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## Use of Occupational Performance Coaching for stroke survivors (OPC-Stroke) in late rehabilitation: A descriptive case study

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## Use of Occupational Performance Coaching for stroke survivors (OPC-Stroke) in late rehabilitation: A descriptive case study

### Abstract

**Background:**Stroke is a leading cause of disability in adults. Following stroke, 60% of people report needing help with everyday activities, and 80% report having very few meaningful activities. These restrictions often continue for years. This study explored the efficacy of Occupational Performance Coaching for stroke survivors (OPC-Stroke) on the participation level of adults in the later stage of stroke rehabilitation.

**Method:** A descriptive case study design was used. One participant in the later stages of rehabilitation was recruited. Outcome measures for participation, goal performance and satisfaction, and emotional well-being were administered pre and postintervention to observe for direction of change. A semi-structured interview was carried out postintervention to explore the participant's experiences of the intervention.

**Results:** The participant who took part in the study reported improvement with his goal performance and satisfaction. However, the level of participation did not improve and emotional well-being decreased. Qualitative data revealed an appreciation of the intervention and a recommendation of the intervention for others.

**Conclusion:** OPC-Stroke was valued by the participant and shows promise for improving goal performance and satisfaction. Further research is necessary to determine the potential efficacy of OPC-Stroke in later stages of rehabilitation.

### Keywords

client-centered, coaching, late rehabilitation, occupational therapy, participation, stroke

### Cover Page Footnote

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### Credentials Display and Country

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## Background

Stroke is a leading cause of death (Centers for Disease Control and Prevention [CDC], 2015; Statistics Canada, 2014) and disability (CDC, 2009) in adults. Among all chronic diseases, stroke has a large impact on the everyday lives of survivors. While 60% of stroke survivors report needing help with everyday activities, 80% of them report having very few meaningful activities in which they can participate after the stroke (Public Health Agency of Canada, 2009). These restrictions often continue for years following the stroke (Desrosiers et al., 2006; Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007). With the introduction of the World Health Organization, International Classification of Disability, Functioning and Health framework (ICF; World Health Organization, 2002), the importance of participation (defined as involvement in life situations) is being increasingly recognized among different health providers as an important part of recovery from illnesses such as stroke. Stroke survivors themselves largely describe their level of recovery in terms of participation in meaningful activities of daily living (ADLs) (Hafsteinsdóttir & Grypdonck, 1997).

While early stroke rehabilitation has been identified as critical for enhancing neuroplasticity, research has shown that therapy in the chronic phase of stroke (Ferrarello et al., 2011) can achieve improvements in functional abilities, such as ADLs and long-distance walking. These findings challenge the concept of the plateau, which might actually stem from delivery of less-intensive therapy. Yet, there are few opportunities for rehabilitation or support from health professionals

in the later stages of stroke recovery. Outpatient and community rehabilitation services are often limited, and stroke survivors frequently are sent home with few resources to face everyday life challenges (Teasell et al., 2012). Furthermore, mobility limitations and limited access to transportation can make it harder, and sometimes impossible, to access community-based rehabilitation programs, such as out-patient clinics and group exercise programs (National People with Disabilities and Carer Council, 2009). Effective home programs targeting participation, satisfaction in life, and independence for stroke survivors that are in the later stages of rehabilitation (12 months or more) are needed (Teasell et al., 2012).

Interventions designed to focus on participation (rather than impairment) are in the early stages of development and testing. To date, interventions that target specific aspects of participation have demonstrated immediate posttreatment success, but the long-term impact is not clear (Desrosiers et al., 2007; Hartman-Maeir, Eliad et al., 2007; Nour, Desrosiers, Gauthier, & Carbonneau, 2002). Of note, these early interventions did not incorporate all of the elements identified in the stroke literature that appear to be important for increasing participation in valued activities; for example, emotional support; collaborative partnership; facilitated goal setting; competency development; targeted, individualized education; the use of personal resources; and the importance of a wider range of social support (Cott, Wiles, & Devitt, 2007; Desrosiers et al., 2007; Egan, Kessler, Laporte, Metcalfe, & Carter, 2007; Reed, Wood, Harrison, & Paterson, 2012).

## **Occupational Performance Coaching for Stroke**

### **Survivors**

Occupational Performance Coaching for stroke survivors (OPC-Stroke) includes the key elements described above (Kessler, Ineza, Patel, Phillips, & Dubouloz, 2014). The aim of OPC-Stroke is to enable people who have experienced a stroke to develop knowledge and skills needed to address current and future participation challenges. The efficacy of OPC-Stroke has been explored immediately postdischarge from rehabilitation services (Kessler, Ineza et al., 2014; Kessler, Egan, Dubouloz, Graham, & McEwen, 2014) but has not been examined with stroke survivors in the later stages of rehabilitation or the chronic phase of stroke (i.e., 12 months or longer poststroke).

This research explored the effectiveness of OPC-Stroke on the participation levels of adults who have experienced stroke and were in the later stages of rehabilitation. Specifically, we sought to answer the following questions:

- Do community-dwelling stroke survivors receiving OPC-Stroke in the later stages of rehabilitation report increased participation?
- Do community-dwelling stroke survivors receiving OPC-Stroke in the later stages of rehabilitation report increased performance and satisfaction with individually identified participation goals?
- Do community-dwelling stroke survivors receiving OPC-Stroke in the later stages of rehabilitation report improved emotional well-being?

- What is the experience of research participants receiving OPC-Stroke in the later stages of rehabilitation?

### **Method**

#### **Research Design and Study Population**

This study used a descriptive case study design. A participant was recruited from an ongoing pilot randomized controlled trial (RCT) of OPC-Stroke (Kessler, Egan et al., 2014). Inclusion criteria for this pilot RCT were the following: (a) first hospitalization with a diagnosis of stroke; (b) discharged from an acute care hospital, inpatient stroke rehabilitation, or outpatient stroke rehabilitation to a non-institutionalized setting; (c) FIM score at rehabilitation discharge of at least three for expression, comprehension, memory, and problem-solving (to ensure potential participants' ability to participate in the coaching process); and (d) residence in the City of Ottawa area.

Participants were excluded if they had another degenerative neurological diagnosis (such as Parkinson's, Multiple Sclerosis) or a current major depressive or psychotic disorder.

As stated above, for our study, the participants who were the members of the control group of this RCT and had completed their involvement in the study were offered the OPC-Stroke intervention and asked by the research assistant if they were interested in taking part in this study. Therefore, at the beginning of this study, potential participants were at least 12 months poststroke and had not yet received the OPC-Stroke intervention. The first participant who met the inclusion/exclusion criteria consented to take part in

the study and was able to identify goals we selected as the case for this study.

### **OPC-Stroke Intervention Structure**

The OPC-Stroke intervention consisted of 10 face-to-face visits with an occupational therapist, who will be referred to as the “coach.” Each intervention lasted approximately one hour. The 10 sessions were over a period of 10 to 16 weeks. The 16-week period was selected to allow adjustment to scheduling conflicts and increased time to take steps needed to achieve the goals.

The first visit consisted of goal setting using the concept of personal projects (Little, 1998) to guide discussion of past and current personally valued occupations. Personal projects consisted of activities that the participant reported as important but was not able to participate in at the time of the research. The participant was asked to establish up to three personal projects that he wished to work on during the OPC-Stroke intervention, and these were framed as intervention goals. The Canadian Occupational Performance Measure (COPM) (Law et al., 1998) was used to rate current performance and satisfaction with the performance of these goals.

During the following sessions, the coach guided the participant to use a problem-solving process to work toward achievement of each goal. The problem-solving framework consisted of setting goals, exploring options, developing a plan of action, carrying out the plan, checking the performance, and generalizing (Graham, Rodger, & Ziviani, 2010). Throughout the sessions, the coach provided emotional support through listening, being empathetic, reframing, guiding, and encouraging

(Graham et al., 2010). Emotional support is considered to be important for creating a therapeutic relationship between the coach and the participant and thereby promoting engagement in the goal setting and problem-solving processes (Kessler, Ineza et al., 2014). The coach also facilitated an exchange of information related to strategies for goal achievement, recovery from stroke, and available resources. At the final session, the coach reviewed the goal progress and the problem-solving process with the participant (Kessler, Egan et al., 2014).

### **Data Collection**

Outcomes measures were administered pre and postintervention. The primary outcome was overall participation, which was measured using the Reintegration to Normal Living Index (RNLI) (Wood-Dauphinee, Opzoomer, Williams, Marchand, & Spitzer, 1988). The secondary outcomes were performance and satisfaction with performance of the intervention goals, measured using the COPM, and emotional well-being, as measured by the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983).

The RNLI was designed to assess the degree to which individuals are satisfied with reintegration into normal activities following an injury or illness (Murtezani et al., 2009). It is an eleven-item scale with proven reliability and validity for mobility limited, community-dwelling people (Stark, Edwards, Hollingsworth, & Gray, 2005). The RNLI includes questions regarding areas of activity and participation (i.e., mobility in the home; mobility in the community; taking trips; self-care; work activities that include volunteering, housework, and

studying; recreational activities; social activities; and family role) and perception of self-items (i.e., comfort with others, comfort with self, ability to deal with life events) (Wood-Dauphinee et al., 1988). A 10-point Likert scale was used in lieu of the original visual analogue scale, as this was found to be more appropriate poststroke (Price, Curless, & Rodgers, 2012).

The HADS is widely used as a brief self-rating instrument that provides a measure of emotional well-being through capturing symptoms of both anxiety and depression (Olsson, Mykletun, & Dahl, 2005). The scale consists of 14 items, seven related to depression and seven related to anxiety. Respondents are asked the extent to which they experience different feelings, interests, and thoughts using categories such as “very often,” “quite often,” “occasionally,” and “not at all.” The HADS has demonstrated reliability and validity (Zigmond & Snaith, 1983). The original version of the measure was enlarged for easier reading.

The COPM was used to rate performance and satisfaction with performance of goals on a scale of one to 10, one being poor performance and low satisfaction and 10 being very good performance and very high satisfaction (Carswell et al., 2004). When using the COPM, total scores are tallied and then transformed into an average score. A change score of at least 2 points is considered to indicate a significant clinical change (Eyssen et al., 2011; Law et al., 1998). The COPM has good reliability and validity (Carswell et al., 2004).

Preintervention, demographic data, the RNLI, and the HADS scores were obtained from the

from which the participant was recruited. The demographic data included the date, type, and location of the stroke as well as age, gender, and living situation. The coach administered the COPM during the first session, as noted above. The COPM was administered by the coach as goal setting is considered to be integral to the intervention process.

Following the OPC-Stroke intervention, research assistants met with the participant to administer the RNLI, the HADS, and the COPM and to conduct a qualitative semi-structured interview. The purpose of the interview was to gain insight into the participant’s experiences of OPC-Stroke. The interview was audio recorded and transcribed verbatim for data analysis.

### **Quantitative Analysis**

Raw data from the RNLI, the HADS, and the COPM pre and postintervention were observed for direction of change to determine if the intervention was associated with a positive change.

### **Qualitative Analysis**

The qualitative interviews were analyzed using conventional qualitative content analysis (Hsieh & Shannon, 2005). The analysis involved identifying codes and grouping them into themes related to the participant’s experiences throughout the intervention (Hsieh & Shannon, 2005). To promote rigour, two research assistants independently analyzed the interview. Once this step was completed, the research assistants compared their findings and came to a consensus of the principal themes that reflected the participant’s experience of OPC-Stroke (Potter & Levine-Donnerstein, 1999). Ethics approval was obtained

from the relevant hospital and the university

Research Ethics Board.

## Results

One case was recruited and examined for this study. A pseudonym is used below for presenting findings.

Charles was an English speaking man in his sixties who suffered a haemorrhagic stroke to the right hemisphere approximately two years earlier. During the study, Charles was living independently in a bungalow in a rural area and had retired poststroke.

The RNLI scores from baseline to postintervention indicate a small decrease in Charles's participation (see Table 1). On examination of the RNLI scores on individual items pre and postintervention, the following changes in scoring were noted. Rating of the item for social participation went down by four points. Rating of satisfaction with time spent in necessary and important activities went down by five points, and rating of participation in recreation activities such as hobbies went up by three points. In contrast, the COPM scores show a large increase in his performance and satisfaction with each of his two self-identified intervention goals. Overall, his average changes in performance and satisfaction were also shown to be clinically significant as these were 7 and 7.5, respectively (see Table 2). For emotional well-being, the HADS scores indicated that Charles's level of anxiety and depression increased from baseline (see Table 1).

**Table 1**

*Reintegration to Normal Living Index (RNLI) and Hospital Anxiety and Depression Scale (HADS) Scores Pre and Postintervention*

| Participant | RNLI |      | HADS |      |
|-------------|------|------|------|------|
|             | Pre  | Post | Pre  | Post |
| Charles     | 83   | 77   | 9    | 15   |

**Table 2**

*Canadian Occupational Performance Measure (COPM) Scores Pre and Postintervention*

| Goals                | COPM Performance |      |        | COPM Satisfaction |      |        |
|----------------------|------------------|------|--------|-------------------|------|--------|
|                      | Pre              | Post | Change | Pre               | Post | Change |
| Return to my hobbies | 1                | 10   | 9      | 1                 | 9    | 8      |
| Organize my home     | 5                | 10   | 5      | 2                 | 9    | 7      |
| Average Scores       | 3                | 10   | 7      | 1.5               | 9    | 7.5    |

During the analysis of the interview with Charles, the categories of general appreciation, perceived benefits, recommendations, social impact, and realization emerged.

**General appreciation.** A sense of general appreciation emerged from Charles's interview. He expressed his appreciation using expressions such as "It was very relaxed, very helpful," and "Well, actually everything that I could think about, the intervention is, is really very good." He also stated, "[The intervention] got me back on track and doing things I need to do." Charles viewed the coach's flexibility as important, stating "So actually we adjusted the sessions to suit the situation at the moment . . . and I think that's the way to do it."

**Perceived benefits.** Charles also expressed many perceived benefits of the intervention. He reported that it gave him a sense of purpose in life:

“[The intervention] gave me purpose again.” The OPC-Stroke intervention coach helped him to feel more supported in pursuing his self-identified activities. “[The coach] put out things I need to do. She learned quite a bit about what I am like . . . and then used that to direct me to go and do those things and it worked well.”

**Recommendations.** Charles also made important recommendations regarding the intervention. He endorsed the intervention, stating, “If anybody wants a, a recommendation whether or not to go through with it, I’d say go through with it.” He also reported that more sessions would have been helpful in order to continue to work toward his incomplete goals: “The only thing that I would change is that I would like to see [the coach] more.”

**Social impact.** The social aspect of the intervention was a big part of Charles’s experience. Charles was living independently in a rural area with little social support. He reported that he “was kind of sad when [the interventions] terminated” because the coach was “more like a friend,” and the intervention allowed him to “meet some really nice people.”

**Realization.** The intervention process allowed Charles to realize how few meaningful activities he currently had in his everyday life. As he commented, “One of the things that I realized during this whole process was ‘holy crap, I was just sitting here waiting to die,’ that’s not a good goal.” This realization helped him actively participate in the OPC-Stroke intervention process. As he noted, “[The intervention] gave me purpose again.”

## Discussion

The aim of this study was to begin to explore the efficacy of OPC-Stroke in the later stages of rehabilitation. Based on the quantitative data there is some support for providing the OPC-Stroke intervention to people in the chronic phase of stroke. While the RNLI did not demonstrate that the intervention improved Charles’s participation, he reported improved performance on all of his self-identified goals and an increase in satisfaction for the same goals. Average change scores on the COPM for both performance and satisfaction were greater than two and are therefore considered to be clinically significant (Law et al., 1998). It is not clear why Charles’s improvements in goal performance and satisfaction did not translate into improved ratings for participation. It could be that as Charles worked through the problem-solving process to achieve his goals, he came to realize that his participation was more limited than he had originally thought. This is supported by the qualitative data related to realization, where he indicated that he had severely restricted participation. While Charles’s perceived performance and satisfaction with the occupations addressed during the intervention improved considerably, there may have been little carry over to other areas of participation. Charles’s goals during OPC-Stroke revolved around his occupations at home. An examination of the RNLI item scores also suggests a lack of social and meaningful participation. Further, the OPC-Stroke sessions related to occupations outside of the home may have been particularly helpful for Charles.



The results of the HADS were found to be higher for Charles at the postevaluation, reflecting poorer emotional well-being. The researchers hypothesized that these results could have demonstrated the participant's sadness at discontinuing the relationship he had developed with the coach as well as the realization that his participation was limited. Charles was living alone and had little social support. While he may have improved in his abilities to carry out his valued activities, he was left without anyone with whom he could perform these activities. It would be beneficial in future research to examine how valued activities are integrated into social roles and how the intervention may be adjusted to better address this area.

The categories that emerged during the qualitative interviews—general appreciation, perceived benefits, social impact, realization, and recommendations—support the usefulness of OPC-Stroke. As well as helping Charles to set and achieve these goals, the process also appeared to help him re-engage in life. Thus, OPC-Stroke in the later stages of rehabilitation was viewed as an acceptable and valued intervention.

Charles suggested that an increased number of sessions would have allowed him to achieve his goals and to feel an increased sense of autonomy when the intervention was terminated. Unfortunately, he was only able to take part in nine of the 10 sessions in the 3-month timeframe allowed by the research. Extending this timeframe may be needed in later stroke rehabilitation to allow for increased scheduling conflicts as participants return to valued activities. Furthermore, with more time,

Charles may have been able to apply this problem-solving process to other areas of his life, particularly to occupations outside of his home, and achieve an end result of improving overall participation. In a qualitative study examining the process of community reintegration following stroke up until 12 months poststroke, Wood-Dauphinee, Opzoomer, Williams, Marchand, and Spitzer (1988) noted that decreased confidence for facing new challenges and engaging in meaningful activity in the community occurred during transitions between goals. Appropriate support during these transitions was noted to help improve confidence (Wood-Dauphinee et al., 1988). Kubina, Dubouloz, Davis, Kessler, and Egan (2013) also identified the importance of social connection that included support for re-engagement as an important ingredient for activity engagement and risk-taking to test abilities during the first 2 years poststroke. Therefore, extending the time frame of the intervention may be needed, particularly for those with few social supports or for whom initial goals were limited to home-based activities only.

While OPC-Stroke has been tested immediately poststroke (Kessler, 2015; Kessler, Ineza et al., 2014), this study sought to examine its potential impact in the later stages of stroke rehabilitation. This case study has provided initial support for the efficacy of OPC-Stroke in the later stages of rehabilitation.

The main limitation of this study was that it was a single case study design. However, findings of this study are similar to those of the pilot RCT of OPC-Stroke in early stroke rehabilitation (Kessler, 2015), and thus provide support for inclusion of

participants in the later stages of stroke rehabilitation in a larger RCT.

### Conclusion

The purpose of this study was to identify whether or not OPC-Stroke in the later stages of rehabilitation was potentially efficacious. The goal was to increase the level of participation in the everyday life of the stroke survivor. While the participation level did not change, the participant reported improved performance and satisfaction with his identified goals. Qualitative findings also support a positive impact of the intervention.

Further research is needed to examine the relationship between achievement of self-identified goals and overall participation in late stroke rehabilitation. Results of this study support the inclusion of stroke survivors in the later stages of recovery in a future RCT designed to provide more rigorous testing of OPC-Stroke.

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