

The Impact of a Community Re-engagement Cue to Action Trigger Tool on the Re-engagement in Valued Activities Post Stroke



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Executive Summary

The needs and issues faced by persons living with stroke are multi-dimensional and complex. They feel dependent on healthcare providers to guide their care and recovery but often have difficulty obtaining the support and information they need to re-engage in meaningful activity¹. Often, persons with stroke and caregivers are reluctant to ask questions or simply don't know what questions to ask their healthcare team^{1,2} to facilitate recovery and re-engagement back into the community. For the purposes of this study, Community Re-engagement (CR) is defined as “a holistic approach to the reorganization of physical, bio-psycho-social characteristics so that an individual can resume well-adjusted living after illness”³.

This project builds on previous Ontario Stroke Network funded study that evaluated the impact of a community re-engagement (CR) education intervention, which integrated concepts of interprofessional collaborative care and a CR framework, on healthcare providers' day-to-day practice¹. The CR framework was used to create a trigger tool for healthcare providers to facilitate conversations with persons with stroke and caregivers.

A recommendation from this study was to develop a patient-mediated question prompt tool for persons with stroke, using the same CR framework to enable a self-management approach to their care. The literature suggests that patients who ask questions are more likely to elicit useful information which consequently leads to an increase in self-efficacy and a greater sense of confidence and control over their care”⁴.

The trigger tool was modified for persons with stroke and caregivers and renamed: Community Re-engagement Cue to Action Trigger Tool (CRCATT). The purpose of the tool is to serve as a starting point for persons with stroke to have meaningful conversations with their healthcare team to better self-manage and anticipate their needs as they transition to community living.

Purpose

The primary objective of the study was to determine if persons with stroke would report higher participation in valued activities and self-report more positive experiences in their re-engagement process than those who were not exposed to the CR CATT. This study also explored if and how

1. the CR CATT prompts persons with stroke to have enhanced discussions with healthcare providers on the topic of re-engaging in valued life roles;
2. the intervention assists persons with stroke to better anticipate their care needs;
3. this in turn results in enhanced inquiry into stroke related services and information; consequently improving life participation post stroke.

Methods and data analysis

This multi-site, single-blind randomized controlled trial was conducted in Toronto, Canada. The study employed a convergent parallel mixed methodology⁵ allowing the quantitative and qualitative portions of the study to provide different but complementary perspectives on the persons with stroke's experience with CR. Informed consent was obtained from each participant who met the inclusion criteria. Approval was granted by research ethics board of each participating institution.

Quantitative data was obtained through the Return to Normal Living Index. A t-test was conducted to compare the intervention and control groups' total RNLI scores. Regression analysis was done to examine group differences while controlling for demographic characteristics including age, gender,

education, and first language. Chi-square analysis and t-tests were also used to compare the intervention and control groups with respect to demographic characteristics.

Qualitative data was obtained through semi-structured interviews conducted with persons with stroke. Interviews were audio-taped and transcribed verbatim, audio-checked for accuracy and thematically coded using an inductive approach.

Data collection occurred 3-4 months after study enrollment. This time frame was selected to allow participants the opportunity to begin to adjust to lifestyle changes post stroke.

Intervention

Participants were randomly allocated to one of two intervention arms. The experimental group received the CRCATT, in-person instructions (at two-points in time) on how to use the tool, a tip sheet on how to communicate with healthcare providers and a booklet developed by the Heart and Stroke Foundation. The control group received only the booklet.

Findings

Seventy-seven persons with stroke were recruited from three rehabilitation hospitals (which include 3 inpatient and 2 outpatient programs) in Toronto, Canada. Of the total sample of 77 persons living with stroke, 57 (control n=27; intervention n=30) completed the RNLI and 35 of the 77 participants (control n=19; intervention n=16) took part in an interview.

An independent sample t-test was conducted to evaluate the hypothesis that the intervention group mean total RNLI scores would be significantly different from the control group mean total RNLI scores. The test was not significant. One-sample chi-square tests and t-tests were conducted to assess whether gender, level of education or English as a first language influenced the treatment group scores. The null hypothesis is that there is no effect between the variables and the treatment group scores.

Multiple regression analysis was conducted to determine the contribution of intervention arm and demographic characteristics to the RNLI total scores. The variables included English as a first language, treatment group, age, gender and level of education, while the dependent variable was the RNLI scores. The linear combination of demographic and intervention variables were not significantly related to the RNLI total scores. Based on these correlational analyses, level of education may be a useful predictor for the RNLI scores. In other words, those with a higher level of education are much more likely to participate in valued activities compared to those with a lower level of education. Statistical power was calculated using Univariate Analysis of Variance to verify the possibility of type II error. Observed power was .062 which suggests the possibility of type II error as a result of a small sample size.

As evidenced in the qualitative findings, there exists a multitude of internal and external factors which emerged as salient to participants' recovery and ability to re-engage into the community. External factors include formal and informal social supports, interactions with healthcare providers and strategies to access information. Internal factors include personal attributes and how one views their recovery through a sense of independence, feeling in control and being able to participate in meaningful activities.

The interplay of the CRCATT with each of these factors was explored to understand the tool's added value on CR. Findings suggest that for some in the intervention group, the CRCATT appeared to have an

impact on facilitating question-asking regarding multiple areas of community re-engagement, enhancing their awareness of needs, and providing participants with a sense of control over their recovery.

There is an abundance of collected works on the effects of stroke, people's lived experience with stroke, and some of the factors that influence recovery. However, literature on factors that contribute to successful community re-engagement and the strategies to facilitate this process remain scarce. To the best of the authors' knowledge, no model currently exists to depict the host of internal and external factors that were said to influence recovery and contribute to community re-engagement. A community re-engagement model constructed and proposed by the authors posits that there exists an influential relationship between community re-engagement and the multiplicity of factors that contribute to it.

The model presented can act as a starting point to illustrate the dynamic interplay of factors that influence recovery and CR. However, further research is required to investigate how additional factors such as function, cognition, mood, the role of the family caregiver, etc. may impact the use and the value of the CRCATT. Future studies may also inform the optimal timing of the provision of the CRCATT and for whom the tool is best suited for. Based on participant feedback of the CRCATT, a next step includes the following modifications: 1) further separating out the questions; and 2) more specificity on the areas of return to work and return to driving.

Conclusion

The CRCATT can be seen as a useful tool for some persons with stroke to take a more self-directed role in their care by asking relevant questions and being able to anticipate their needs. The tool did complement the complex external and internal factors that persons with stroke draw on to recover and participate in valued activities post stroke.

1.0 Background

Stroke is a sudden and unanticipated event affecting all facets of a person's life, leaving them and their families ill-prepared to deal with the complex range of disabilities and the uncertain future which it brings⁶. There are a number of different beliefs about what is most important to recovery, ranging from stroke prevention to physical rehabilitation, but community re-engagement (CR) is often overlooked⁷. Not surprisingly, persons with stroke express a low level of satisfaction with community re-engagement as they return to community living⁸.

CR is defined as “a holistic approach to the reorganization of physical, bio-psycho-social characteristics so that an individual can resume well-adjusted living after illness³” and should be considered as central in the stroke recovery process. Furthermore, according to the International Classification of Functioning, Disability and Health (ICF) model endorsed by the World Health Organization, activity (i.e. the execution of a task or action by an individual) and participation (i.e. involvement in a life situation) are important components of health and functioning⁹.

To be adequately prepared for their transitions to community living, patients, families and caregivers must be provided with information, education, training, emotional support and community services specific to the transition they are undergoing¹⁰. Despite this Canadian best practice recommendation, studies have shown that persons with stroke and their caregivers are not given enough timely and relevant information about their recovery process^{11,12,13}. Improving meaningful and targeted communication between healthcare providers and persons with stroke may be a critical piece in the recovery process to ensure they receive the care and support they need. Equally important to this dynamic is the role of the caregiver/family. Families are often centrally involved in providing and/or supporting care once the person with stroke returns home therefore their ability to communicate with health care professionals is equally vital.

Often overwhelmed with an unexpected stroke event, persons with stroke and caregivers are reluctant to ask questions or simply don't know what questions to ask their healthcare team^{1,2}. The literature suggests that patients who ask questions are more likely to elicit useful information consequently leading to an increase in self-efficacy and a greater sense of confidence and control over their care⁴. According to a Cochrane review, the provision of information strategies which actively involve patients and caregivers should be used in routine practice¹⁰.

Patient-mediated interventions, in particular ‘Question-Asking Tools’ or ‘Prompt Sheets’ have been documented as an effective approach to actively involve patients to implement appropriate, effective, informed and responsive self-care¹⁴. Question-asking is a form of patient-mediated intervention designed for patients to elicit useful information from healthcare providers and to engage in meaningful conversations¹⁵ and improve clinical decision-making¹⁴. In a number of healthcare contexts including cancer, diabetes, primary care, cardiology, providing patients with a structured list of questions (also known as a question prompt list) have been shown to reduce anxiety, improve knowledge, increase patient involvement, access to services and create positive perceptions around communication and satisfaction with care^{15,16,17}.

The work presented here builds on previous research (Cheung and McKellar, 2012)¹ that evaluated the impact of a CR education intervention, which integrated concepts of interprofessional collaborative care and a CR framework, on healthcare providers' day-to-day practice. An initial tool was created to help healthcare providers interact with persons with stroke about CR and facilitate collaboration across

healthcare settings. A recommendation from this study was to design and develop a similar tool for persons with stroke that would empower them to ask their healthcare providers questions related to CR. This tool was named: [Community Re-engagement Cue to Action Trigger Tool \(CRCATT\)](#).

To date, and to the best of our knowledge, no studies have examined the use of question prompt lists as a means to facilitate self-reported re-engagement in valued activities post stroke. Results of this study may help close the current knowledge gap in this area. Findings may also inform the use of a communication tool as a way for persons with stroke and their caregivers to begin self-directing their care and anticipating their CR needs.

Using a mixed-methods design, our primary objective was to determine if persons with stroke would report higher participation in valued activities and report more positive experiences in their re-engagement process than those who were not exposed to the CRCATT, a patient-mediated question prompt list. This study also set out to explore if and how:

1. the CRCATT prompts persons with stroke to have enhanced discussions with healthcare providers on the topic of re-engaging in valued life roles;
2. the intervention assists persons with stroke to better anticipate their care needs;
3. the results enhanced inquiry into stroke related services and information; consequently improving life participation post stroke.

2.0 Methods

2.1 Design

This multi-site, single-blind randomized controlled trial was conducted in Toronto, Canada. The study employed a convergent parallel mixed methodology⁵ allowing the quantitative and qualitative portions of the study to provide different but complementary perspectives on the experience with CR of persons with stroke. All data collection occurred 3-4 months after study enrollment. This time frame was selected to allow participants the opportunity to begin to adjust to lifestyle changes post stroke. Informed consent was obtained from each participant. Approval was granted by the research ethics board of each participating institution.

2.2 Participant recruitment

Patients were recruited from one of three rehabilitation organizations in Toronto with inpatient and/or outpatient stroke programs between January 2012 and December 2012. Based on the following criteria, staff within the patient's circle of care approached potential patients about their interest to participate in the study:

Inclusion criteria

- aged 18 years or older
- have a primary diagnosis of ischemic or hemorrhagic stroke
- sustained either a first stroke or did not require a multi-week in- or outpatient rehab program for a previous stroke;

Exclusion criteria:

- were unable to engage in the informed consent process
- had severe aphasia and language barriers

- were being discharged to institutional living
- had cognitive deficits significant enough to preclude the informed consent process.

Caregivers were also included if/when available. Caregivers are defined as individuals centrally involved in the provision or coordination of care for persons with stroke without financial compensation. They were included if they understood the purpose of the study, spoke English and provided care to a person with stroke who met the inclusion criteria.

The qualitative sample was derived from the larger sample and was purposive to include a range of ages, gender, levels of education and availability of live-in caregiver support.

2.3 Randomization

A restricted randomized procedure, known as blocked randomization¹⁸, was used with a 2 and 4 block design. A one-to-one allocation was used to achieve balanced randomization. To preserve unpredictability of participation allocation, a statistician not otherwise involved in the study selected the block size and used a computerized random number generator to allocate the treatment assignment (intervention vs. control). An allocation schedule for each study site was encrypted and sent to the principal investigator (PI). Only the PI had access to the random allocation sequence. The research coordinator contacted the PI by phone to receive the allocation assignment once participants enrolled in the study.

2.4 Blinding

In this single-blinded study, the study assessor who conducted the interviews was blinded to the allocation. Healthcare providers may have become aware of those who were part of the intervention group if participants used the tool during treatment sessions or other interactions. Healthcare providers were asked not to change their usual practice but were informed that they might be asked questions from the CRCATT at the discretion of the participant. The study assessor became aware of study allocation during the qualitative interviews due to participants' responses to questions from the interview guide.

2.5 Intervention

The CRCATT was designed to help prompt persons with stroke and their family/caregivers to better anticipate their needs following stroke and take a more active role in directing their care. This tool covers eight areas for CR: 1. My Health; 2. Where I live; 3. Getting Around; 4. Social Support; 5. Life Roles; 6. Caregiver Support; 7. Communication; 8. Money Matters. Each area is comprised of questions persons with stroke and their family/caregiver may have about their needs as they return to live in the community. The tool is meant to serve as a starting point for meaningful conversations with healthcare providers and others engaged in their recovery.

Participants were randomly assigned to receive the CRCATT or usual care. The intervention consisted of two 20-30 minute scripted conversations that took place with participants at week two and again at week four following their admission to inpatient or outpatient rehabilitation. Based on the literature¹⁹, it is believed that participants would benefit most from the intervention during the rehabilitation phase of their recovery. During this phase, persons with stroke's medical condition has stabilized, they are able to focus on accessing information and resources, practice new skills and deal with psychosocial issues needed to adapt to their new situation¹⁹.

Participants received the CRCATT, a tip sheet on how to communicate with healthcare providers²⁰ and the Let’s Talk about Stroke booklet (an information guide for survivors and their families) created by the Heart and Stroke Foundation of Canada. The intervention was delivered outside of therapy times, minimizing any disruptions to participants’ usual care. Family/caregivers were encouraged to be present during the intervention.

A scripted conversation guide was used by the research coordinator to optimize consistency in the messaging during the interventions. The purpose of the first session was to introduce and orient the participant to the use of the tool. The second session was to reinforce the use of the tool and address any questions. A description of the process for each session is stated in the table below.

Table 1: Intervention Procedure

Week 2	Week 4
<ul style="list-style-type: none"> • The research coordinator began by providing a copy of the Let’s Talk about Stroke booklet and the CRCATT. • The research coordinator introduced the purpose of the CRCATT and reviewed each section. Participants were asked to recount what they had understood between each phase of the explanation process. • A tip sheet on how to effectively communicate with members of the healthcare team²⁰ was provided. Discussions around this document included encouraging the participant to review the CRCATT, identify components or specific questions they may have and to discuss their concerns formally or informally, with members of the healthcare team. • There was an opportunity to practice role play using the CRCATT to demonstrate how they could use the information on the tip sheet to engage the healthcare team. • Participants were provided with an appointment card indicating the date and time the research coordinator would be returning. 	<ul style="list-style-type: none"> • The research coordinator began the session by enquiring as to how the tool had been used since the initial visit. • The research coordinator reviewed the tip sheet from week two and held discussions with participants on their experiences with trying to incorporate the CRCATT during their formal/ informal interactions with the healthcare team. • Participants were provided with another opportunity to role play with the research coordinator to build comfort (or confidence) in using the CRCATT. • Specific questions related to their recovery, concerns with services received, issues with their healthcare team, discharge planning, goal setting, accessing resources and information were redirected to their healthcare team.

Control Group (Usual Care)

The interaction with the control group was limited to providing participants with a copy of the Let’s Talk about Stroke booklet.

2.6 Outcome Measures

Return to Normal Living Index Questionnaire

The primary outcome was satisfaction with CR as measured by the Reintegration to Normal Living Index (RNLI). The RNLI provides a patient-centred assessment of re-integration and has the strongest association with the rating of quality of life³. The RNLI is a standardized assessment tool designed to assess, quantitatively, the degree to which individuals who had experienced traumatic or incapacitating illness achieve reintegration into normal social activities (e.g. recreation, movement in the community, and interaction in family or other relationships)³. The RNLI has been tested for use when self-administered by individuals with stroke and was selected as a standard outcome measure by the Canadian Stroke Strategy. Reintegration to normal living was defined by the scale authors as “*the reorganization of physical psychological and social characteristics of an individual into a harmonious whole so that one can resume well-adjusted living after an incapacitating illness or trauma*”³.

The RNLI consists of 11 declarative statements representing the domains 'daily functioning' (indoor, community, and distance mobility; self-care; daily activity (work and school); recreational and social activities; family role(s); personal relationships; and 'perception of self'(presentation of self to others, general coping skills²¹. Each statement is rated by the respondent on a 10 cm visual analogue scale with the anchor statements of “*Does not describe my situation*” (1 or minimal reintegration) and “*Fully describes my situation*” (10 or maximum reintegration).

The scores for each item were summed and then normalized to 100, with a score of 100 indicating that the participants were fully satisfied, scores of 60 through 99 indicating mild to moderate restrictions in self-perceived community reintegration, and scores of less than 60 indicating severe restrictions in self-perceived community reintegration⁸.

Procedure

The study questionnaire (RNLI), a cover letter explaining its purpose and a self-addressed stamped envelope was mailed to all participants 3 months after enrolment in the study. The Dillman Total Design Method²² was utilized to optimize the response rate. A telephone reminder was done with all participants 1-week later. If required, a reminder letter with a replacement questionnaire was sent to participants. After 3 weeks, non-responders received another reminder letter and replacement questionnaire by mail.

Qualitative Interviews

Semi-structured qualitative interviews with a sub-set of participants selected from both the intervention and control groups were conducted to elicit participants' own stories as they relate to CR and their ability to anticipate their recovery needs. The interview guide was designed to be focused, yet flexible and conversational²³ to understand participants' experiences of having conversations with healthcare providers, and their perceived understanding of their needs for community re-engagement.

Purposive sampling (age, gender, level of education, mother tongue and availability of caregiver support) was used to select participants for an interview in order to learn about the factors that may influence engagement and use of the CRCATT.

Procedure

Interviews were held at a mutually agreed upon time and location between the interviewer and participant. All interviews were digitally recorded with permission and subsequently transcribed verbatim with all identifiers removed.

The same interview questions were asked of all participants to ensure the interviewer was blinded to group allocation. If the participant brought up the CRCATT during the interview, the interviewer would then probe further about the CRCATT. If the CRCATT was not discussed during the interview, the interviewer presented the CRCATT at the end of the interview to uncover whether or not they had seen the tool. If they had received it as part of the intervention, the interviewer asked questions about its use and value. If the tool had not previously been seen, the interviewer provided the participant with a copy to review for about 10 minutes. Participants were then asked to provide their initial impressions on the tool.

2.7 Quantitative Data Analysis

Summary statistics were used to describe the participants. Data were coded to ensure confidentiality. Missing data were omitted on an analysis by analysis basis. Chi-square analysis and t-tests were used to compare the intervention and control groups with respect to demographic characteristics. T-test was also used to compare intervention and control group scores on the RNLI. Regression analysis was used to examine group differences while controlling for demographic characteristics including age, gender, education, and first language.

2.8 Sample size

Allowing for a 20% attrition rate in the intervention and control groups, a sample size of 63 participants was needed in each of the two groups. For the Reintegration to Normal Living Index, considered a primary outcome for this study, estimated change for the study population is .5 of the standard deviation. A sample size target for the qualitative interview was 25% of the total number of participants recruited. This target as expected to allow for theme saturation and capture a variety of lived experiences.

2.9 Qualitative Data Analysis

Interview transcripts were analyzed using an inductive approach (Glasser and Strauss, 1967), that follows the conventions of thematic analytic procedures, and which focuses on developing categories, derived inductively from the data itself, rather than from a priori theory, to enable systematic description of the data²³. Rigor was ensured through several methods. Three members of the research team hand coded the same data independently of each other before comparing their results. Each member read the transcripts a number of times, selected and defined categories and assigned coding labels. Interpretations of the categories were compared and discussed which led to the refinement and relabeling of some of the categories.

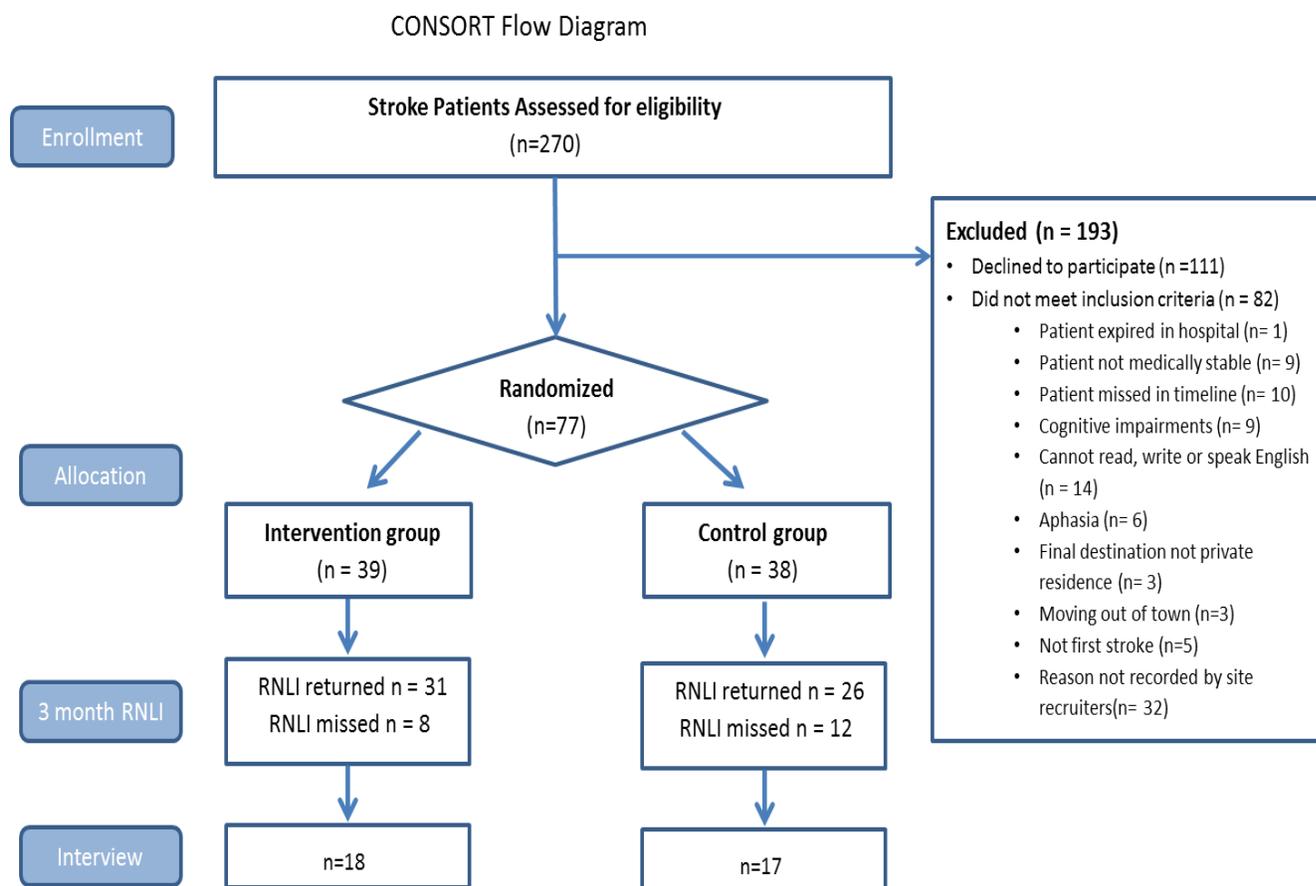
The final analysis was based on the consolidation of major categories extrapolated from the transcripts and deleting those that were under-represented, ultimately generating two major themes grounded in the data. At the analytical level, data were analyzed with a focus on similarities and differences between intervention arms.

3.0 Results

3.1 Recruitment

Recruitment took place over a 12 month period (January 2012 to December 2012) with follow-up occurring between March 2012 and February 2013. 77 of the 270 people referred to the study agreed to enroll (see CONSORT diagram).

Figure 1: Patient recruitment flow diagram



3.2 Participants

Participants included 77 persons who experienced a stroke (48 men and 29 women); they ranged in age from 25-93 (median age of 58); had different levels of education (51.9% had a college of university degree and 41.6% had a high school diploma or less); 75%, spoke English as a first language; and just over half had live-in caregiver support. (See table 2)

Table 2. *Characteristics for all participants (N=77)*

Total Characteristics	Controls	Interventions	
	(N= 38)	(N=39)	(N=77)
Age (range)	58 (25-93) [†]	57 (29-90) [†]	58 (25-93) [†]
Gender			
Male	24 (63.2%)	24 (61.5%)	48 (62.3%)
Female	14 (36.8%)	15 (38.5%)	29 (37.7%)
Level of Education			
High School or Less	18 (47.4%)	14 (35.9%)	32 (41.6%)
College or University	17 (44.7%)	23 (59%)	40 (51.9%)
No answer	3 (7.9%)	2 (5.1%)	5 (6.5%)
English as a First Language			
Yes	31 (81.6%)	27 (69.2%)	58 (75.3%)
No, Other	5 (13.2%)	11 (28.2%)	16 (20.7%)
No answer	2 (5.2%)	1 (2.6%)	3 (4.0%)
Caregiver Support			
Yes	22 (58%)	21 (53.8%)	43 (55.8%)
No	14 (36.8%)	17 (43.6%)	31 (40.2%)
No answer	2 (5.2%)	1 (2.6%)	3 (4.0%)

[†] Median (Age range of participants)

Table 3: Participant characteristics for completed RNLI and Interviews

Characteristics	RNLI (n=57)			Interview (n=35)	
	Control N=27	Intervention N=30	P value	Control N=19	Intervention N=16
Age	60.22 (25-85) [†]	57.70 (29-78)	0.420	61 (25 – 85)	58 (42- 83)
Gender					
Male	19 (70.4%)	19 (63.3%)	0.574	14	10
Female	8 (29.6%)	11 (36.7%)	0.574	5	6
Level of Education			0.237		
High School or Less	14 (51.9%)	11 (37.9%)		9	3
College/University	12 (44.4%)	18 (62.1%)		10	13
Not reported	1 (3.7%)				
English as a First Language			0.273		
No, Other	4 (14.8%)	8 (26.7%)		18	14
Yes	23 (85.2%)	22 (73.3%)		1	2
Caregiver Support*			0.269		
No	8 (29.6%)	14 (46.7%)		11	9
Yes	17 (63%)	16 (53.3%)		8	7
Not reported	2 (7.4%)				

[†] Median (Age range of participants)

*5 caregivers (1 sister; 1 mother; 3 spouses) participated in the interview with the person with stroke.

3.3 Quantitative Results

Descriptive statistics

Of the total sample of 77 persons living with stroke, fifty-seven (control group n=27; intervention group n=30) completed the RNLI 3-4 months after the intervention. Twenty percent more participants in the intervention group had a higher level of education than those in the control group, and fewer had no live-in caregiver support. Please refer to table 3 a more detailed summary of participant characteristics.

Statistical tests

An independent sample t test was conducted to evaluate the hypothesis that the intervention group mean total RNLI scores would be significantly different from the control group mean total RNLI scores. The test was not significant, $t(57) = -.163$, $p = .87$. The total RNLI scores in the intervention group ($M = 85.7$, $SD = 3.45$) on average had the same total RNLI scores as those who were in the control group ($M = 84.8$, $SD = 23.53$).

One-sample chi-square tests were conducted to assess whether gender, level of education or English as a first language influenced the treatment group scores. The null hypothesis is that there is no effect between the variables and the treatment group scores.

Table 4 reports the results of the multiple regression analysis conducted to determine the contribution of intervention arm and demographic characteristics to the RNLI total scores. The variables included English as a first language, treatment group, age, gender and level of education, while the dependent variable consisted of the RNLI scores. The linear combination of the demographic and intervention variables was not significantly related to the RNLI total scores, $F(5, 49) = 2.176, p > .05$.

Indices to indicate the relative strength of the individual predictors are presented. Only one of the five indices was statistically significant ($p < .05$). Based on these correlational analyses, level of education may be a useful predictor for the RNLI scores. In other words, those with a higher level of education are much more likely to participate in valued activities compared to those with a lower level of education. Furthermore, the beta for gender being .24 and for education .43, suggests that education has a larger impact on community reintegration than gender.

A power calculation using Univariate Analysis of Variance was done to determine if the sample size was large enough to demonstrate treatment benefit. Observed power was .062, which suggests the possibility of type II error, indicative of insufficient power to detect a difference, and a limitation in testing the study's primary hypothesis.

Table 4: Multiple Regression Analysis of the Predictors with RNLI total scores

Model	Coefficients ^a			
	Unstandardized Coefficients		Standardized Coefficients	Sig. p value
	B	Std. Error	Beta	
1 (Constant)	65.846	16.400		.000
Gender**	-10.720	5.924	-.243	.076
Treatment Group	-.339	5.444	-.008	.951
Age	.181	.223	.116	.422
Level of Education	18.067	6.212	.434	.005
English as a First Language	4.376	7.114	.085	.541

* $p < .05$

** gender was coded using the following: male is 0 and female is 1

Seventy-four percent of participants completed the RNLI. After statistically controlling for the effects of gender, treatment group, age, and language, no between group differences were observed due to small sample size. Of note, although not statistically significant, those with higher education are more likely to participate in valued activities.

3.4 Qualitative Results

As previously stated, qualitative semi-structured interviews were conducted to learn through participants' own accounts, about their experiences in engaging healthcare providers in conversations and in anticipating their needs as they relate to community re-engagement. Thirty-five interviews were completed, of which 19 were from the control group and 16 from the intervention group. No individual caregiver interviews were conducted. Interviews lasted between 29 and 90 minutes, with an average length of 50 minutes. The sample population for the interviews consisted of 24 males and 11 females, ranging in age from 25 to 85. See table 3 for a more detailed summary of participant characteristics.

Through the analysis four noticeable and distinct categories and sub-categories were represented in the transcripts. Each category emerged as particularly salient to the participants' recovery and ability to re-engage into the community. These four categories (and respective sub-categories) were subsequently classified into two main themes which illustrate how these seemingly played a role in participants' recovery and community re-engagement.

The first theme refers to the factors external to a person's environment and the outside influences perceived to contribute to recovery and community re-engagement. The first category in this theme relates to the role that formal and informal sources of support play on participants' ability to re-engage into the community and the meaning it holds in recovery. The second category pertains to participants' interactions with healthcare providers which encompass participants' ability to engage healthcare providers in conversations and their access to information to support their community re-engagement needs.

The second major theme relates to internal or personal influences as enablers to community re-engagement. The first category pertains to personal attributes of the person with stroke. The second category relates to how the person with stroke views their own recovery. This theme serves to illustrate how personal outlooks affect recovery as well as how participants perceive their recovery by the degree to which they feel independent, have control over their recovery and are able to anticipate their needs.

Similarities and differences between intervention arms will be highlighted in the following descriptions of themes. The interplay of the CRCATT within each of the categories is also explored to understand the tool's added value on CR. Direct quotes are used to illustrate interpretation of the findings.

3.4.1 External Factors for Recovery and CR

i. Formal and Informal Support as enablers to community re-engagement

Participants described the availability or actual provision of a range of informal (caregivers, friends, family, colleagues) and formal (health and social care system) sources of supports perceived as important to their overall recovery and community re-engagement.

The key sources of informal supports were family members. Family, and in particular family caregivers, were often stated as centrally responsible for many aspects of a person's care and recovery once they left rehabilitation. *"I know I would have never ever got to where I am, have I not [Sic.] had my husband"* (01A 033, control, female, higher education, caregiver, retired). This quote serves to illustrate the important role played by caregivers in assisting the person with stroke to cope and re-engage in daily

living. Participants also recounted that when they felt emotionally supported; they were content and felt re-engaged with their social network.

In addition to the emotional support, participants discussed the various roles adopted by live-in caregivers and family members that served to facilitate recovery and community re-engagement. Some of these roles included advocate, cook, shopper, nurse and homemaker. A recurrent example of an activity requiring support from others was transportation. While it caused some participants to feel like a burden, access to transportation through family supports made them feel less isolated from the community.

In the absence of a familial network, many of these roles fell to friends, relatives and neighbours. Based on participants' accounts, there appeared to be a relationship between the perceived strength of social support they received from friends and colleagues, and their sense of feeling connected to the community. This type of informal support also emerged as important for participants in being able to manage and cope with their stroke.

By sharing the CRCATT with others, several participants in the intervention group found it helped to facilitate communication between themselves and family members concerning needs and "hidden worries". The tool was a means by which common concerns for current and future community re-engagement needs were "brought to the surface". This gentleman commented on how he and his wife used the tool to discuss issues about the future.

"Yeah, it helped us (wife) talk about the issues involved. I think more so than individual issues. It's just comprehensive, you know there's a lot you are thinking about, nervous, you don't know what's going to happen, and it asked the questions "(01A-024, intervention, male, working, higher education, has live-in caregiver)

In addition to their informal support network, participants described their need to access formal systems of support to resume activities and actively participate in their community. Formal supports are defined as publicly funded or fee for service programs or amenities provided by community, health or social programs.

Access to health and community supports was discussed less often by participants who described a strong support network of family and friends. Many described how formal services were often inadequate in meeting their personal care needs or were simply not always readily available to support their need to re-engage into the community. For this participant in the intervention group, attending a social recreation program was identified as important for her physical and psychosocial well-being and a feeling of being connected to her peers.

"And you know what really helped me was going to stroke survivor's program on Fridays, because there is this other lady she's in a wheelchair and she had the same stroke as I did on the same side. Her right side never regained feeling and it affected her voice. But she can communicate and I understand her now....., I'm still recovering, I still have 1 to 2 years left. you know a lot of the people there they are very courageous. They are 9 and 12 years into their stroke, 20 years whatever. They have productive lives and they do things and I said well I still have a chance and I'm just sitting with my thumb in my mouth. It helped me." (01B-015, intervention, female, working, higher education, no caregiver,)

The CRCATT was identified as enhancing this participant's knowledge of formal supports. The same participant gained awareness of her mobility needs and understood that accessing services would enhance her ability to get out into the community.

"It made me aware of things that I need to do or need to know, stuff like transportation, I need to know how I was going to get out and how I need to move around. (...) (03A-011, intervention, female, higher education, working, has live-in caregiver)

In short, while there was no substantive difference in the role or value of social support across groups, the assistance participants received from either formal or informal supports was perceived to contribute to their ability to re-engage into the community. Moreover, the presence and availability of informal supports seemed to enable participants to adapt to the consequences of stroke and address reported feelings of isolation. Furthermore, several recipients of the CRCATT spoke of its usefulness both in generating conversations with family members and in seeking out available services to support their re-engagement into the community.

ii. Interactions with healthcare providers

This category speaks to the perceived value that participants ascribed to their interactions with healthcare providers to find strategies to access information and get answers about their care, prognosis and recovery needs. Overall, participants reported feeling comfortable and at ease in conversing with healthcare providers. Several differences were found in how the intervention and control groups engaged in conversations with their healthcare providers. These differences are discussed below.

Healthcare provider engagement

The manner in which participants engaged healthcare providers in conversation differed between groups. The following quote illustrates how the intervention group appears to take a more proactive approach in initiating conversations and question-asking regarding their community re-engagement needs. This participant in the intervention group recounted how the research coordinator from this study discussed with him the importance of asking questions and how he was able to take this advice using the CRCATT.

"I ask questions, I feel comfortable asking questions....there was a lady that first came to talk to me. She's the one who was telling me if there is anything that is bothering you, you've got to ask the questions.....if something bothering me I just, if I go through it (CRCATT) and I see something in here, then I go to the doctor and ask" (01A-019M, intervention, male, working, high school, no caregiver,)

In contrast, those in the control group appeared more passive, waiting and relying on healthcare providers to initiate conversations.

"The therapists are the ones who initiated conversations about safety, returning home, transportation, equipment, etc. when I was there, I had to depend on them" (01A-039 control, male, retired, high school, has live-in caregiver,)

However, some participants who received the CRCATT discussed how it was not overtly useful because they had minimal deficits and already felt capable of asking questions without the tool. They

commented on how the tool would be of better use to those with more severe impairments and had more difficulty in knowing what questions to ask. However many acknowledged that the tool contained something useful or relevant to any person or caregiver living with stroke.

The second difference is the value participants attributed to their interactions with healthcare providers. While many participants accounted both negative and positive stories of their healthcare experience, those in the intervention group shared a more positive experience than those in the control group. The following woman in the intervention group felt that her questions were answered, that she was provided with adequate information and felt prepared for the future.

“Yeah they are good. Whenever I ask any question they use to give me good feedback.... This book is really good because before that I never think about what happen to me, I just heard it is a stroke. But I never try to find out why it happened, what are the things I can avoid in the future. Now my healthcare provider in ___ she have shared me so much information, She prepare me for the future. Now she is very, very nice. It gives me moral support also, when you can speak to somebody and you can share your feelings with somebody, so I’m very happy with her.” (01A-038F, intervention, female, working higher education, has live-in caregiver)

Contrary to the previous woman’s experience, many in the control group shared a similar experience to this gentleman who felt his conversations with healthcare providers were quite general and he felt he was on his own to figure things out:

“Like just general conversations, nothing in detail. Like they would suggest to me like what I could do to improve my movement, but nothing really other than that [...]. Like most, how I get to understand whatever was going to happen afterwards it would be like I was on my own, you understand.” (03A-006 control, male, high school, no caregiver, working)

The final difference pertains to the types of questions asked by participants and their knowledge of what questions to ask. While the intervention group asked a variety of questions related to their CR needs, those in the control group were more preoccupied with understanding the cause of their stroke, risk factors and the recurrence of stroke, as well as their time to recovery. Their questions were typically focused on their perceived needs in the moment versus what they might need in the future.

Yeah I ask some questions. Like when I was sick I try to find out what caused my stroke, and I get skipped around.....No, I didn’t ask much questions, I just worry what happened to me, how am I going to get out of this, that was my only concern of how to walk away from it, get better really” (03B-012, control, male, high school, no caregiver, not working)

Strategies to access information

The timing and amount of information provided by healthcare providers were important elements for participants to feel engaged in their care and recovery. There was a general sense from participants in both groups that information and support was provided most often from the nursing and rehabilitation staff. Doctors were also seen as a source of information; however they were often singled out as not providing sufficient information about the cause of their stroke and time to recovery.

Participants in both groups used different strategies to obtain information and manage their interactions with healthcare providers such as accessing the internet, referring to written information

received during the course of their treatment, and obtaining medical information and experiential knowledge from family members. For individuals who felt they received too much information or not the right type of information, the CRCATT was perceived as beneficial.

Some participants felt the tool helped “*provoke questions and thoughts*” about areas of needs they might otherwise not have been aware of. For example, this woman discussed how the CRCATT helped her prepare for the discharge home:

“And when I was coming out [of hospital] I have to figure out this and figure out that. We should have done this, should have done that. It brought everything to a point that you should do these things regardless if you are sick or not. We never think about those things, nobody thinks they are going to get sick. It came at a good point where I had to say, I need, we need to do this, this is something that we need to get done or it will not be beneficial to anyone. So it came at a good time.” (03A-011, intervention, female, working, higher education, has live-in caregiver, working)

For this gentleman who also received the CRCATT, he felt the tool helped with organization and ensuring all his needs were addressed:

“I found it helpful... it organized things a lot better. It was all there when I needed it. You know caregiver support, how are they dealing with it, are they showing signs of depression or burnout?.....it was useful to make sure everything was covered that they told me....it you went strictly to your GP you would need this if would be 100% essential” (01B-009, intervention, male, working, higher education, has live-in caregiver)

In summary, the data illustrates differences between how the intervention and control groups engaged in conversations and asked questions of their healthcare providers. Participants receiving the CRCATT asked questions they may not have thought of or found to be incomplete. Participants who did not receive the CRCATT seemed to rely more on healthcare providers to initiate and guide conversations and at times felt they were on their own. Overall comments on the CRCATT were positive in that the tool helped participants to get organized and prompted questions and thoughts about recovery and care needs

3.4.2 The Influence of Internal Factors on Community Re-engagement

In addition to the various external factors that may impact CR, many internal factors were considered influential in enabling CR. These included personal outlooks and attributes, coping skills and strategies as well as the degree to which the participant felt a sense of control over their recovery.

i. Personal attributes

There are several examples in the transcripts of the significant role personal attributes played in the participants’ recovery. Personal attributes denote the individual character traits that are inherent to a person’s identity. Participants in both the intervention and control groups used descriptors such as hard work, will power and motivation to describe their determination to overcome their limitations and re-engage into the community.

There are several examples which illustrate how a resolute disposition can sometimes influence one's ability/willingness to surmount the restrictions imposed by the stroke. Even with an optimistic outlook, this participant still perceived the CRCATT to be helpful for him

"There were some things in there where what would you do in this case, what would you do in that case.....I'm so positive in my thinking that when I went through it I learned some stuff from it, important stuff from it in general"(03A-014, intervention, male, high school, caregiver, retired)

ii. *One's own view of recovery*

From the stories recounted by participants, recovery holds a different meaning for different people. It is in these reflections that we define recovery. For some, it meant regaining independence while for others it signified re-engagement in meaningful activities. The concepts of independence, control and the anticipation of needs were repeatedly linked to this category.

Indicators of independence

Independence refers to the person's ability to do things on their own. Several aspects emerged in the data as contributing to participants' independence. These included being able to perform various instrumental activities of daily living (shopping, banking) and managing their self-care needs (bathing, dressing).

A significant number of participants felt that return to driving facilitated CR and was synonymous with independence. Many felt their inability to drive rendered them feeling isolated and dependent on others to get out into the community. The CRCATT empowered one gentleman to collect driving information that was accessible to him when he needed it, but which he otherwise might not have done:

"It didn't change the questions that I asked it helped form them, structure them I guess that's a better term.....I have certain notes about driving that I collected while I was doing and looking through it (CRCATT) that I have used I haven't followed up on it yet but it's something that I least I have it. I have it at my fingertips."(03B-005, control, male, working, higher education, no caregiver)

Financial constraints were another factor which was perceived to limit independence. Several participants suggested that due to limited financial resources they were unable to access services (taxis, private rehab services, recreational programs) and equipment required for independence. These participants who received the CRCATT felt the money matters section was helpful.

"..... it tells you about how you can manage your money, if you need financial help, you can get financial help, before that I was not aware of ODSP. Because we don't need at that time, we were not aware about the support from the government side."(01A-038, intervention, female, working, higher education, has live-in caregiver)

Feeling in control

Sense of control and anticipation of their needs were often discussed by participants when talking about their own recovery. For the most part, people felt they had some control over their recovery, holding themselves accountable for reaching their goals. Those who felt less in control spoke about the fear of

recurrent stroke and a lack of awareness of what to anticipate in their recovery. Fear of the unknown caused stress, anxiety and frustration for some.

Some participants reported a lack of control of their recovery during inpatient rehabilitation. It wasn't until they were discharged home that they began to feel in control. A select few expressed that no longer being dependent on healthcare providers, who did everything for them) forced them to push their own recovery forward.

For some CRCATT recipients the tool helped them to feel a sense of control knowing they were on the right path towards recovery and that they had considered the many elements that support their re-engagement.

"I kept reading it and I feel in control of my recovery...yeah it was a contribution to get my health back, it definitely helped.....it helps to keep track."(01A-017 intervention, male, working, higher education, has live-in caregiver)

Participating in meaningful activities

The need to participate in meaningful activities and feel a part of the community was strongly expressed by many participants of this study. Their ability to re-join sports and other physical activities was perceived as important to their sense of well-being. The meaning that people ascribe to CR was different for those who were still working prior to their stroke and those in retirement.

For those, who were employed, full recovery and community re-engagement seemed to hinge on their ability to return to work.

Retirees spoke more of re-engagement in terms of socializing, volunteering and resuming hobbies. Formal social recreational programs such as stroke peer support groups, aquatic programs, organized sports teams and exercise programs for persons with stroke were identified by participants as important to feeling socially connected. This participant who did receive the CRCATT found the tool helped him think about these areas.

"Well most of it (CRCATT) was thinking about what do I need in addition to what I know, what government assistance is there..... Do I want to go to any social, recreational or fitness programs...getting around...yeah it just made me think about them?" (03A-013 intervention, male, higher education, caregiver, retired)

Definitions of recovery were unique to each participant. The identified internal factors reported to contribute to their recovery included the possession of positive personal attributes, feeling a sense of independence and/or control and being able to participate in meaningful activities. It appeared that the CRCATT did play a role in helping participants feel a sense of independence and control and to consider additional activities and programs to promote re-engagement.

3.4.3 Suggested Improvements to the CRCATT

Analysis of the interviews also generated informative comments on the CRCATT and how it could be improved upon. Some participants who received the CRCATT discussed how it was not overtly useful because they had minimal deficits and already felt capable of asking questions. They found the tool would be of better use to those with more severe impairments and had more difficulty in knowing what questions to ask. Some commented that many questions were strung together as one question, yet to them it could be answered by both “yes” and “no”. This made it confusing for them to answer and was not helpful for them in determining their next steps. Others stated that more resources were required for the sections on return to work and return to driving.

A few participants also stated that they would have appreciated more ongoing involvement and reminders from healthcare providers and their caregivers to work with them in using the tool. Nonetheless, many acknowledged that the tool contained something useful or relevant to any person or caregiver living with stroke.

3.4.4 Control group’s perceptions of the CRCATT

Although it was not an objective of the study, it is interesting to note the initial reflections of those in the control group upon receiving and reviewing the CRCATT at the end of the interview. This group was provided about 10 minutes to review the tool and was asked to reflect on how the tool could impact on their interactions with the healthcare team and on their ability to anticipate their needs, if they had received the tool.

Many of the participants in the control group commented on how the tool could have been helpful. This caregiver of a participant felt the CRCATT was well organized and would have helped them think about the right questions to ask, at the right time and to keep things on track.

“I think this helps because many of the questions here, you are not thinking about them. You don’t even think, we were just living and thinking.....a caregiver should at least know at what point you can talk to the sick person about certain things. So we have to think about this or you are getting to a certain stage, this is what this suggests” (Caregiver of ...01A-039, control, male, high school, caregiver, retired)

This last quote by a gentleman in the control group captures the possible value of the CRCATT and how healthcare providers’ tend to focus on physical recovery, but need to move towards the emotional aspects of stroke and be more all-encompassing.

“Yes this one would have helped me at least think about questions, these are good questions..... I never thought about this stuff, questions like that. There’s no support about how this thing change your life.I feel changed.....nobody warn you, [there’s] no emotional support, no help. They care more about physical, you move you speak,[it’s] more important you have emotional peace then you can improve.....that was missing from the therapists, missing the emotional part, family part,than they send you out To me the emotional part is most important it will keep you going and fighting so you don’t give up” (01A-040 control, male, higher education, caregiver, working)

3.4.5 CR Model

There is an abundance of collected works on the effects of stroke, people’s lived experience with stroke, and some of the factors that influence recovery. However, literature on factors that contribute to successful community re-engagement and the strategies to facilitate this process remain scarce. To the best of the authors’ knowledge, no model currently exists to depict the host of internal and external factors that were said to influence recovery and contribute to community re-engagement.

The community re-engagement model (figure 2) proposed by the authors posits that there exists a correlational relationship between CR and the multiplicity of factors that contribute to it. Recovery and CR are at the core of the model. Surrounding the core are many influences which may impact the ability of a person with stroke to achieve optimal recovery and successful CR. Many of these influences have been discussed here, but further research is required. The inner layer represents the internal factors while the outer layer depicts the external ones. Each factor is represented by a different color because while important, they may not have the same relevance or importance for everyone. It is also unclear to what extent each factor contributes to CR.

Figure 2: Community Re-engagement Model



4.0 Discussion

Those living with stroke are not a homogeneous group. There are variations in how people adapt to the challenges they face after stroke and what influences their ability to successfully re-engage into the community. The purpose of this study was to determine if persons with stroke exposed to the CRCATT would assign higher scores to their participation in valued activities and would self-report more positive experiences in their re-engagement process than those who were not exposed to the CRCATT. The CRCATT is a question prompt list developed to serve as a starting point for persons with stroke to have meaningful conversations with healthcare providers to better self-manage and anticipate their needs as they transition to community living. Numerous researchers outside the realm of stroke have examined the use of question prompt lists in physician consultations as an approach to improve patient-physician communication and patient engagement^{2,15,16,24}. However, none have examined the use of such tools with those living with stroke.

Although the quantitative data was not able to identify a significant difference between the intervention and control arms, findings from the qualitative data suggest that for some in the intervention group, the CRCATT seemed to facilitate conversations, prompt question-asking, enhance awareness of community re-engagement needs, and provide participants with a sense of control over their recovery.

Also evidenced in our findings, there exists a multitude of internal and external factors which affect to varying degrees, participants' ability to anticipate their needs and re-engage in valued activities post stroke. These factors did differ between intervention arms. Social support, meaningful conversations, personal attributes, indicators of independence and a sense of control over recovery were found to positively (or negatively in case there was a lack of these attributes) contribute to community re-engagement. Similar factors were discovered in studies by Gallagher (2011)²⁵ and Jones (2008)²⁶. These and other factors may account for the finding of no significant difference in RNLI scores between the intervention and control groups. Pang (2011) states that a multitude of factors may underlie an RNLI score. As demonstrated in his study, advancing age, widowed and living alone, co-morbidity, and poor functional mobility may contribute to limitations in reintegrating to community living⁸. These and other factors such as mood, problem solving ability and socioeconomic status were not measured in this study. It is therefore possible that these variables may have played a role in participants' ability to manage, cope and resume well-adjusted living post stroke. Further research is needed to obtain a deeper understanding of the value of the CRCATT as it relates to these factors.

External factors

Qualitative research has repeatedly shown the positive contributions of social support on a person's well-being, recovery and their ability to adjust to crisis²⁶. Our findings are consistent with these studies in that participants identified the need and value of informal and formal sources of support to adjust to their daily activities and support their re-engagement back into the community. According to the Commissioning Support in the UK, stroke survivors and their carers often cite lack of information as a major barrier to engaging in active citizenship²⁷. What is unique to this study is the role that the CRCATT played in raising participants' awareness to the types of assistance or formal services they may require following stroke.

An unanticipated outcome of the study was how the CRCATT prompted participants to have conversations with family/caregivers around topics that may be difficult to discuss. It appears that the tool was more than just a list of questions but rather enabled the person with stroke and family to be

more involved in their care. Frederikson (1995) found that many studies equated patient involvement and questions asking together. He also acknowledges that patient involvement extends beyond questioning since the inclusion of information about concerns, beliefs, doubts, needs and views are equally important²⁸.

Similar to other findings in the literature^{12, 29}, there was a strong desire from participants to better understand the causes of stroke, prevention strategies and the availability of local community support services. However, the types of questions differed between the control and intervention groups. The questions asked by those in the intervention group covered a broader range of topic areas. The tool appeared to direct people to what is coming, allowing for much better preparation for the future. This was reflected by the fact that those in the intervention group moved forward in their questions and did not just focus on what caused their stroke. This difference could be explained by findings in a study by Cameron (2008)¹⁹ which highlights through the “Timing it Right” framework, the need for foundational information on what was the cause of the stroke and understanding what a stroke is for those in acute care and rehabilitation. It could be speculated that by understanding the types of questions to ask and understanding what is expected, those participants in the intervention group were able to pass through the initial information seeking period quicker. They may have reached a more adaptive phase where their questions were more succinct about the future and they were able to access the specific information that they needed through the CRCATT, hence taking a more proactive role.

Internal factors

Several participants expressed a strong fortitude and optimism to overcome the restrictions imposed by their stroke. The significance of hope, optimism and a positive mental health outlook on outcomes has been examined in the literature^{30,31}. Robinson-Smith (2000) states the extent to which a person with stroke believes they can control their activities and their autonomy is a critical factor in both their emotional state, their reported quality of life and their belief that they can live successfully after stroke³². For some participants who were provided with the CRCATT, it gave them a sense of control by helping them to keep things on track.

Participants judged their recovery by the degree to which they felt independent, in control and were able to anticipate their needs. Similar to a study conducted by Jones (2008) participants described how resuming meaningful activities, performing instrumental activities of daily living (shopping, banking) and managing their self-care needs (bathing, dressing) were confirmation of their progress²⁶. In fact, their ability to participate in these activities is a reflection of their independence.

For most, return to driving and return to work were symbolic of independence, recovery and community re-engagement. Poole, Chaudry and Jay (2008) state that a major contributor to post stroke patients' independence is their ability to drive³³. Griffen et al (2009) also concluded that driving has unique and substantial influence on community integration³⁴. Return to work was significant for the younger cohort in the study, and was perceived as indicative of their recovery. Corr and Wilmer (2003) also found that return to work is evidence that progress is being achieved and is the final hurdle to getting their life back³⁵. Given the importance that people ascribe to these life roles, more specificity may be required in the CRCATT to address these areas.

There is a shared perspective among individuals with stroke which relates to the importance of taking charge and being involved with decisions and active engagement in decisions³⁶. As seen in the data, participants spoke about their personal journey and the complex interplay of a number of factors. As noted, the CRCATT had perceived value by participants as it provided them with questions to ask related

to the eight areas of community re-engagement, or giving participants a sense of control over their recovery by knowing what to expect, to seek out information and having a reference of things to consider in living with stroke.

Individual factors cannot be viewed in isolation. Therefore, it is important for healthcare providers to recognize, assess and address the interplay of factors which may impact recovery, adaptation and community re-engagement to varying degrees.

The CRCATT is one possible strategy that can be used to support the re-engagement process by facilitating persons with stroke to think about their overall needs and to engage their healthcare providers by asking questions to take a more active role in their care and recovery.

5.0 Limitations

The recruitment of persons with stroke interested in participating in the study was challenging. Many patients did not meet inclusion criteria for reasons of medical instability, cognitive impairments, and poor proficiency in English. Organizations involved in the study also encountered challenges including staff turnover and involvement in other corporate priorities.

Interviews with persons with stroke provided rich qualitative data on their perceptions of their experiences with stroke recovery. However, relying on interviews alone does not provide adequate observational data to document actual behavior in the use and integration of the CRCATT. Our sample size was not adequate to achieve 80% power to detect a difference between groups, at a significance level (alpha) of 0.05. Deviation from the original sample size of 126 occurred in order to conform to the study funder's prescribed timelines. Several reasons were attributed to the inadequate recruitment of study participants: patients' failure to meet the inclusion criteria, significant number of patients who declined participation, and staff turnover both within organizations and within the research team

Our study did not include a truly representative sample of the stroke population. Compared to the provincial stroke population³⁷, there was an unequal representation of men and woman with proportionally more men than women recruited and an overall younger cohort. Furthermore, participants were restricted to those who could read or engage in the interview process in English and had no more than minor aphasia because of the language and communication skills of the research team. Those with cognitive impairments were also excluded from the study. Therefore results cannot be generalized to a larger population of persons with stroke. Notwithstanding, some of our results are in line with previous qualitative studies and bring forth new knowledge about the use and potential benefits of question prompts lists for those living with stroke. Further research that includes these individuals and/or their family/caregiver is required to understand the full reach of the CRCATT.

6.0 Future research

It is possible that the many variables presented herein play a role in participants' ability to manage, cope and resume well-adjusted living post stroke. Further research is needed in the following areas to obtain a deeper understanding of:

- 1) the value of the CRCATT as it relates to the many factors outlined above
- 2) the extent to which each individual factor contributes to CR
- 3) whom the tool is best suited for and
- 4) the optimal timing of the provision of the CRCATT.

Ongoing research in the aforementioned areas will help to inform how persons with stroke and their caregivers can begin to self-direct their care.

7.0 Conclusion

Using a randomized approach, this study set out to discover whether persons with stroke who had received the CRCATT would report higher participation in valued activities and more positive experiences in their community re-engagement process than those who were not exposed to the CRCATT, a patient-mediated question prompt list. There were no statistically significant differences between groups on satisfaction with reintegration into normal social activities following stroke (as measured by the RNLI). Themes generated from the interviews provided a depth of understanding of the multiplicity of factors that may be considered influential to a person's recovery and CR. Data revealed how the CRCATT held a different meaning/significance for different people depending on their context.

This study lends itself to expanding knowledge and contributes to the existing body of literature on the use of question prompt lists as a means to enhance conversations with healthcare providers to support CR for those living with stroke. The model presented can act as a starting point to illustrate the dynamic interplay of factors that influence recovery and community re-engagement. However, further research is required to investigate additional factors such as function, cognition, mood, the role of the family caregiver, etc. to understand how these may impact the use and the value of the CRCATT. This would have implications for the types of patients that would benefit most from receiving the CRCATT. Future studies may also inform the optimal timing of the provision of the CRCATT as a way for persons with stroke and their caregivers to begin self-directing their care.

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