but certainly not equal to that of face-to-face interaction.

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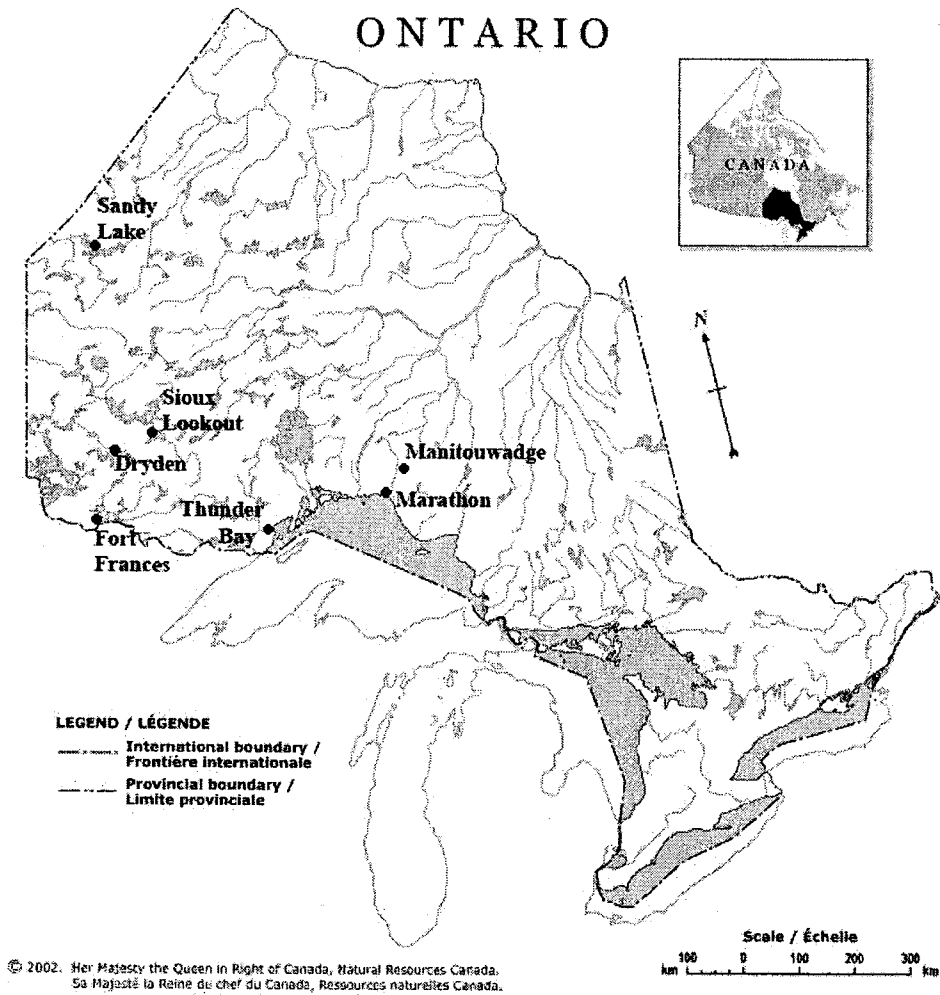


Figure 1. Map of Participating MOST-TR Rural Sites within Northwestern Ontario.

Table 1. Summary of focus group findings for participants

Categories	Factors Enabling Participation	Perceived Barriers to Participation	Overall satisfaction	Suggested improvements/strategies
Accessibility and Distance Impact of VC on Participation in Discussion	<ul style="list-style-type: none"> *accessibility without travelling long distances *video connection in addition to audio connection *open microphone, continuous presence connection *use of site coordinators *feeling as if already met in person *feeling of being in the same room with everyone *easier to talk across VC 	<ul style="list-style-type: none"> *audio lag *visual limitations: <ul style="list-style-type: none"> -chosen focus of room; -decreased facial details & expressions *limited representation of feelings and emotions, 'distance feeling' *local side conversations limited feeling of being in same room *more difficult to talk over VC, easier to talk in person *possible lack of confidentiality with volunteers 	<ul style="list-style-type: none"> *appreciation of opportunity to participate *positive experience but not equal to in person experience *would have preferred delivered locally in person but understood not available 	<ul style="list-style-type: none"> *use of preset close-ups of each participant so that when talking, focus is on speaker *ability to control camera at all sites from host site *better orientation/ set-up of VC equipment during first few sessions *larger viewing screens *more than one participant at each site *facilitators directly invite participants to talk
Impact of VC on Exercise Participation	<ul style="list-style-type: none"> *camaraderie benefits of exercising with a group *felt safe 	<ul style="list-style-type: none"> *difficult to discern level of difficulty of exercises for facilitator *limited exercise facilities for walking 	<ul style="list-style-type: none"> *appreciated supervision 	<ul style="list-style-type: none"> *use of volunteers at local sites
Impact of VC on Group Experience	<ul style="list-style-type: none"> *met needs for information and support 	<ul style="list-style-type: none"> *didn't feel experience of stroke was enough to 	<ul style="list-style-type: none"> *positive group experience 	<ul style="list-style-type: none"> *encourage more than one participant at each site

	<p>*group benefits achieved i.e. empathy, motivation, altruism</p> <p>*felt group connection regardless of age and geographical differences</p>	<p>connect with group</p> <p>*didn't feel got to know the other caregivers as well without in person connection</p> <p>*difficult being a single participant at a remote site</p>	<p>*appreciated equality of refreshments</p>	<p>*one face-to-face meeting toward the beginning and possibly at the end</p> <p>*facilitators do in person assessment</p>
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Appendix A: Interview Guide

1. Have you ever been involved in another education series, support group?
2. Have you ever been involved in another videoconference experience?
3. How did the MOST program compare with these other experiences?
4. Think back to the first day of the session, in September,
 - a. There was a site coordinator/volunteer in the room....
 - b. Did you find your way to the room...
 - c. You met others for the first time.....
 - d. Introductions of the group/ purpose of the sessions....
 - e. What were your initial thoughts about the videoconference?
 - f. About the program?
 - g. How did you feel?
5. What things helped you come back for subsequent sessions?
6. Do you feel you got to know and interact with the people in Thunder Bay and the other videoconferenced site the same way as the people in the room with you?
7. Was there ever a point at which you thought of yourself as being in the same room as all the other participants?
8. Do you think you would have participated differently if all the participants and facilitators had been in the same room? For the discussion portion? For the exercise Portion?
9. What did you think of the videoconferencing? Did the videoconferencing seem distracting?
10. How would you feel if a volunteer were available for the program to?
OR IF VOLUNTEER WAS INVOLVED: How did you feel about having a volunteer available for the program?
11. Can you think of anything that would have improved the program as a participant across videoconference?
12. Would you be willing to participate in a group connected via videoconference again?
13. If you could think of something to share with another participant that was beginning the program, what would it be?

Additional question added for Marathon, Fort Frances and Sioux Lookout:

14. One of the other participants has suggested that it would be really beneficial to have one face-to-face meeting where we were all in the same room. What are your thoughts on that?

- a. If that was the case, when do you think that meeting should take place, the first meeting, after we have met via videoconference for a few, middle of the sessions or toward the end?
- b. Do you think that this would be feasible to attend a face-to-face session for both cost and time?

Appendix B: Ethics Approval from Participating Sites

Lakehead

UNIVERSITY

Office of Research

April 25, 2007

Tel (807) 343-8283
Fax (807) 346-7749

Ms. Denise Taylor
Master of Public Health Program
Lakehead University
955 Oliver Road
Thunder Bay, ON P7B 5E1

Dear Ms. Taylor:

Re: REB Project #: 083 06-07
Granting Agency name: N/A
Granting Agency Project #: N/A

On the recommendation of the Research Ethics Board, I am pleased to grant ethical approval to your research project entitled, "Clients' perspectives on supports for and barriers to participating in a group stroke self-management program using videoconference".

Ethics approval is valid until **April 25, 2008**. Please submit a Request for Renewal form to the Office of Research by March 25, 2008 if your research involving human subjects will continue for longer than one year. A Final Report must be submitted promptly upon completion of the project. Research Ethics Board forms are available at:

<http://boff.lakeheadu.ca/~research/www/internalforms.html>

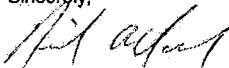
During the course of the study, any modifications to the protocol or forms must not be initiated without prior written approval from the REB. You must promptly notify the REB of any adverse events that may occur.

Completed reports and correspondence may be directed to:

Research Ethics Board
c/o Office of Research
Lakehead University
955 Oliver Road
Thunder Bay, ON P7B 5E1
Fax: (807) 346-7749

Best wishes for a successful research project.

Sincerely,



Dr. Richard Maundrell
Chair, Research Ethics Board

/len

cc: Dr. S. Dale Stone, Department of Sociology
Faculty of Graduate Studies
Office of Research



955 Oliver Road Thunder Bay Ontario Canada P7B 5E1 www.lakeheadu.ca



ST. JOSEPH'S CARE GROUP

St. Joseph's Hospital
Corporate Office
P.O. Box 3251
35 N. Algoma St.
Thunder Bay, ON
P7B 5G7
Tel (807) 343-2431
Fax (807) 345-4994

St. Joseph's Heritage
63 Carrie St.
Thunder Bay, ON
P7A 4J2
Tel (807) 768-4400
Fax (807) 768-8820

Lakehead Psychiatric Hospital
P.O. Box 2930
580 N. Algoma St.
Thunder Bay, ON
P7B 5G4
Tel (807) 343-4300
Fax (807) 343-4373

Hogarath Riverview Manor
300 N. Lillie St.
Thunder Bay, ON
P7C 4Y7
Tel (807) 625-1110
Fax (807) 625-1155

Sister Margaret Smith Centre
P.O. Box 3251
35 N. Algoma St.
Thunder Bay, ON
P7B 5G7
Tel (807) 343-2425
Fax (807) 343-9447

Behavioural Sciences Centre
300 N. Lillie St.
Thunder Bay, ON
P7C 4Y7
Tel (807) 623-7677
Fax (807) 623-7697

Diabetes Health Thunder Bay
285-A Memorial Ave.
Thunder Bay, ON
P7B 6H4
Tel (807) 344-3422
Fax (807) 346-8006

www.sjcg.net

May 16, 2007

Denise Taylor
Moving On After Stroke Program – 3 North
St. Joseph's Hospital

Dear Ms Taylor:

**Re: Research Project: Number 2007004
Clients' Perspectives on Supports for and Barriers to Participating in a Group
Stroke Self-management Program Using Videoconference**

This is to notify you that following review of the documents regarding the Research Study noted below, the status of approval has been allocated to the research project by the St. Joseph's Care Group Board Ethics Committee and subsequently by the Board of Directors at their meeting of May 16, 2007.

Study Title: Clients' Perspectives on Supports for and Barriers to Participating in a Group Stroke Self-management Program Using Videoconference

Principal Investigator:

Denise Taylor

As per the St. Joseph's Care Group Research Ethics Agreement, please provide us with annual progress reports as well as a copy of the final report when the study has been completed. Reports can be sent to the Research Department, St. Joseph's Care Group.

Sincerely,

ST. JOSEPH'S CARE GROUP

Susan Geschwender
Chair, Ethics Committee
Board of Directors

Jef

Copy: Kelly Morris, Coordinator, Research Department, St. Joseph's Care Group
Trish Nelson, Program Manager, Neurological Rehabilitation, St. Joseph's Care Group



To: D. Taylor
 From: Bev Junnila
 Date: June 5, 2007
 Subject: Clients Perspectives on Support for and Barriers to Participating in a Group Stroke Self-Management Program Using Videoconference

Protocol Identification Number: 46.05
Meeting Date: May 28, 2007

The Thunder Bay Regional Health Sciences Centre RET has conducted a review of the research protocol that is referenced above, and has approved the involvement of human subjects as specified in the protocol. The quorum for approval was free from conflict and did not involve any member that is associated with this project.

The Thunder Bay Regional Health Sciences Centre Research Ethics Team is guided by the policies and ethical standards put forth by the Tri-Council Policy Statement: Ethical Conduct for Research Involving Human Subjects as well as the ICH Good Clinical Practice (GCP) guidelines.

Should your study continue for more than one year, you must submit a progress report and request a renewal a minimum of three (3) weeks before the renewal date that is specified below. Please note that approval for this study will expire on this date unless the TBRHSC RET is otherwise notified.

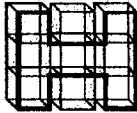
If, during the course of your research, there are any changes in the approved submission or any new information that must be considered with respect to the study, these should be brought to the immediate attention of the Research Ethics Team.

Type of Review: _____ **Date (dd/mm/yyyy)** _____
 Full Board Meeting 28/05/2007
 Chair with notification to all Board Members _____

Type of Submission and Version Date	Approved	Received	Revisions Required	Not Approved
Protocol				
<input type="checkbox"/> Initial _____ (Version Date)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Amendment _____ (Version Date)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Consent				
<input type="checkbox"/> Initial _____ (Version Date)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Revision _____ (Version Date)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Investigator Brochure				
<input type="checkbox"/> Initial _____ (Version Date)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/> Amendment _____ (Version Date)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other- Correspondence May 1, 2007	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bev Junnila
 Chair, Thunder Bay Regional Health Sciences Centre RET

June 5, 2007
 Date



LAKE OF THE WOODS DISTRICT HOSPITAL

21 Sylvan Street • Kenora • Ontario • Canada • P9N 3W7 •
Telephone: (807) 468-9861 • Fax: (807) 468-3939 • E-Mail: admin@lwdh.on.ca

May 31, 2007

Denise Taylor
Project Coordinator, MOST
St. Joseph's Care Group
Box 3251
Thunder Bay, ON
P7B 5G7

Dear Denise Taylor:

**RE: "COMPARISON OF FACE-TO-FACE AND VIDEOCONFERENCE
DELIVERY OF THE CHEDOKE-MCMMASTER STROKE ASSESSMENT
TRAINING WORKSHOP: EFFECTIVENESS AND COST"**

I am pleased to inform you that Senior Staff of Lake of the Woods District Hospital approved, at their May 24, 2007 meeting, the above research project.

Please forward the results of this study to our Ethics Committee.

Thank you.

Yours sincerely,

Donna Makowsky, RN
Chair, Ethics Committee
Lake of the Woods District Hospital
/mm

c. Clinical Stroke Nurse, LWDH



**P.O. BOX 12
SANDY LAKE, Ontario
POV 1V0**

Phone: (807) 774-3421
(807) 774-5121
FAX: (807) 774-1040

22 May 2008

Dr. Maria Huijbregts
Baycrest
3560 Bathurst St.
Toronto, ON M6A 2E1

Dear Dr. Huijbregts,


We are very pleased to participate in the study:
Filling the Stroke Community Programming Gap in Northern Ontario: Telehealth Dissemination of a Stroke Self-Management Program.

In our region, there is a serious lack of programming for stroke survivors, who return to the community after their inpatient and outpatient rehabilitation, and for their care partners. We believe that stroke survivors in these more remote regions of the province miss out on the opportunity to connect with other people with similar experiences, to learn from these experiences, and to move forward in their lives.

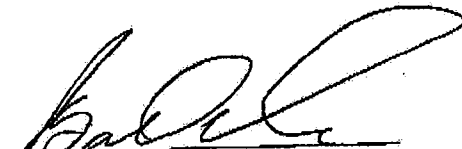
We believe that the Moving On After Stroke-Telehealth Remote Program (MOST-TR) will provide this opportunity. We are therefore looking forward to the opportunity to participate in this study.

Please accept this formal approval from Sandy Lake First Nation for our participation.

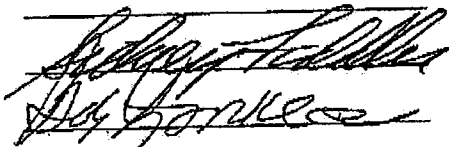
Sandy Lake First Nation Chief & Council



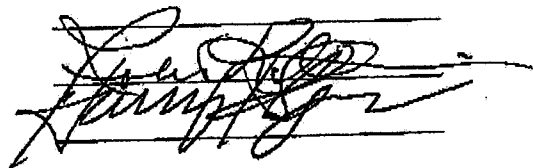
Chief Adaar Fiddler



Deputy Chief Bart Meekis



Denise Taylor



Project Coordinator

Cc: Denise Taylor, Moving on After Stroke project coordinator



Dryden Regional Health Centre

58 GOODALL STREET, P.O. BOX 3003, DRYDEN, ONTARIO P8N 2Z6
TELEPHONE (807) 223-8200 MAIN FAX (807) 223-2370
ADMINISTRATION FAX (807) 223-8628

KATHY BRYCK
CHAIR, BOARD OF DIRECTORS

WADE PETRANIK, CMA, CHE
CHIEF EXECUTIVE OFFICER

January 20, 2006

Denise Taylor, PT
Moving On after Stroke (MOST) Project Coordinator
St. Joseph's Hospital
P.O. Box 3251, 35 N. Algoma Street
Thunder Bay, ON, P7B 5G7

Dear Ms. Taylor:

The Ethics Research Committee at the Dryden Regional Health Centre has reviewed your proposal regarding the Stroke Self Management Program utilizing Telehealth. I wish to inform you that this proposal has been approved by this Committee.

We are forwarding this information to the Medical Staff for their review.

Regards,

Robert van Oort
Director, Quality, Risk and Service Development
Dryden Regional Health Centre

cc: Ethics Committee



Riverside Health Care Facilities Inc.

110 Victoria Avenue, Fort Frances, ON P9A 2B7 • 807-274-3266 • Fax: 807-274-2898 • riverside@rhcf.on.ca

May 29, 2007
ADM-201

Denise Taylor
Master of Public Health Program
Lakehead University
955 Oliver Road
Thunder Bay, ON P7B 5E1

Dear Ms. Taylor:

RE: 1. Quality monitoring procedures for the Filling the Stroke Community Programming Gap in Northern Ontario: Telehealth Dissemination of a Stroke Self-Management Program
2. Clients' Perspective on Supports for and barriers to Participating in a Group Stroke Self-Management Program using Videoconference Technology: A Qualitative Study

On the recommendation of the Riverside Ethics Committee, I am pleased to grant ethical approval to the above named research projects.

Our committee would be very interested in receiving a report from the Clients' Perspective study on Videoconferencing Technology as it is a topic we have discussed in the past.

Best wishes for a successful research project.

Sincerely,

D.C. Clifford
fr

Tammy McNally, RN, HBScN
Chair of the Ethics Committee

/dc

Connecting Communities - Committed to Caring

La Verendrye Hospital
Fort Frances, ON P9A 2B7
807-274-3266
Fax: 807-274-2898

Emo Health Centre
Emo, ON P0W 1E0
807-482-2881
Fax: 807-482-2493

Rainy River Health Centre
Rainy River, ON P0W 1L0
807-852-3232
Fax: 807-852-3565



SIoux LOOKOUT
Meno Ya Win
HEALTH CENTRE

Sioux Lookout Meno Ya Win Health Centre
P.O. Box 909 Sioux Lookout, On P8T 1B4
Tel: 807 737-3030 • Fax: 807 737-5109
www.slmhc.on.ca

September 27, 2007

Denise Taylor, PT
MOST Project Coordinator
C/o St Joseph's Hospital
PO Box 3251
Thunder Bay, ON
P7B 5G7

Dear Denise:

Your research project "MOST amendment" was reviewed at the recent Research Review Committee meeting held on September 20, 2007. The decision was to approve this amendment to the research within Sioux Lookout Meno Ya Win Health Centre.

Two specific suggestions that we would ask you to consider for the future are:

- Anonymity for anyone who refuses consent for videotaping, by the inclusion of a statement to that effect in the outline letter. We see this as a way to reduce peer pressure into consenting when someone may actually be uncomfortable with the taping.
- Also if in the future you need to use interpreters for consent please feel free to use the format that we have developed at SLMHC. This has been vetted through our institution, legal advice and practice.
- A witness signature on the consent form.

We hope these suggestions are of use to you as this important project continues. Please feel free to contact myself, as Chief of Staff (todriscoll@slmhc.on.ca) and Ms. Cindy Hunt, Director of Health Information and Privacy (chunt@slmhc.on.ca) if you have any further questions.

Sincerely,

T.A. O'Driscoll, MD, CCFP, FCFP
Chief of Staff
Sioux Lookout Meno Ya Win Health Centre

(Enclosure)

Working hand in hand with our communities to build a healthier future

Wilson Memorial General Hospital



Marathon,
Ontario
P0T 2E0
(807) 229-1740 Fax: (807) 229-1721

15 May 2006

Dr. Maria Huijbregts
Baycrest
3560 Bathurst St.
Toronto, ON M6A 2E1

Dear Dr. Huijbregts,

We are very pleased to participate in the study:

Filling the Stroke Community Programming Gap in Northern Ontario: Telehealth Dissemination of a Stroke Self-Management Program.

In our region, there is a serious lack of programming for stroke survivors, who return to the community after their inpatient and outpatient rehabilitation, and for their care partners. We believe that stroke survivors in these more remote regions of the province miss out on the opportunity to connect with other people with similar experiences, to learn from these experiences, and to move forward in their lives.

We believe that the Moving On After STroke-Telehealth Remote Program (MOST-TR) will provide this opportunity. We are therefore looking forward to the opportunity to participate in this study.

Although we don't have a formal Research Ethical Review Board at our facility, our Medical Advisory committee and administration is pleased to provide approval of our participation.

Yours Sincerely,

Jill Pascoe
Director of Client Services



MANITOUWADGE GENERAL HOSPITAL

Quality Service, Pride, Trust & Teamwork

July 13, 2006

Dr. Maria Huijbregts
Baycrest
3560 Bathurst St
Toronto, ON M6A 2E1

Dear Dr. Huijbregts,

Manitouwadge General Hospital is pleased to participate in the study "*Filling the Stroke Community Programming Gap in Northern Ontario: Telehealth Dissemination of a Stroke Self Management Program*".

We believe that clients who return to our communities post stroke will definitely benefit from the "Moving On After Stroke- Telehealth Remote Program (MOST-TR)" and look forward to participating.

Our administration is pleased to provide approval for participation.

Yours truly,

Debbie Hardy
DON

Appendix C: Informed Consent

INFORMATION LETTER FOR CLIENT

Clients' Perspectives on Supports for and Barriers to Participating in a Group Stroke Self-management Program using Videoconference Technology: a Qualitative Study

Investigator:

Denise Taylor
Master's of Public Health candidate
St. Joseph's Care Group, Thunder Bay
Tel: 807-343-2431 ext. 2562
Email: taylord@tbh.net

Advisors:

Dr. Maria Huijbregts
Director of Evaluation
Baycrest, Toronto
Tel: 416-785-2500 ext.2677
Email: mhuijbregts@baycrest.org

Dr. Mary Ann Mountain
St. Joseph's Care Group, Thunder Bay
Tel: 807-343-4359
Email: mountaim@tbh.net

Dr. Sharon Dale Stone
Department of Sociology
Lakehead University, Thunder Bay
Tel: 807-343-8530
Email: sdstone@lakeheadu.ca

**St. Joseph's Care Group
Research Ethics Board Chair:**
Susan Geschwender
Tel: 807-343-2450

**Lakehead University
Research Ethics Board:**
807-343-8283

March 6, 2007

Dear _____,

Thank you for considering participation in this study concerning Telehealth and the Moving on after Stroke (MOST) Program. As a student in the Master of Public Health program at Lakehead University, I have collaborated with staff in the Master of Public Health program to develop a study titled:

Clients' Perspectives on Supports for and Barriers to Participating in a Group Stroke Self-Management Program Using Videoconference

Research Description

I am investigating the thoughts of the MOST participants connecting from the rural and remote regions of Northwestern Ontario. In particular, I am looking at the impact of videoconference on the MOST programs. The study will require participation in an in-person, in-depth interview. Each interview will be approximately 60-minutes long, at an agreeable time and place. The purpose of the interview will be to determine what your feelings are about the MOST program, specifically thinking about the videoconference aspect. There are no right or wrong answers; it is your opinion I am interested in. Any comments you make may improve the way videoconferencing is used to deliver programs in the future.

Information about the research process

With your consent, the interview will be recorded on an audio digital recorder to ensure all the information you share is captured. The recorded data will be transcribed into an electronic word document. All of the information you shared will be securely stored at St. Joseph's Care Group for seven years. Your confidentiality will be assured. A pseudonym will be used in place of your name. Your participation is completely voluntary and you may choose not to participate at any time. You may choose not to answer any question asked in the interview. Your participation in this interview will not affect your participation in the larger MOST study. A summary report will be available upon completion of the study. In addition to journal articles, the results of this study

will be presented at Rehabilitation Rounds at St. Joseph's Care Group and may be presented at other relevant education opportunities.

If you have any questions or concerns about this study, please do not hesitate to contact me at telephone number below. You may also contact my advisors: Dr. Maria Huijbregts at Baycrest in Toronto (416-785-2500 ext 2677), Dr. Sharon Dale Stone at the Sociology Department of Lakehead University (807-343-8530) or Dr. Mary Ann Mountain at St. Joseph's Care Group (807-343-4359). If you have any ethical concerns, you can contact Susan Geschwender, Chair, Board Ethics Committee at St. Joseph's Care Group, at (807) 343-2450 or Lakehead University Research Ethics Board at (807) 343-8283.

Thank you,

Denise Taylor, MPH (candidate), BScPT
807-343-2431 ext. 2562
Enclosure (1)

Title: Clients' Perspectives on Supports for and Barriers to Participating in a Group Stroke Self-Management Program Using Videoconference

My signature on this sheet indicates that I, _____, agree to participate in a study by Denise Taylor. It also indicates that I understand the following:

1. I have read the information letter and received explanations about the nature of the study, its purpose, and procedures.
2. I am a volunteer and can withdraw at any time from the study.
3. I understand this study may improve videoconference delivery of programs in the future.
4. There is no apparent risk of physical or psychological harm.
5. I agree to have my interview recorded on audio digital recorder.
6. I may choose not to answer any question asked in the interview.
7. An electronic copy and written transcript of my interview will be securely stored at St. Joseph's Care Group for seven years.
8. I may request a copy of the summary report following the completion of the project.
9. I will not be mentioned by name in the report as a result of this study.

Signature of Participant

Date

Appendix D: Description of Participants

The participants are listed here in alphabetical order:

Andrew is a 56 year old male. He attended MOST with his wife Ellen and five other participants at a local site. Ellen and Andrew live just outside of the small town and traveled 30 minutes to attend the MOST sessions. I interviewed him at his home on October 18, 2007, one month after completing MOST. I had met both Andrew and Ellen when they stopped in for a visit at my office, near the end of the MOST program. Andrew had an ischemic stroke just three months prior to participating in MOST. In addition to visiting family and spending time in Arizona, he enjoys boating, fishing, and photography. He had not returned to work since his stroke.

Arianna is a 54 year old woman. She had her stroke four months prior to participating in the MOST program. She attended the MOST program with another couple at a rural site. Arianna lives more than 100 Km. from the closest MOST telehealth site. Her interview took place in her home, on August 31, 2007, eight months after completing the MOST program. Arianna is married with three daughters and many grandchildren. She is strongly supported by her sisters who also live in the community. Although she recovered well cognitively from her stroke, she has difficulty with mobility and depression. Arianna's husband spends much time away from home working. Her living conditions at the time of the interview were a matter of concern. Her home was being renovated due to mould and she was living in a plywood shack as a temporary measure, with a tarpaulin door and cut out windows with no glass. Arianna was very concerned about her housing at the time of the interview and mentioned that she spends much time under her blankets in bed with the electric heater on. I had never met Arianna in person prior to the interview.

David is a 76 year old male. His stroke was 15 months prior to attending MOST. David and I had never met in person prior to our interview on December 8, 2007, three months after completing MOST. David attended MOST at his local hospital, approximately a 45-minute drive from his home. Although he was married, his wife was unable to attend the sessions. David was the only participant at that rural site. Our interview took place at my place of work in Thunder Bay as David was in Thunder Bay for a family visit. David enjoys gardening, fishing, and puttering around the house since his retirement.

Donada is a 48 year old woman and caregiver to her husband Paul. I interviewed Donada in her home on June 11, 2008, one month after her husband completed MOST. Although Donada only attended MOST with him a few times, she welcomed the opportunity to share her experience. I had met both Donada and Paul in person while he was in rehabilitation in Thunder Bay and they also attended one MOST session in person in Thunder Bay. Donada and Paul have two girls and two sons, two with children of their own, and one teenage daughter living at home. Donada is busy caring for her family and working full time.

Doug is a male stroke survivor, age 84. He had a ischemic stroke 14 months prior to attending MOST. The interview took place three months after completing MOST, on June 23, 2007. Doug lives with his wife Martha who attended the sessions regularly with him. The two of them participated at a local site with five other participants. I had met Doug and Martha once in person, during his second assessment for MOST. Doug continues to have some difficulties both physically and cognitively and relies on his caregiver Martha.

Ellen is a 56 year old female caregiver to her husband Andrew. I interviewed Ellen one month after completing MOST, in her home on October 18, 2007, while Andrew was out cutting the lawn. She and Andrew attended MOST at the local hospital, approximately 30Km from their home, with five other participants. Ellen spends her time exercising, looking after the household affairs, and enjoys planning healthy eating choices for her and Andrew.

Frank, is a 81 year old man who suffered a stroke 18 months prior to attending MOST locally with Paul. I had never met Frank in person prior to our interview at the local telehealth studio on June 11, 2008. Frank is the father of two children and grandfather of many. Frank is a retired school teacher and the proud father of two children and two grandchildren. He is a very enthusiastic hunter and fisherman and enjoys many days out in the Northwestern Ontario bush camping.

Glen is a 66 year old male. He suffered a hemorrhagic stroke 11 months prior to attending MOST with his wife Rosemary. I had never met Glen in person prior to our interview on October 18, 2007, one month after completing MOST. Glen and Rosemary are the parents of five children and have many grandchildren. Glen grew up in England and has lived in his present community for over 30 years. He is now retired. Prior to his stroke, Glen was an avid golfer, woodworker, baker, and he and Rosemary enjoyed vacationing in Western Canada for the winter months since his retirement. Glen's stroke left him with no short-term memory and many difficulties in orientation to time and place. He continues to enjoy watching sports on television and fishing with his friends. Although he was very pleasant and jovial, Glen did not remember me, or attending the MOST sessions at all. Our interview was short as I realized that many of my questions were difficult for him to answer.

Henry is a male survivor, age 72. He had his stroke 16 months prior to attending MOST. The interview took place on June 23, 2007, three months after completing MOST. He lives with his wife, although Henry attended MOST independently. He attended the group at a local site with five other participants. I knew Henry well. I was his physiotherapist during his inpatient rehabilitation in Thunder Bay after his stroke. He is a wonderful storyteller and enjoys sharing many tales of his life and traditional cultural ways. He is also very involved in his community and participates in community forums and board of Directors for many local companies.

Judy is a woman of 80 years. She is the mother of four children, and grandmother of many. She has been a widow for more than ten years. I had never met Judy in person at the time of our interview, in her home, on June 9, 2008. She had finished MOST 15 months earlier. We had scheduled interviews twice before but required rescheduling to accommodate Judy's busy travelling schedule. Judy had just moved to her community within the last three years. Her stroke had resulted in minimal physical or cognitive deficits and she was able to resume with her community activities. Judy was the only MOST participant at that rural site, 17 months after her ischemic stroke.

Laura is a 74 year old woman who had an infarct stroke three months prior to attending MOST with her husband and caregiver **Simon**, a 76 year old male. They attended MOST at a local site with five other participants. I interviewed both of them separately, in their home, Simon on October 17, 2007 and Laura the next day. They had completed MOST just one month previously. Laura's most recent stroke was her second stroke, the first being a Transient Ischemic Attack (TIA). Laura enjoys bus trips to see her family and with the Red Hat Society. Laura and Simon have seven children and many grandchildren, all living outside the region. Both are very

involved in a variety of community activities. I had met both Laura and Simon when they attended a MOST session in Thunder Bay.

Leila is a 55 year old woman, caregiver to her husband who had his stroke just over one year prior to participating in the MOST program. Leila participated regularly with her husband in the MOST sessions, although her husband was not able to participate in an interview. The two of them were joined by five other participants at their local site. Leila's interview was August 31, 2007, eight months after completing MOST. Leila is a retired school teacher. Leila's children from a previous marriage live in other cities outside the NWO region. She is able to visit them annually. Leila just became a new grandmother at the time of the MOST program. Her visit to her son and the new twin babies, shortly before starting the MOST program, was Leila's first time leaving her husband overnight since his stroke. I had met Leila and her husband in person in Thunder Bay as they attended a focus group after the MOST program, when they happened to be travelling through Thunder Bay.

Martha is Doug's wife and caregiver. She is 76 years old. Martha's interview also took place at their home on June 23, 2007. Martha spends most of her days homemaking and doing crafts. . She and Doug have many long-standing, supportive friends.

Paul is a 48 year old man who suffered a hemorrhagic stroke 16 months prior to attending MOST. He and one other participant attended at a local site and completed the program just one month prior to the interview on June 11, 2008. I had met Paul and his wife in person on two occasions in Thunder Bay prior to the interview. Our interview took place at the local nursing station telehealth room at his convenience. His stroke left him fatigued with limited endurance

and he continued to struggle emotionally. He enjoys carving, playing the guitar, and spending time with his family.

Rosemary is a 69 year old woman who attended MOST with her husband Glen. I interviewed Rosemary in her home on October 18, 2007, 1 month after they completed MOST. I had never met either one in person prior to the interview. They lived just outside of the small town and drove in about 50 minutes for each session. Rosemary had an active caregiver role but was supported daily by friends.

Tim and Jennifer participated in MOST as a couple. Another couple also participated at their local site. Tim was 60 years old at the time of the interview which took place on June 23, 2007, six months after completing MOST. He suffered a severe hemorrhagic stroke 20 months prior to participating in MOST. Jennifer was 69 at the time of the interview. They requested to participate in the interview together, rather than separately, as Tim continues to have great difficulty with his short term memory and finds it very difficult to answer questions. He had not been able to return to work as an engineer since his stroke. I had never met Tim or Jennifer in person prior to the interview at their home.

Vic is a 58 year old male who had just completed the MOST program at the time of our interview on June 9, 2008. His stroke was 12 months prior to participating in MOST. He attended MOST alone for the majority of the sessions although his wife occasionally accompanied him. They were the only participants at that rural site. Our interview took place at the local hospital telehealth room rather than his home, at his request. Vic and I had met once before. He and his wife attended a MOST session in person while in Thunder Bay. Vic had just returned to modified work since his stroke at the time of our interview. Prior to his stroke, he was extremely

involved in Toastmasters and was just starting to get involved with this social public speaking group again. He is the father of three children and has four grandchildren.

Appendix E: Detailed Description of First Two Interviews

Prior to the first set of interviews, in the first community, I was slightly nervous. I was excited to meet the five people I was interviewing that day as I felt I had a strong positive rapport with all the participants. They had participated in two separate groups, but I also knew from talking with them that they were acquainted with one another. However, the anxiety was still evident. This was the real thing. As I drove to the first town, I prepared myself by reviewing some of the questions I wanted to ask, so that I would not need to read directly from the interview guide during the interview.

I arrived at my first appointment slightly ahead of schedule, so did a quick shopping errand prior to arriving at the first house. The first couple I interviewed was Martha and Doug (all names are pseudonyms). Both had participated in the sessions. Martha greeted me at the front door and escorted me through the house to the kitchen. Doug was standing at the sink doing the breakfast dishes. We had a brief welcoming chat about how nice it was to meet in person again. Our first meeting had been brief, during an assessment meeting more than six months previously. I presented them with a thank you card and some coffee gift certificates for taking the time to do the interview on such a beautiful summer day. I knew from our phone conversation to arrange the interview that they were traveling the next day by bus to southern Ontario. The two of them were aware that the interviews would be done with each of them separately. They had decided, prior to my arrival, that I would meet with Martha first while Doug had some errands to do within the house, and then I would meet with Doug while Martha had some shopping in town to complete.

Martha and I took a freshly poured cup of coffee outside on the deck to a patio table. There was a lovely large pear tree in full leaf perfectly shading the deck and table. The day was warm, even at such an early hour, but the shade of the tree made the temperature pleasant, but not

too cool in my capri pants and t-shirt. I reviewed the statements on the consent form and assured Martha of confidentiality and anonymity. I showed her the digital audio recorder and again asked for permission to use the recorder to ease transcription and to be able to actively participate in our conversation rather than taking notes. She was agreeable. Both of us were comfortable on the sling back nylon patio chairs but remained in an upright sitting position at the edge of the chair rather than completely reclined. We were both comfortable, but engaged.

I started with an explanation of my role and the objectives of the study and then opened with my first question. As the interview progressed, Martha was very thoughtful with her responses. As the interview appeared to be drawing to a close, I quickly glanced over my interview guide sheet to ensure that I had not missed any key points or questions. Assured, I started to summarize the key points that I felt that Martha had presented during the interview that directly related to the impact of the videoconference on her participation and experience as well as the barriers and suggestions that she spoke of. I then asked for assurance that her points had been captured correctly and that she had nothing further to add. I was pleased with my probing, summarizing, and active listening during the interview as her reflection and shared experiences were both reaffirming and novel, even surprising. My interview with Martha lasted about thirty minutes.

Martha went into the house to tell Doug it was his turn. I remained on the deck. When Doug arrived on the deck with Martha, she bid farewell and excused herself to do her shopping errand in town. Doug started the interview by asking the question himself about the purpose of the interview. I reviewed the purpose and with his satisfaction, then reviewed the consent form again. Upon approval, I started the audio recorder. The interview with Doug was more challenging than with Martha. He was very analytical and questioned his own interpretation of each question. He was also very reflective of the MOST program as a whole and his participation during the sessions. He contemplated his personality and personal biography as having an impact

on the nature of his participation during the group. With some probing, he also questioned the impact of the videoconference on his participation for the discussion part of the session. He was unable to distinctly differentiate the difference or relative impact of his personal experiences growing up and his personality, with the videoconference technology, the group itself and its members, or with his cognitive and memory difficulties which he had been aware of since his stroke. I finished the interview with a quick visual reference to the interview guide to make sure that I hadn't missed any key points or questions. I then reviewed each of the key points that I felt he had made and asked for assurance that my interpretation was correct and there was nothing more he would like to add.

There were many times during the interview that I attempted to clarify his reflection or opinion, as much of his discussion was repetitive with no clear conclusion. Later, during extensive review of the transcription, I became aware of another train of reasoning- that he was finding difficult to express during the interview, or at least I was having difficulty understanding during the interview; he was very astute about saying something during the group that would impact another's feelings. He was actually very empathetic towards the others and certainly did not feel that he should share some of his experiences, or suggestions, for concern that the other group members may feel judged, or inadequate. As I said, upon completion of the interview, my perception was that the data would not be useful, or certainly would be difficult to analyze as he appeared to have had so many difficulties expressing his thoughts coherently and it almost appeared that he was confabulating, possibly to counteract his memory difficulties. Upon my own analysis and re-reading of the interview transcription at a later time, I realized that it was me that was having difficulty, during the moment of the interview, following his elaborate, very insightful, and reflective thinking. Again, the interview was about thirty minutes. At the end of the interview, I stood up with Doug to thank him. I followed him into the kitchen with my coffee cup and to say goodbye. Martha had arrived back from her shopping so I was able to give them

both a hug goodbye, thank them again for the interview and time that morning and wish them well on their travels and summer vacation the next day.

At the end of the interview, I returned to my car. My next interview was not for thirty minutes so I drove down the streets to a quiet public park on the riverfront with my laptop and digital recorder. In front of the river, with the mill of the other side, leaning against a tree, I downloaded the audio files from both interviews and wrote notes on my personal reflections of the interviews including description of the environment and situation. I then reviewed the question guide and started thinking about the next participant I would be interviewing.