# A Novel Rehabilitation Therapy Design for Stroke

by Marta Lynne Scythes Submitted to OCAD University in partial fulfillment of the requirements for the Degree of Master of Design In Strategic Foresight and Innovation

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# ABSTRACT

Background: The type of rehabilitation therapy available for stroke survivors, and when they receive it is crucial to optimize recovery. This study investigated the problems surrounding upper limb rehabilitation, relevant neuroscience research and potential avenues for enhancing recovery. Therapies employing visual art have been shown to improve psychological outcomes, yet no studies have identified a correlation between art engagement and sensory-motor recovery.

Methods: Practical experience with patients was gained over a 16-month period through volunteer placement at a hospital complex care unit. Structured interviews were conducted with experts in the field of rehabilitation science. Their insights into potential benefits of art for stroke therapy were recorded and analyzed. Innovative design tools were used to understand key stakeholder's needs and perspectives. Literature reviews on stroke care is presented in the introduction and art therapy practices plus relevant neuroscience research was reviewed in separate chapters.

Results: A brief analysis of publicly funded stroke programs revealed services were viewed as uneven regionally, inequitable and lacking in resources and patients are dissatisfaction with quality of care. Empirical evidence from fieldwork revealed art activities for stroke were typically unstructured and facilitated by placement students, volunteers and family members. Experts interviewed expressed a common theme: art therapies, that may benefit sensory-motor outcomes beyond psychotherapy, warrant testing and measuring. An analysis of Art Therapy research uncovered its benefits and shortcomings. Current neuroscience that supports the need to design more effective therapies was discussed. Results from research tools showed the benefits of collaborative design solutions.

Conclusion: The paper included a proposal for an art program and recommended that it be implemented in a hospital facility. The prototype is patient-centered, comprising an art focus program for survivors, family members and volunteers and an art intervention: an 8week, clinical trial (including functional assessment) to be co-designed and implemented by a collaborative health care team. Finally, the knowledge gained from this research is a starting point for further investigation into patient centered, value-based art programs for stroke recovery.

Keywords: stroke, rehabilitation, physiotherapy, upper limb, quality of care, visual art

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### SUMMARY

This study identifies a pressing need for change in the health care sector that serves stroke survivors. Rehabilitation programs are not currently serving this population in a timely and effective manner and, if this trend continues, the situation will be exacerbated in the future due to an increasing demographic of stroke survivors and lack of accessible services.

Several years ago, an emerging pattern was observed in the form of community members seeking creative outlets for rehabilitation from brain injury, stroke and various other health conditions. Few community programs are available for these special populations and rehabilitation services in the health care system struggle to provide funding for recreational activities. Recovering individuals, who have the inclination, capabilities and means, seek out college courses and private arts programs for self-help and creative outlets.

Prior and limited teaching experiences with stroke survivors was the initial driver of interest in this field of research. To increase the scope of knowledge and strength of this study, the author sought practical experience in stroke care through volunteering in a complex care facility from 2015 to the present. In addition, valuable knowledge and training was obtained by attending seminars, hands-on stroke workshops and numerous conferences.

After identifying current problems in rehabilitation services for stroke and reviewing literature on arts based therapies, this study found scientific evidence that supports rethinking rehabilitation practices and presents an argument that could drive policy change affecting stroke care in Ontario. After a divergent research process and convergent analyses, coupled with hands-on practical experiences in the field, the author presents fresh insights and makes recommendations for a novel clinical intervention for physical and cognitive recovery for stroke. The intent was to establish an understanding of the need for improved stroke care and to present a convincing evidence-based argument for modifying rehabilitation theory and practice to better meet the needs of survivors, their families and caregivers.

Considering the type of evidence needed to accurately make sense of the problem and affect change in the sector, appropriate research methods, including expert interviews, empathy maps, personas and value propositions selected from a large collection in the SFI Masters of Design program at OCAD University were employed to gain valuable insights that could drive change.

Finally, the information gleaned from this project informed the design of a feasible, viable and desirable novel intervention for stroke survivors to be implemented in a hospital setting. A two-tiered solution that has the potential to improve quality of life and enhance overall recovery for survivors was prototyped. Need necessitates change and change in the way stroke patients recover is the end goal of this study.

# SECTION ONE CHAPTER ONE: INTRODUCTION

#### BACKGROUND: A SYNOPSIS OF STROKE FACTS & DEFICITS

Stroke survivors find themselves in an unexpected and debilitating situation, unprepared to deal with a multitude of issues while recovering in hospital and often well after discharge. The devastating effects of stroke are unique to each person and dependant on their clinical presentation, making stroke one of the most difficult conditions to treat effectively. Rehabilitation services include speech, physical, behavioral and cognitive therapies. Many post-stroke disabilities make communication and understanding difficult and sometimes impossible. Family members of survivors are greatly affected by this change, unsure of their future and how to give and find support.

Stroke is a leading cause of neurological disability (Heart & Stroke Foundation, 2015) and it is third leading cause of death in Canada (Stats Canada, 2015). A stroke most often affects the elderly but may happen at any age. A blood clot or bleed cuts off blood supply and thus oxygen to the brain and consequently, brain tissue dies, resulting in physical and or cognitive deficiencies. (Patient Ombudsman, Government of Canada, 2015).

Survivors may be left with multiple deficits such as behavioral, emotional, cognitive, sensory and physical disabilities (Ontario Brain Injury Association, 2015). Approximately 88% of survivors of acute stroke are left with *hemi-paresis*, a paralysis/weakness on one side of the body. Resultant physical disabilities have been the most studied of all stroke impairments, (Bruno-Petrina, 2014).

Of the many deficits one of the most devastating is the loss of motor function and mobility. Rehabilitation therapies are specialized for upper and lower extremities. Lower limb therapies concentrate on gait, standing, sitting and mobility where as upper extremity interventions focus on repetitive exercise training for reach, grasp and movements required to perform daily tasks.

Regaining motor function in the upper limb is often more difficult than in lower extremities and multiple types of therapies are needed (Foley, 2016). Upper limb deficits are debilitating if the stroke affects a person's dominant side, and therefore all tasks normally performed must be re-learned with the non-dominant arm and hand. These effects of stroke are lessened if the stroke caused paralysis on the non-dominant side allowing patients to use their dominant arm and hand to perform everyday tasks.

Sensory deficits include visual neglect and loss of depth perception and an awareness of where your limbs and body are in space, a sensation called proprioception. Loss of these abilities is devastating and dangerous, causing survivors to poorly plan and execute physical actions and have trouble with directional grasp.

A final and debilitating deficit from stroke is loss of the means to communicate. *Aphasia* results in the loss of the ability to speak, read and write and understand language. The main treatment for aphasia is speech therapy. Survivors must attempt to re-learn language and are taught other ways to communicate, namely identifying and communicating ideas by drawing and with visual images.

Receiving the best possible care across the care continuum is of utmost importance to survivors and all those who are involved in providing care, including collaborative teams of health care professionals. Front-line caregivers strive to meet the needs of stroke survivors yet studies point to the need for improved quality of care and increased rehabilitation services for stroke. Factors such as reduced funding, an over burdened health care system and increased incidents of stroke are current barriers to achieving effective change.

Publicly funded health care cuts in addition to lack of quality care only lead to longer disability, lower quality of life, increased institutionalization and higher health care costs, (Saposnik, 2009). Considering the health care system challenges surrounding stroke care uncovered in this study, a pressing need to discover ways to improve and increase the efficacy of stroke rehabilitation is identified.

This paper discusses personal experiences in the field of stroke care and presents experts' perspectives on potential benefits of art engagement for stroke. The author reviews literature on current art therapy and offers insights into its benefits and shortcomings. The author argues that novel therapies should be designed, tested and measured to determine potential benefits and attempt to validate efficacy for improving outcomes. The paper uncovers intriguing neurological correlations between cortical structures in artist's brains and structures often spared in stroke.

# MAIN RESEARCH QUESTION

How might rehabilitation programs be enhanced to better meet the needs and improve outcomes of a growing population of stroke survivors?

Two preliminary questions will first be addressed to frame issues in stroke care and determine if substantive evidence exists to support the primary thesis question.

- 1. How is the current health care system falling short in providing adequate rehabilitation services for stroke?
- 2. What evidence supports the argument to incorporate more structured and specialized programming in stroke care for cognitive and physical therapy?

# **CHAPTER TWO:** PROBLEMS FACING THE HEALTH CARE SYSTEM

1. How is the current health care system falling short in providing adequate rehabilitation services for stroke?

A pattern is emerging in Ontario's public health care system. Challenges caused by federal and provincial budget cuts and rising health care spending have resulted in the reduction of services for some conditions such as stroke (Expert interview, 2016). Health care spending exceeds government revenue raising concerns over the sustainability of our publicly funded health insurance system (Micieli, 2014). The main drivers placing demands on the system include an increasingly unhealthy population, an aging demographic, inflation, medical technology and IT, and drug coverage (Bhatia, 2012). To compensate for increased spending in some areas of health care, other valuable services have been reduced or discontinued.

The problem currently facing service providers working with recovering stroke patients is complex: few institutions have specified stroke units with trained staff and those that do, have overflow, making it difficult to provide effective and sufficient care (Hill, 2009). Services are facility dependent, not always based on need. Access is regionally dependant and rural areas are typically under serviced. These issues were recently discussed in a news release from the Heart & Stroke Foundation of Canada:

> "stroke patients in Canada are not getting the rehabilitation they need...research findings strongly suggest that such decisions are being made based on what services are available in the health system rather than what patients really need," (Heart & Stroke Foundation, 2014).

#### REHABILITATION FALLS SHORT IN DURATION

The incidence of stroke is on the rise in Ontario as the population ages (Ontario Stroke Network (2016) pressing the need for increased spending, not funding cuts that affect duration of stroke rehabilitation services.

An overwhelming number of people recovering from stroke are discharged from hospital prematurely, and are often unprepared for resuming a normal life (Heart & Stroke Foundation, 2014). Out patient rehabilitation programs provide regular sessions for a limited number of weeks (usually four) at local clinics and in home care. After this publicly funded therapy is terminated, survivors are forced to pay for additional services or rely on family and friends for assistance.

#### TIME LIMITED THERAPY

Time-limited therapy is the current norm in stroke rehabilitation because the longstanding and accepted view has been, until recently, that the human brain is only repairable for approximately 6 months post injury (Taub,1999). After this time period, it was thought, the brain cannot repair any further and rehabilitation plateaus. This paradigm has recently been challenged since findings from researchers at Vanderbuilt University, in Nashville (Merzenich,1984) and at the Taub Clinic, University of Alabama (Taub,1999) revealed healing continues long past the 6-month window.

A recent study has shown the "cerebral cortex undergoes significant structural plasticity for several weeks to months" after stroke, (Tzika, 2013). This Harvard Medical School study confirmed brain plasticity is present in post stroke patients beyond 6 months. They challenge conventional theory that stroke patients' ability to recover 'plateaus' and that structural change is not possible past 6 months. Due to traditional beliefs, prolonged rehabilitation services were not typical. Patients were discharged prematurely, often with limited mobility and according to Dr. Mark Bayley at University Health Network in Toronto, they still are (Eurek Alert, 2014). Part of the problem might stem from the fact that every stroke patient's abilities are different and therefore require unique and tailored rehabilitation programs. Yet, program resources are limited and unless a family member takes on the challenge of providing continual care, patients often are unoccupied for much of their day.

The need for extended treatment is supported by the concept of brain plasticity that is slowly changing cultural beliefs and theory in rehabilitation (Doidge, 2007). It has been shown the brain can change, repair (structurally and functionally) and adapt after injury. The health care system continues to limit duration of service.

"...hospitals are failing to provide the kind of post-stroke therapy that can prevent victims from suffering long-term loss of function, according to a new study in Canada, which looked at 60,000 stroke and mini-stroke cases... After a stroke, the clock starts ticking on a crucial window for treatment that can help people get back to living normal - or at least functional - lives. But of the 40 percent of patients who could benefit, only 16 percent get access to this kind of rehabilitation, " (Wolford, 2014).

The start time, duration and type of rehabilitation therapy stroke patients receive is key for optimal recovery yet the health care system is having difficulties providing these services to all survivors. The extent of brain damage from stroke can be significantly mitigated if intensive rehabilitation treatments are sought immediately following a stroke. (SE Ontario Stroke Conference, 2016). If initial rehabilitation therapy is limited or delayed, until after patients are stabilized and transferred to a long-term care facility, that crucial window starts to close and recovery may be negatively affected. "Evidence from clinical trials supports the premise that early initiation of therapy favorably influences recovery from stroke. When the initiation of therapy is delayed, patients may in the interim develop avoidable secondary complications." (Bruno-Petrina, 2014).

#### REHABILITATION FALLS SHORT IN ACCESSIBILITY

In the current Ontario health care system, age plays a role in stroke survivors' access to services. Middle age stroke survivors are not eligible for the same amount of government-funded therapy as those under 20 or over 64, (Government of Ontario, 2016). The issue has been brought to the attention of Ontario's Minister of Health, Erik Hoskins, yet no changes have been brought forward to date.

Interestingly, recent findings conclude age of stroke survivors is not a factor affecting benefits derived from intense stroke care. In an American Heart Association study, of 3631 patients with ischemic stroke, "it was found that benefits derived from organized stroke care are similar across all age groups" including the very old and frail. The study also concluded, "fatality was lower for patients admitted to a stroke unit compared with those admitted to general medical wards and that, "increasing levels of organized care were associated with lower stroke fatality or institutionalization." (Saposnik, 2009).

A Heart & Stroke Foundation study (2104) has shown, "in addition to the variation in access to inpatients age related rehabilitation services, community-based rehabilitation programs are not available in many regions, and those that do exist are not equitably covered by provincial health insurance programs."

Another study revealed patient need is overlooked due to availability of resources. They stressed that, "access to and the use of inpatient rehabilitation after stroke is highly variable, so variable that it likely depends upon practice patterns and resources, rather than patient disability and needs." (Eurek Alert, 2014).

"Stroke patients are falling through the cracks," says Dr. Mark Bayley, co-chair of the Canadian Stroke Congress and a physiatrist (rehabilitation specialist). "This has huge implications for their future quality of life and use of healthcare and social service resources," (Wolford, 2014).

REHABILITATION FALLS SHORT IN QUALITY OF CARE

Expert quote: "historically a complaint of patients is that rehab is boring and they do not see the connection between the processes in rehab and real life. Patients need motivation."

Traditional upper limb tasks for improving grasp, reach and movement are basic and target gross motor skills. A medley of therapies is available dependent on the severity of a patient's disabilities, and facility resources. Physiotherapy and occupational therapy often involve intense, repetitive and "forced use" exercises. (O'Dell and Lin, 2009). Repetitive exercises that translate to everyday tasks often discourage and frustrate patients. These tasks, though necessary, often have little meaning for patients, and produce no pleasure.

There is conclusive evidence showing stroke patients are frustrated with the caliber of their rehabilitation care. In an Australian study, a systematic international review of stroke survivors rehabilitation experiences, including 3039 records and 95 full text publications, it was found there is a considerable gap in rehabilitation (Luker, 2015).

" The thematic synthesis provides new insights into stroke survivors' experiences of inpatient rehabilitation. Negative experiences were reported in all studies and include disempowerment, boredom, and frustration. Rehabilitation could be improved by increasing activity within formal therapy and in free time, fostering patients' autonomy through genuinely patient-centered care, and more effective communication and information." (Luker, 2015). Our aging and unhealthy demographic in Ontario is driving these issues in stroke care, putting a huge strain on the system. If current trends of funding cuts and increased incidents of stroke continue, the situation will be compounded in the near future, quality of care for stroke survivors will decline resulting in longer disabilities, lower quality of life and increased institutionalization

### **CHAPTER THREE:** TRADITIONAL ART THERAPY

It is necessary to understand what the practice of traditional Art Therapy accomplishes for stroke survivors and assess how the profession may be self-limiting in methodology. Art Therapy has proven to be effective for stroke as a psycho-therapeutic tool. Determining how art engagement actually benefits the stroke patient is important for future research and it seems unclear to date. Determining how to assess efficacy in future, whether it be for psychological, cognitive or physical benefit, is key and may affect stroke rehabilitation, in theory and practice.

#### A PROVEN PSYCHOLOGICAL APPROACH TO REHAB

Traditional Art Therapy or 'expressive arts therapy' has been practiced for decades as a socialization tool and emotional outlet aimed at "restoring a clients' functioning, reducing anxiety and fostering self-awareness," (Am. Art Therapy Assoc., 2013). Its roots are in the integration of visual art and psychotherapy. This therapeutic practice has been widely used in several fields of rehabilitation, including, addiction and mental health, sexual abuse and grief counseling, (TATI, 2015). Historically, art was used for rehabilitation in an attempt to heal the stresses of war and aid in veterans' reintegration into their communities and families. More recently Art Therapy is used for many forms of Post Traumatic Stress Disorder, (Collie, 2006).

Art Therapy has been recognized as a legitimate mental health profession and is governed by private career colleges that train and certify practitioners who then work in private and public clinical settings. Private clinics use art making for psychotherapy with clients of varying physical and cognitive disorders and diverse needs. These services are costly and offer limited to no access in rural areas. The scope of Art Therapy programming is wide and varied including art-making activities and processes as therapy for patient self-expression and personal growth. These include: crafts, painting, drawing, sculpture, photography, dance, animation and film. The goal of engaging people in these processes is to provide enjoyable and expressive activities that may help improve their quality of life. Clients have shown significant improvement over time and there is a body of qualitative evidence verifying the value of such programming, (Landgarten, 2013). Many clients retain the practice for life. (Cervoni, 2011).

Qualitative trials analyzing emotional states and social interactions of participants after participating in art programs (group and individuals) were reviewed for this study.

In a UK occupational therapy study, (Symons et al., 2011) discuss the importance and benefits of using visual arts (not 'Art Therapy') in *physical* rehabilitation programs when run by qualified art teachers and occupational therapists. Regular art classes contributed to participants "meeting their rehabilitation goals by occupying time, building confidence, increasing enjoyment and planning for future activities," validating the importance of using visual art in rehabilitation. The study reports positive outcomes in patient wellbeing but does not report directly on physical gains as the paper's title suggests. The paper cites no other research that found physical benefits were recovered from participating in art programs. Interestingly, the paper is titled, "Visual Art in *Physical* Rehabilitation: Experiences of People with Neurological Conditions." The study concludes, "The findings of this study inform clinical practice in the use of visual art with clients in rehabilitation and validate its place in a physical rehabilitation programme."

In a second British study, patients in a hospital rehabilitation unit were invited to participate in two weekly art sessions for a total of 6 weeks. The paper suggests, "The holistic aspect of stroke rehabilitation to include psychological well-being is currently neglected, with more emphasis placed on physical recovery despite anxiety and depression being common...it seems that creative strategies such as art therapy can be beneficial in reducing isolation and anxiety among stroke patients," (Ali, 2014).

The patient group produced several art objects and photographic images used to create a stop frame animation. Results showed reduced anxiety and depression by 25% after therapies were implemented. This qualitative study showed positive correlation between individual patients participating in a group project and the process of art therapy. Whether it was the actual art process or the social interaction that improved quality of life, is unknown as the paper concluded, "...our study showed that art therapy was a feasible intervention that helped patients explore the sequel of stroke in an open supportive environment." The authors made no mention of possible physical benefits gained through the art therapy process.

A pilot project conducted in 2013 in the UK showed weak evidence of the benefits of Art Therapy on a small group, (n=6) of post-stroke, older male patients. Included in the byweekly program was basic drawing and painting, sculpture, and film-making delivered in a group setting. The study was designed for a coed recruitment, yet only six men chose to participate, (Waller, 2014). The group of "skeptical and very anxious men" decided to "do something practical" and successfully made a film, the result being an animation filled with symbolism. This study produced weak evidence as to the benefits of art. The paper concluded the participants felt visual art such as drawing and painting was not, "practical," but the film-making was of benefit.

An Australian research team explored the benefits for community dwelling stroke survivors (n=16) in an art program (Beesley et al., 2011). Results showed improved confidence, self-efficacy, quality of life and increased community participation through

involvement in the art program. The authors concluded, "implementation of an arts health programme after stroke made a substantial impact on well-being and quality of life. Results from this study are promising and this is a model that warrants rigorous investigation regarding the impact of art on wellbeing. "

The team added health care services need to address community re-integration using art group programs for stroke survivors. The paper did not identify whether the improvements gained in quality of life were due to the art process or the social interactions with other participants and the facilitators. (the study did not term their intervention, 'Art Therapy'). Results were inconclusive as to *how* art interventions affected their participants and therefore, their results.

(Morris et al, 2014) found, "participation in visual arts creative engagement interventions during rehabilitation after stroke may improve mood, self-esteem, hope and some aspects of physical recovery." This paper highlights rehabilitation currently available post-stroke, where in-patients receive physiotherapy, occupational therapy, speech and language therapy to restore lost function (Stroke Unit Trialists' Collaboration, 2013).

The Morris group conducted a feasibility trial of 80 in-patients in Scotland: a two arm, single-blind, randomized controlled trial. Two professionally qualified visual artists with experience in arts programs in healthcare settings offered the program. Of the 80 patients 40 received Art Therapy: "creative engagement intervention" (CEI) and 40 control subjects received standard rehabilitation: physiotherapy and occupational therapy. Unofficial results sent via email to the author of this study, from Dr. Morris, were as follows, "we did run the trial and have the results, which indicated that improved mood, self-efficacy and social participation are the potential effects of art participation. A second email inquiry (re: physical benefits achieved), Dr. Morris responded with,

"Participants told us they thought it improved arm function. You will find that in other qualitative studies. However in the trial we used the stroke impact scale which asks patients to rate their arm recovery and there was no difference between the groups. We didn't ask them to do performance tests though. I suspect that the intervention exposure was insufficient to improve motor function but that it improved patients confidence to use their arm." (Morris, 2015).

A study of this size has credibility over the smaller qualitative papers reviewed. Follow up studies of this nature, including performance tests to ascertain upper limb functionality benefits from extended engagement in art, have not been done.

There is a body evidence supporting Art Therapy for psychological purposes in stroke rehabilitation. No visual art programming, specifically to aid *physical* rehabilitation, has been investigated. However, two articles were found suggesting Art Therapy may aid in motor skill recovery: an article on Post Traumatic Syndrome Disorder, (Collie, 2006), and second study from Korea on stroke recovery, (Kim, 2008). Neither research group collected quantitative data assessing motor skill improvement from participating in Art Therapy programs.

The Korean study illuminated the potential for art programs to holistically enhance recovery of stroke survivors. The goals of the study were to "improve spatial perception, colour and shape recognition, size comparison" along with inducing emotional expression and improved socialization. Results from the Korean tests conducted before and after patients had received 10 weeks art training showed "improvement in visual perception and cognition and in an increase in motor activity as a secondary effect," (Kim et al, 2008) but that motor skill benefits are a by-product of Art Therapy. Interestingly, Kim's literature review included an intriguing passage: "Wilson (2001) found that the *visual-motor functions* of stroke patients with communication disorders were improved by

the creation of visual images," but Kim did not elaborate on the subject or further investigate that field of research.

These intriguing findings present a new hypothesis: that visual art processes may be beneficial for sensory and motor recovery for stroke. The Kim paper suggested a specific type of Art Therapy intervention may improve visual-motor functions in stroke patients. No evidence to date has tested or measured the benefits neurologically or physiologically. It appears the knowledge presented in this study has not led to further inquiry in this area of research.

A common psychiatric complication of stroke is Post Stroke Depression (PSD) resulting in severe deficits in performing activities and lowering functional outcomes (Eum, 2015). In this study, Art Therapy was shown to overcome psychological disabilities through non-verbal treatment and therapeutic processes giving patients the opportunity to express emotions, share feelings and reduce anxiety. The authors labeled Art Therapy as, "clinical art therapy" as their intervention is used for diagnosis, training and therapy. The study illuminated the benefits of Art Therapy that provide, "visual and cognitive training that is effective in strengthening performance intelligence. (Performance intelligence is a person's ability - or mental capacity - to perform non-verbal and language-based skills).

Visual elements explored in this study included lines, shapes, textures, colour, three dimension and perspective: The Elements of Design in visual art. The paper concluded stating, these visual tools, "act as rich stimulation that offer a means of non-verbal communication and promote cognitive and sensory development, " during rehabilitation. The authors do not expand upon the, "lower functional outcomes, " mentioned early in the paper.

Carolan, (2001) argued for a bridging of science and Art Therapy research in order to consider potential benefits and efficacy of art making for rehabilitation. He considers art therapy an old practice "yet young in its modern form as a helping profession." He postulates,

"We have a responsibility to make the healing interventions of art available to all who can benefit, not just those affluent enough to have the freedom to focus on self-actualization. We have a responsibility to pursue knowledge concerning what is healing about working with art so that others may be healed. We have a responsibility to communicate with other professionals who do not understand the language of art therapy."

The paper did not consider the art making as a medium for anything beyond psychotherapy but did argue that paradigms around visual art and therapy can filter and restrict research. Carolan sees the role of the scientist and the artist to challenge current paradigms in Art Therapy, to conduct research that addresses cause and effect. This area of research is uncharted.

No evidence was found indicating researchers study visual art exclusively for sensory or physical rehabilitation therapy. All of the research reviewed supports the need and benefits of Art Therapy programming for *psycho*-therapy to improve quality of life and increase motivation but does not use it specifically for physical rehabilitation purposes. A positive correlation between making art and sensory motor recovery may exist, yet there is weak evidence supporting the correlation and therefore, no incentive to fund new research initiatives. Evidence-based research to assess and validate possible benefits of art engagement for physical and cognitive recovery has not been conducted.

# **CHAPTER FOUR:** BRIDGING ART AND SCIENCE

#### ADVANCES IN NEUROSCIENCE

In the early 20<sup>th</sup> century, Broadman divided the brain into 50 different parcels related to structure and function. This framework has been governing neuroscience research for over 100 years. Building on the work of German and Canadian researchers who recently produced a three-dimensional atlas of the brain with 50 times the resolution of previous such maps, a team at the Montreal Institute of Neurological Sciences is currently refining Broadman's 'brain maps,' (Humphries, 2014). The findings will provide researchers with highly detailed brain maps enabling more accurate study of brain function.

Recent research supports the notion that brain matter is plastic (Doidge, 2007) and able to change, repair and adapt to adverse conditions, far beyond what was traditionally understood to be possible. (Schaechter, 2004) attempts to "bridge... our understanding of the effect of motor rehabilitation and brain plasticity on recovery after hemi-paretic stroke," and speculates on understanding how "rehabilitation-induced motor recovery will permit brain mapping technologies to be applied toward optimizing post-stroke motor rehabilitation."

#### CURRENT NEUROSCIENCE RESEARCH

Traditional thought in rehabilitation science assumes that the role of visual art therapy has psychological benefits only. These beliefs are limiting and create barriers to expanding research in art engagement for sensory and motor rehabilitation. Researchers recognize that advances in neuro-imaging present an opportunity to shed light on the efficacy of visual art for stroke recovery.

Neuro-imaging has increased our understanding of brain structures and functions involved in information processing (Carlson, 2001), (Humphries, 2014) and these studies

invite inquiry into connections between the visual processes involved in art-based therapy and brain structures affected during these processes. (Lusebrink, 2004).

Brain maps can be assessed using functional Magnetic Resonance Imaging (fMRI) to determine damaged brain areas. They can also provide critical information showing changing input to cortical areas during specific cognitive and physical activities including when a person is engaging in activities such as visual art.

#### ARTIST'S BRAINS DIFFER

"Artists are in some sense neurologists, studying the brain with techniques that are unique to them, but studying unknowingly the brain and its organization nevertheless, " (Zeki, 1999).

In a novel Belgian study, the brains of 44 artists and non-artists were compared and found to have consistent structural differences in the cerebellum, frontal and parietal cortices. The authors found:

"An increase in grey matter density in the left anterior cerebellum and the right medial frontal gyrus was observed in relation to observational drawing ability, whereas artistic training (art students vs. non-art students) was correlated with increased grey matter density in the right precuneus."

The study concluded,

"that observational drawing ability relates to changes in structures pertaining to fine motor control and procedural memory, and that artistic training in addition is associated with enhancement of structures pertaining to visual imagery." (Chamberlain, 2014). The precuneus, (Fig.1) in the medial parietal lobe is involved with episodic memory (events - times, places, associated emotions, and who, what, when, where, why knowledge), visuo-spatial processing, reflections upon self, and aspects of consciousness. It is also associated with motor and sensory cortices. The location of the precuneus is protected and it is rarely subject to isolated injury due to strokes or trauma, (Cavanna, 2006).



Figure 1: Precuneus

#### The Precuneus:

Due to its location, protected in the medial longitudinal fissure, between the two hemispheres, the precuneus is an ideal part of the brain to study, as it is often spared in stroke. Since this area has been identified as unique to artists it therefore invites further investigation.

#### FUTURE OPPORTUNITIES IN NEUROSCIENCE FOR STROKE

Future research in neuro-imaging could further investigate specific cortical areas and connectivity developing or changing, during and after patients participate in visual artbased therapies. Should these therapies show intriguing results, future health care rehabilitation programs could expand services to facilitate art-based rehabilitation that targets integrated motor function and sensory perception rehabilitation.

Recent studies show motor skills are improved through the use of virtual therapies, mirror therapy (Doidge, 2007), robotic aids and constraint induced therapy (Taub, 1999) for learned non-use of paretic limb. These areas of inquiry are of significance in this project as they support the potential of art-based therapies for improving motor and cognitive abilities during recovery from stroke.

These findings invite further research to determine whether therapies using visual art could and may already aid in sensory-motor function.

#### VIRTUAL REALITY ENVIRONMENTS

There is evidence to suggest virtual reality (VR) environments are beneficial for motor and spatial rehabilitation for stroke and brain injury patients. (Holden, 2005) discusses the scientific rationale for using VR in rehabilitation as movements learned often transfer to real world tasks. Holden presents evidence from studies showing an advantage to VR learning over traditional real world learning in motor rehabilitation. These findings have shown: people with disabilities appear to learn movement skills from VR and that these learned actions are transferable to real world activities.

Virtual reality rehabilitation systems and gaming are gaining popularity as therapies in the treatment of upper limb motor impairments. Regenbrecht, (2012) has developed a system for stroke recovery and motor rehabilitation called augmented reality environment which, "fool's the brain" by visually amplifying a user's hand movements, "whereby, a small hand action will be perceived by the participant as a larger movement. This initiates a mental reward system and with repetitive training, creates lasting memories of the action."

It has been found post-stroke impairments can come from secondary causes, namely acquired non-use. Patients often maintain residual function in the affected side of the body but elect to under-utilize their paretic limbs, (Ballester, 2015). (It should be noted here that many rehabilitation programs encourage use of the unaffected limb thereby facilitating "non-use" of the affected limb). The authors hypothesized that acquired nonuse can be reduced through virtual environment training strategies where "patients were asked to reach targets appearing in either the real world or in a virtual environment. During the intervention the movement of the virtual representation of the patients' paretic limb was amplified towards the target." Results confirmed the "amplification of the movement of the paretic limb in a virtual environment promotes the use of the paretic limb in stroke patients...and may modulate motor performance in the real world."

The potential for integration of VR environments into rehab practice is intriguing as any modality that initiates mental rewards encouraging further physical participation (and potential motor recovery) could be used successfully in stroke rehabilitation. If a patient "sees" their arm action as larger than reality and is "fooled" (cognitively) with this positive feedback, then it may be feasible to incorporate VR into studies, potentially leading to future quantitative research and measurable outcomes.

To counter this argument, a keynote speaker at a stroke conference in Kingston revealed the most recent evidence stating there is no benefit to using technological based, (robotic) therapies over non-tech therapies. He also revealed that several barriers to integration exist especially from the health care providers employing these devices. Lack of support, confidence and knowledge are key deterrents. As well, there is a perceived mismatch between patient needs and the devices capabilities. He concluded that uptake of research based knowledge is slow and the need for training of staff costly, (DePaul, 2016).

An example was given of one such costly device that was installed in a hospital and use for one year, then abandoned. It was suggested that any therapies for physiotherapy should be easy to learn for both patient and staff, easy to implement (set up and take down and deliver) and can be used by an individual or in a group and finally, be measurable.

Virtual Reality physical therapies remain task-oriented, with a concentration on daily living activities or tasks and often, the focus is on what survivors cannot do, rather than on what they can do (Reed, 2010). Employing art-based therapies and practices to promote

recovery (such as drawing), instead of performance of daily tasks while movements are amplified in VR, has not been researched.

# **CHAPTER FIVE:** METHODS

The methods used in this study helped the author understand the people who are intimately touched by stroke. The empathy maps and personas were excellent tools and methods to characterize the individuals and capture personal perspectives of patients and those who support them. The expert interview insights, recorded 6 months prior to the research project were a significant motivator to pursue this study in depth and to embark on a future initiative: the design of a clinical trial.

#### METHOD ONE: PERSONAL EXPERIENCE & OBSERVATIONS IN THE FIELD

Prior experience teaching high functioning stroke patients in a college setting was the incentive and driver for this study. More substantial practical experience was gained over a 16-month period through volunteer placement at a hospital complex care unit. The purpose was to understand the process of working with patients and possible concerns in rehabilitation practices. Duties included assisting patients create photographs, paintings and sculpture in open studios and in a structured program funded by the Ontario Arts Council and delivered by the John Tett Centre, Queen's University. Other duties: transporting patients to activities and events, accompanying on outings and friendly visits. Fig. 2 a) and b) are photos taken of the author by another arts volunteer during a photo shoot with patients at an evening activity.





Figure 2a: Author helping during a staged photo shoot where patients make the decisions.

Figure 2b: Author, being directed by patients.

#### **METHOD TWO:** EXPERTS INTERVIEWS

Structured interviews were conducted with ten consenting experts in the field of rehabilitation science and their insights into potential benefits of art programs for stroke therapy were recorded and analyzed. Practitioners and researchers were recruited from a variety of health care professions relating to stroke rehabilitation to gain a broad base of insights and perspectives. Seventeen experts were contacted in the form of an email which included an introduction to the study author, a brief description of the research project, a request for an interview and the expert's role should they decide to participate.

Letters of consent were sent to the 13 experts who agreed to participate, 10 of whom followed through with the commitment. Participants were given several weeks to sign and return their consent letter indicating their choice of online participation or a scheduled private meeting. Three experts agreed to a 30-minute private interview at a research office in an academic centre.

Data was collected in the interviews in the form of hand written, verbatim documents or as on-line questionnaires. The online questionnaire was consistent with the private interview questions. No names, places or personal information was collected. All expert information is stored securely on a personal computer and will not be used for any other purposes than this masters research paper. All experts gave permission to use their ideas for the purpose of this study.

The questions and insights from the 10 experts who participated were analyzed and summarized in the results section and in chart form at the end of the paper (Appendix A).

#### **METHOD THREE: EMPATHY MAPS**

EMPATHY MAPS were generated to gain empathy to build better experiences for the four key stakeholders. Life experiences of patients, family, health care worker and student/volunteer dealing with stroke were mapped to build empathy by understanding their environment, thoughts, actions and most importantly, needs. This type of methodology is speculative but helps in the design of more human centered solutions.

#### **METHOD FOUR: PERSONAS**

PERSONAS capture the essence of each stakeholder group. The purpose of studying personas is to gain insights into the motivators and perspectives of key players. Using the information gleaned from the empathy maps, four personas were created to illuminate each group's unique situation while interacting in hospital and dealing with stroke. By painting a general picture with a very broad brush, their points of view, goals and frustrations were visualized.

NOTE: Before the empathy maps and personas were written, an introspective journey by the author took place, resulting in the generation of several imaginary visual images, painted after an extended volunteering experience. Gallery of images on pages: 65-70.

#### METHOD FIVE: VALUE PROPOSITIONS

The insights gained in the empathy and persona tools informed the design of potential solutions in the form of value propositions for each of the four stakeholders.

# **CHAPTER SIX:** FINDINGS

Question 2. What evidence supports the argument to incorporate more structured and specialized programming in stroke care for cognitive and physical therapy?

#### 1. PERSONAL EXPERIENCE & OBSERVATION IN THE FIELD

My experiences with stroke as an art teacher have accumulated over many years. Most people that participated in classes were high functioning and able to engage fully in activities. I am only aware of their condition as they shared this information.

My recent experiences and observations in the field (long-term care ward) were unexpected as I developed many close relationships with patients and other volunteers. I worked with complex care patients with all levels of physical and cognitive abilities. The experience was enriched by interaction with family members, other volunteers, program coordinators and health sciences students on placement.

Occasionally, questions about my duties and proper protocol for procedures went unanswered as I was sometimes in a position to make decisions without the guidance of a professional. For example: whether or not to touch or move a patients' wheelchair to assist them. After a short period volunteering at the hospital, volunteers were instructed to porter patients to and from wards to participate in art programs and other activities, as it seemed there were not enough health care workers to fulfill this job.
2. EXPERT INTERVIEWS: gaining insights from professionals in the field

Opinions from experts in the field were an also unexpected outcome of this study. All of those professionals who participated in the interview held strong views as to the benefits of art-based therapy for stroke recovery. There was a consensus on benefits for psychotherapy and all stated art as a therapy may enhance motor and cognitive recovery. All experts were supportive of increasing the amount and length of recreational art activities that a survivor receives. All ten believed art programming for stroke was worth studying and measuring including one participant who questioned why this has not been done before.

The final expert panel included:

- Occupational Therapists (3)
- Physiotherapist (1)
- Speech therapist
- Physiatrist/MD
- Neuroscientist & Researcher
- Professor & Researcher in School of Rehabilitation Sciences
- Learning Specialist for persons with disabilities
- Hospital volunteer coordinator

#### EXPERT INTERVIEW QUESTIONS:

- 1. What is you professional involvement in stroke/physical and cognitive rehabilitation?
- 2. Do you any knowledge of funded or volunteer run arts programs in your workplace?
- 3. Is it worth assessing potential physical/cognitive benefits of participating in art programs?
- 4. Do you foresee any short or long term positive outcomes to regular/structured art sessions?
- 5. Are repetitive, sequential exercises more or less beneficial than unstructured sessions?
- 6. Are you aware of any negative outcomes with clients if they participate in art sessions?
- 7. When might art programs be most effective to a survivor, early or later on in their recovery?

" There are physical and cognitive benefits and I can't understand why this has not been done before ~ there are existing tools that can measure motor recovery ~ you can measure art benefits," (Expert interview, 2016).

#### SUMMARY OF EXPERTS' INSIGHTS: (full text found in Appendix A)

One expert indicated there is funding for the arts at their institution which includes a weekly art group run by a salaried staff, a behavioral therapist, and volunteers. Occasionally, occupational therapists incorporate arts into their therapy, but it is a choice. A second occupational therapist/director indicated some of her therapists use art programs but that it is more widely and routinely used in the United States, where she had worked previously.

#### BENEFITS OF USING ART FOR STROKE PHYSICAL REHAB

Expert quote: "art can stimulate the brain, physically and cognitively."

Expert quote: "historically a complaint of patients is that rehab is boring and they do not see the connection between the processes in rehab and real life. Patients need motivation."

General perspective shared among the experts was that art as a mode of therapy could possible improve patient experience during rehab and may potentially enhance motor and sensory recovery. All 10 experts felt art programming was worth studying and measuring, if possible.

When asked if experts foresaw any benefits to including visual arts in rehabilitation programs, all 10 supported the idea and all said that this activity would improve

outcomes. Three suggested the earlier the better, once the patient is in rehab, for motor function recovery.

#### RISKS

Potential negative outcomes or risks: three of the 10 experts said occasionally, patients experience a level of frustration when trying to do art. Three experts outlined the possible emotional risks explaining a patient experienced, "frustration" when participating in art programs. One OT said they are always looking for "creative ways to engage their patients." One expert said that only once in their career, a patient expressed anger (because, pre-stroke, they practiced as a professional artist).

#### EARLY VS. LATE INTERVENTION

All health care experts felt that early intervention for rehab is more desirable. One said as soon as the patient is stabilized and in long-term rehab, art would produce, "major enrichment in parts of the brain related to spatial and motor skills." This contrasted another expert, an acute care therapist who said of rehabilitation interventions, "the sooner the better."

#### STRUCTURED VS. OPEN/UNSTRUCTURED SESSIONS

The opinions were varied on this answer. One said it depends on what your goals are but that both early and late interventions are of benefit. Some thought repetitive and guided sessions using both hands would be of benefit. Three experts stressed the audience determines the nature and pace of visual art programs for rehab.

Expert quotes: "repetitive, more guided, structured sessions encouraging use of both hands...easy to ignore the affected hand...called learned disuse."

and, "active sustained engagement in a structured task can drive positive change."

One occupational therapist said they use art to "help with gross and fine motor skills, regulating mood or helping with relaxation." This is a key finding and the sole indicator from the expert interviews of visual art currently being used for motor skill rehabilitation in the public health care system.

#### 3. EMPATHY MAPS: understanding needs to build better experiences

Stakeholder situations were unknown until personal experience as a volunteer revealed hospital inter-relationships between health care professionals, volunteers, patients and families. I gained insights into the thoughts, actions and needs of patients, family members and volunteers primarily. Health sciences placement students changed often - they were rarely at an event twice – and therefore, no meaningful insights were gained from interacting with them at events and activities.

Health care professionals were occupied and did not seem to interact with patients as much as I expected. Doctors were rarely seen in patient wards and physiotherapy took place in the basement where I never ventured. Family, students and volunteers figured prominently in the lives of patients and fostered a caring and warm community. The volunteer, family and patient maps are the most accurate depictions of stakeholder as I spent the most time with and learned the most from these three groups.



Figure 3a: Empathy Map of Nurse

This empathy map of the nurse (Fig. 3a) was difficult to generate as I had little interaction with nurses. I learned they were not often visible in the ward I worked in. An assumption I made is that they were attending to patient needs (who I did not work with) or performing duties that took them out view. Visible nurses were always focused, preoccupied with other nurses, paperwork/computer duties and with patients. Any interaction of volunteers with nurses was always pleasant and they were keen to help, if questioned. The empathy map for the nurse is derived from observation at this hospital and personal knowledge of nurses' roles and is therefore the least credible of the four stakeholder maps. Since they are the front line caregivers and rarely seen, I assumed they were working over capacity and were not visible because there were not enough nurses to serve the ward.



Figure 3b: Empathy Map of Patient

The patient's empathy map (Fig. 3b) is built from a compilation of all the people I met volunteering at the hospital and prior acquaintances from teaching art courses. The needs, fears, concerns are all real life emotions that I feel I understood but some insights may be biased and based on assumptions. Some experiences I had with patients were upsetting, most were incredibly rewarding. Patients were a mix of positive and negative emotions. Some expressed concerns about family and others distrusted the nurses. Some could not speak but I learned to communicate and found ways of learning their needs. Patients had many physical and emotional concerns but were always kind and grateful to have caring volunteers helping them. When they were not otherwise engaged, they defaulted to watching TV. They patients I worked with were always interested in leaving their rooms, participating in activities, especially art.



Figure 3c: Empathy Map of Family Member

The experiences that informed the family empathy map (Fig. 3c) are based solely on those patients who had a family or friends visit regularly, stay for extended periods and partake in events and activities. The map is a composite of these individuals. They were dedicated to the patient, showed obvious concerns but always remained positive and supportive. Family members took on a great deal of the care for the patient and showed obvious fatigue and stress. Occasionally, I witnessed raw and heartfelt emotions between family members.



Figure 3d: Empathy Map of Volunteer/Placement Student

The volunteer/student was the easiest map (Fig. 3d) to generate as it was based on practical experience and other volunteers' and students' methods and advice. One common concern for both student placements and volunteers was that we had limited training and were confused as to our roles when there was a decision to make. Maneuvering wheelchairs was always a challenge and although volunteers are not to move chairs, we were often recruited to transport patients. Dozens of volunteers answer to a handful of coordinators making it difficult for communication lines to stay open. The fear of doing something wrong was always present. The joy experienced helping patients and family participate in activities was addictive.

4. PERSONAS: capturing the essence of each stakeholder

Each persona is a fictional character representing the essence of each of the four key stakeholders. The personas allowed the author to design value propositions for each stakeholder, keeping in mind, the "customer" perspectives, motivators and needs. Family, students and volunteers figured more prominently than professionals in the lives of patients as they had the gift of time, in the hospital setting, to share with patients, assisting them in many activities and tasks. Health care workers were not visible or when in view, always busy, performing duties. Employable time (of family, volunteers and students) was identified as an underused commodity to take advantage of in the value propositions - to add value to the system.

Considering the concept of 'positive and negative time' and analyzing this across the four personas, it became apparent time could be used more effectively to better the lives of survivors. Health care professionals had negative extra hospital time (Fig. 4a) to devote to patients (Fig. 4b) as they had duties and responsibilities to fulfill in a set timeframe. Nurses, doctors and therapists were occupied often beyond capacity where as, the other three personas: family, volunteers and students shared the gift time when in the confines of the hospital setting. Volunteers (Fig. 4d) were there to help, students were there to help, learn and gain experience. Family members and friends were often present but seemed unoccupied much of the time. Family members (Fig. 4c) often sat at bedside and waited (making conversation with the stroke survivor is often limited due to patient attention and communication deficits).

The time concept is a key finding, because it was used in the solution planning to build better experiences in a cost effective system. Patients need more time doing rehab oriented activities (tasks) and volunteers and family can/do help with these activities, thus alleviating the "needs" pressures put on health care professionals.



Figure 4a: The Nurse persona. Health care workers have negative hospital time.



Figure 4b: The Patient persona. Patients have positive time and need help with rehab tasks.



Figure 4c: The Family member persona. Many family members have time to help patients.



Figure 4d: The Volunteer/student persona. Giving of time is the reason for volunteering.

VALUE PROPOSITION: observe customers and create added value to the system

Four value propositions were generated for the each of the four personas. The purpose was to identify jobs to be accomplished, pains and gains to be solved and then match their wants and needs by attempting to align jobs and problems with a value-based product or service. Functional, emotional and social jobs plus pains and gains are described in the circles. A holistic proposal that offers solutions to unmet jobs, needs and to increase gains is described, on the left, in the square.

The fit, between the jobs to be accomplished, pains and gains to be addressed in the circle and gain creators, pain relievers and services offered in the square, was successful, especially for the patient (Fig. 5b). The fit for the nurse (Fig. 5a) was less credible as the author was less familiar with their duties, gains and frustrations that they may have experienced while working. The value to be gained by family was moderately strong as the services of art programs and videos offered in the square (Fig. 5c) would help keep them occupied while engaging with the patient. The value created by the program for volunteers and students (Fig. 5d) was the strongest as they are employed by the hospital to serve the needs of the patient and therefore have much to gain emotionally, socially and functionally from an easy to learn and deliver art program.



Figure 5a: Value Proposition: The Nurse. (Osterwalder, 2015).



Figure 5b: Value Proposition: The Patient. (Osterwalder, 2015).



Figure 5c: Value Proposition: The Family Member. (Osterwalder, 2015).



Figure 5d: Value Proposition: The Student or Volunteer. (Osterwalder, 2015).

### **CHAPTER SEVEN:** INADEQUATE COMMUNITY SERVICES

There is no scientific evidence supporting the need for visual art-based curriculum in rehabilitation beyond psychotherapy and therefore there no funded art programs are available for outpatients after discharge. Few other community services (such as college continuing education programs) are appropriate for stroke survivors. Physiotherapy service for survivors is available and funded for a finite time period, approximately four weeks, after hospital discharge but does not typically involve the visual arts or virtual reality programs.

Dr. Nancy Harris, a retired Ontario family physician and friend, stated at a college art course the author was giving, "any modality that increases the capacity of an individual who has acquired or cognitive impairment is important." Harris believes Ontario health care system is currently not (but should be) using visual art for physical rehabilitation, and that, "very limited art based therapies are used," (Harris, 2015). Art-based therapy programs could benefit survivors far beyond their health coverage period. Patients could be encouraged to engage in self-directed, Do-It-Yourself art-based therapy, as a form of self-help.

Interestingly, discharged stroke patients are often encouraged by therapists and physicians to seek out art programs for self-help and as an occupation. Survivors, once back in their community, can enroll in costly private or adult education courses - if they are aware of the programs, interested, or able. Some stroke survivors may want to participate in courses but may not have the monetary or physical means to access these programs. Art courses are most often not available in rural areas limiting resources for survivors who have no means to access urban centers.

In addition, physically or cognitively challenged stroke survivors may find the ordeal of participating in an art course intimidating and avoid the experience out of fear. Making or creating art is frightening for many people, and those who are recovering from trauma may feel uncomfortable enrolling in an art class due to limited physical or perceived performance ability. Art programming implemented before patients are discharged may prepare them by giving them practical skills and experience as well as the incentive and confidence needed to continue pursuing art while recovering after their hospital discharge.

### **CHAPTER EIGHT:** VISUAL ART'S UNTAPPED CURATIVE PROPERTIES

Children learn from an early age to see and understand the world through looking, seeing and drawing or painting and repeating the processes over and over. As previously mentioned, artists that continue on this path, have structurally and physiologically different brains (Hogenboom, 2016) due to enhanced grey matter in several cortical regions. Practice and repeat actions and tasks, found in basic primary art activities, may help stroke patients stimulate and train the unaffected, residual parts of the brain to relearn lost motor skills and acquire new skills.

The change art making brings to persons of all ages is psychological, social and *physical* because it takes creative thought, interpretation *and movement* to create visual art and it connects these processes neurologically. "Scale, or pace or pattern(s)" learned while creating art, can "amplify or accelerate existing processes" (McLuhan, 1964) enhancing visual awareness: spatial perception, colour, value, and size recognition, and perspective, concepts stroke survivors may need to relearn, concepts children absorb over years of observation and schooling.

By participating in pleasurable, recreational activities beyond traditional physiotherapy and occupational therapy, including via digital means, patients might improve outcomes simply by passing time creating art. The "process" may (in the future) be shown to be of benefit for physical recovery but, to add to the experience, patients create a product, something to be proud of, a artifact to discuss in a discipline they can explore. The art is unique to them and it is something the patient had complete autonomy over.

For many stroke survivors, drawing and painting are already a significant form of nonverbal communication that enables people with right-sided hemi-plegia to convey information and express feelings. These survivors may experience speech and language aphasia (Cervoni, 2011) thus, drawing is used as one of their main communication tools. If structured appropriately, drawing could also be used as a technique in art-based therapy programs to improve physical and cognitive recovery from stroke.

Visual imagery as a communication tool helps stroke patients exchange ideas but may be more effective if patients *learned* to draw, paint and sculpt to improve sensory awareness, communication and motor skills. Professional instruction is essential for the disciplines in visual art, as most people need and want to be shown, *how* to do something before they are confident and independent. Instruction can help eliminate frustration when learning visual art techniques, which is especially important for stroke patients who would face challenges learning anything new.

Many rehabilitation programs in Ontario offer loosely structured arts and crafts leisure activities for stroke rehabilitation. These programs could be updated and align more closely with current scientific knowledge and technology. With well thought out programs, designed by professional artists, in collaboration with clinicians, patients, family and volunteers, stroke patients may be more interested and encouraged to participate and better served.

Future physical rehabilitation programs targeting upper limb recovery could encompass a broader range of interventions that include more structured activities - specifically for reestablishing motor function, (grasp, fine and gross motor skills) - and sensory awareness, (proprioception) after stroke. Research initiatives are needed to test the efficacy of these programs, re-evaluate, improve techniques and methods to further benefit recovery during rehabilitation. Because creating art heightens spatial awareness and perception, value, colour and shape recognition while using both fine and gross motor skills, imaging stroke survivors' brains during art activities and after extended art programs, may shed light on neural activity, connectivity and repair processes. This information would broaden the limited knowledge that is currently available on the re-wiring of undamaged cortical areas during recovery from stroke.

Visual arts programs for rehabilitation and follow-up assessment trials made available in hospital stroke units could be a straight forward, viable solution to engaging patients in repetitive and creative exercises that could be measured for efficacy. Rehabilitation therapists could use the underutilized therapy of art making for stroke survivors to relearn the visual and spatial world as a child would - through looking, seeing and interpreting visually, repetitively – building new and different neural connections - committing information about the world to memory again while potentially improving sensory and motor skills.

Bridging human centered design, art and science will elevate the discipline of visual art for stroke rehabilitation beyond its present-day purpose (essentially art *psycho*therapy). It may be accomplished through integration of the two modalities (art programs for psychotherapy and physiotherapy) providing holistic, physical and psychological rehabilitation. Alternatively, art for physical and sensory rehab could and ideally should function as a separate and unique discipline.

## **CHAPTER NINE:** GOVERNMENT INITIATIVES

With evidence-based knowledge, comes the incentive to drive change. By researching, developing and acting on new evidence-based research for stroke, and mobilizing and engaging physicians to support hospital best practice rehabilitation care, services could be significantly improved. Invigorating the disciplines of physio- and occupational therapy with art-based therapies may be found to be important in advancing stroke research, ultimately improving outcomes, especially at this crucial time and in the near future when the incidence of stroke is increasing.

A long-term goal for the future is to be a political voice for the population of stroke survivors (often silent) and to make decision makers aware of new knowledge that may direct attention to the problems and opportunities in rehabilitation services. There is a great need to influence post-secondary institutions curriculum planners, hospital boards and policy makers to recognize the need to research potential benefits of art engagement for stroke.

The Ontario Government needs to listen to and act on the evidence already brought forward by the Heart & Stroke Foundation of Canada: that stroke patients are "falling through the cracks." Policy makers need to consider how and at what cost to the system improvements to stroke care can be made.

### WHAT IS CURRENTLY BEING DONE: ONTARIO GOVERNMENT INITIATIVES

- Patients First
- Health Quality Ontario
- Ontario Patient & Family Advisory Council

The Ministry of Health & Long-term Care is, "making strides in providing quality care," through the Patients First: Action Plan for Health Care initiative. The Action Plan (laid out December, 2106) is the next phase of Ontario's plan for changing and improving Ontario's public health care system. It is designed to, "put people and patients first by improving their health care experience and their health outcomes." The commitment is to put people at the centre of the system by focusing on patients' needs first through:

Access – providing faster access to the right care.

Connected services – delivering better coordinated and integrated care Support – providing the education, information and transparency patients need to make the right decisions about their health.

Health Quality Ontario works in partnerships to "help initiate substantial and sustainable change to the province's complex health system," (Health Quality Ontario, 2017). The provincial organization analyzes how well individual micro systems that make up our health care system are working. They produce evidence-based reports and make recommendations for improvements.

The Provincial government is, "creating a Patient and Family Advisory Council to advise government on health policy priorities that have an impact on patient care and patient experiences." This initiative is in the planning and invites members of the public to apply and nominate suitable candidates Government of Ontario, 2017). (The author of this paper applied in March, 2017 and hopes to be on the advisory council).

Interestingly, change in stroke care best practice is lagging behind other health care priorities and stroke patients may not be in line to receive better care in the near future. All non-essential recreation programs for stroke and brain injury have been discontinued in Ontario and the SE Ontario Stroke Networks reports local research funding for stroke has been cut, leaving only limited public money available for conferences, field training and educational support programs. NSERC and CIHR funding bodies have very limited opportunities for funding stroke research.

## **CHAPTER TEN: RECOMMENDATIONS**

TO ANSWER THE MAJOR RESEARCH QUESTION:

How might rehabilitation programs be re-designed to better meet the needs and improve outcomes of a growing population of stroke survivors?

The goal of this project was to identify gaps in stroke rehabilitation, investigate what is known about art-based therapies and find evidence that supports researching visual art for physical and cognitive recovery. A new understanding of the problem, supported by the author's personal experiences, analyses of four personas affected by stroke and notable scientific findings, has led to developing possible solutions that could drive future initiatives. Insights presented here support future investigations that may address this underserved population's unmet needs and improve outcomes.

## RECOMMENDATIONS

#### 1. EXTEND REHABILITATION DURATION BEYOND SIX MONTHS

This study found rehabilitation services in Ontario are limited temporally based on an outdated paradigm of the brain's inability to repair past six months, post-injury. Multiple studies, including work done by the Harvard group report to the contrary: that the human brain has the capacity to continue to repair, adapt and build new connections beyond that period. Essentially, the brain continues to change and learn for life. Researchers and clinicians need to bring this information forward and consider pressuring decision makers to design new funding models that may provide needed, extended and improved rehabilitation services.

#### 2. IMPROVE QUALITY OF CARE

Until funding models for stroke rehabilitation change, a structured art initiative for stroke could be considered, involving the community, placement students, volunteers and family members. An initiative such as a basic, regular art program has the potential of enriching the lives of survivors and persons connected to them. Structured and regular art sessions for in hospital and outpatient clinics may not only enhance quality of life and potentially promote physical recovery but could prepare survivors with a means to self rehabilitate using a meaningful skill, once home. Programs could include the disciplines of drawing, painting, photography, printmaking, digital techniques, sculpture, pottery, woodworking, etc.

In the future, a variety of structured, sequential art programs with easy to deliver curriculum could be offered in hospital as optional activities in which to register, just as patients register for outings. These programs would not replace traditional physiotherapy, rather, they would enhance it. Patients could choose streams they wanted to study. Family members could co-learn the skills required to assist the patient in the discipline they found enjoyable and retain those skills to continue rehab after discharge. This phenomenon was observed on a very small scale by the author while volunteering in a long-term care hospital.

#### 3. IMPROVE ACCESSIBILITY AND EQUITABLE SERVICE

Front line caregivers, patients and family members need to lobby provincial and locals governments to fund more, longer and improved services for stroke survivors. By encouraging small community art organizations to deliver tailored programs to inpatient community, patients could benefit in many ways. This inclusive initiative could provide the inpatient population with services that are typically only available in the greater outside community, usually at a cost.

Disability programs could also be offered in public education institutions including schools and colleges, specialized services that could be made available to survivors at no cost. Arts students could be employed in coordinated placements in this initiative, with home outreach services available to reach non-mobile survivors.

Governments need to consider making all services available for all ages of survivors, including those between the ages of 19 and 65 currently not served in some extended rehabilitation programs. This change, although costly initially, is important in promoting equality and inclusivity to a largely disadvantaged part of society. In the long view, it may eventually reduce health care spending by speeding recovery, reducing re-admittances and decreasing hospitalization stays.

#### 4. ACT ON CURRENT NEUROSCIENCE

New rehabilitation programs, based on current scientific knowledge and the evidence proving the brain's ability to repair, need to be co-designed and implemented. It is imperative that rehab education curriculum and practical service in stroke care catch up to the current knowledge disseminated by researchers. The system is lagging far behind the science. This is probably a symptom of funding allocation, (rather than lack of funds) and poor coordination across the system. Policy makers need to address this gap in service and recommend the re-allocation of resources to improve quality, type and amount of services for stroke.

#### 5. USE AVAILABLE WORKFORCE

While in hospital visiting, some family members, all volunteers and all students have the time to engage in activities with the patients. That is their purpose: to help and offer their time. Some family members stay for extended periods in a given day and most observed by the author are more than willing and do participate and assist their loved one in recreational activities. Whether all family members would have the interest or means to participate, remains to be seen.

Some volunteers are regular fixtures and know much more of the art programming than staff as they are regular front line workers with patients. Programs would not run effectively or at all if it were not for these extra people who give of their time. Large hospitals already take advantage of this free labour and coordinate volunteers to deliver art programs. Unfortunately, it is a very limited and sporadic event.

People who volunteer their time are more than willing to train and deliver programs to stroke patients in hospital. Visual arts and health sciences students, volunteers, and family members could be widely employed to provide art programs. They all have *hospital time* to dedicate to patients, in contrast to nurses, physicians and therapists who can only give limited time to each patient due to volume of patients.

In the near future, hospitals could scale up their recreation departments and begin serving stroke survivors with much needed programming while funding and research initiatives develop. In addition to the available workforce of volunteers and collaboration with local community groups and organizations, hospitals could tap into education institutions' human resources and skills, to build larger volunteer and placement bases to deliver new initiatives. The Provincial organization, The Ontario Arts Council, recently funded an in-hospital community arts programs in Kingston and could be approached to expand upon this initiative in other, smaller communities.

This student/volunteer initiative could be developed, moved out into the community and scaled out regionally. Local community centers, clubs and schools could provide facilities

to host arts based programs form discharged survivors. Placement students and volunteers could be organized to provide structured programs until the health care system re-instates recreation programs for stroke rehabilitation therapy.

The element of time could be capitalized on, used to a much greater extent in the design of volunteer services. Simply by employing this available and willing workforce, hospitals could initiate cost-effective art-based programs.

#### 6. COLLABORATE TO DESIGN HOLISTIC PROGRAMS

Based on the fit assessment in the value propositions, co-designing an interdisciplinary model may prove more beneficial to survivors, their family and other caregivers than the current rehabilitation model. A collaborative project, involving all stakeholders in the design, where the disciplines of art, science and rehabilitation therapy converge with lived experience of survivors, could prove fruitful in exploring many possible and unknown therapies for improved recovery from stroke.

Ideal outcomes for survivors would be to rebuild all lost abilities: motor function, sensory awareness and fine motor skills. For many, this is not possible due to the extent of the tissue damage and for others it is a slow and arduous process with little guarantee of complete rehabilitation. Future research, designing a variety of methods and treatments in the arts field (including digital) could promote recovery for survivors after they are discharged and home, when funded therapy sessions are complete or unavailable and motivation in self directed therapy may decrease. By enhancing rehabilitation practices in hospital to be continued at home, some of the most debilitating losses resulting from stroke, may be recovered faster or at least, lessened. The information gleaned from prior research in the field coupled with this master's project findings formed the design of a feasible, viable and desirable prototype that may add value to rehabilitation practices in the future. After completing the research project, a prototype clinical trial for stroke was designed. The author proposes, in Section Two, an innovative solution that may realize the value propositions presented in the paper through the implementation of a novel intervention: an art-based program for stroke rehabilitation.

The intervention could be considered an adjacent innovation to art *psycho*-therapy. It could also be a transformational innovation because art rehabilitation therapy specifically for sensory-motor recovery has not yet been clinically studied. Should art programming prove effective in stroke physical recovery it may lead to larger studies and advance knowledge in the field.

## SECTION TWO BRIDGING ART, DESIGN AND SCIENCE

#### A PROTOTYPE: CLINICAL TRIAL DESIGN

The mobilization of knowledge in this study is in its infancy. It is necessary to build a collaborative research team to design a feasible and effective study that may provide clear evidence. The author has begun a process of sharing these early findings with health care professionals and has gathered a small research team to investigate the use of art-based therapy for stroke in a clinical setting.

At the point of writing this paper, three individuals at Queen's University and Providence Care Hospital in Kingston, Ontario had committed to the co-design and implementation of a small clinical trial. The team considered, that in future, art programming could be used to expand the breadth of rehabilitation practice presently available for stroke and act as an adjunct to current physio- and occupational therapy.

The team will comprise: researchers, at least one physician, occupational and physiotherapists, artists, volunteers and stroke survivors. The clinical trial will take place at Providence Care Hospital. As this is novel territory, the initiative will entail significant research, revisions and design iterations.

The purpose of the initial trial is to design a scalable art program with testable, measurable outcomes based on non-invasive, low risk, modifiable visual art tasks. After the art program, functionality tests will assess the patient's upper extremities to measure any benefits that might have been gained from art-based therapy.

Initially, start-up resources will be low cost. Volunteers, family and friends may have time

to assist, which is an important asset. By recruiting willing family members, volunteers, previous patients, medical students on placement, all of whom will be trained in the delivery of easy to learn art sessions, a short intervention will be implemented. Time, people and a comprehensive design are the key elements necessary to carry out the initial program. Funding avenues for this small trial are currently being investigated.

Questions to consider in the design of the trial:

- 1. What type of art tasks are most suitable and could be measurable?
- 2. Will family members and community group be interested in participating?
- 3. Should both upper limbs be involved in the program and KINARM assessment?
- 4. Should prior data of KINARM assessment be used to compare results?
- 5. Would other institutions be interested in participating in a co-pilot study?

Future funding could be secured to launch a feasibility study designed to analyze cognitive activity in the visual, parietal and motor cortices while patients are engaged in art making. The analysis would use brain-imaging technology to illuminate the areas stimulated during therapeutic art interventions. The data collected on activity in the precuneus section of the parietal lobe, the area often spared in stroke and uniquely more developed in artists, may be of use in future research.

#### INTERVENTION PROPOSAL

The clinical study will comprise:

1. structured art program consisting of daily, repetitive tasks and practice strategies codesigned with a multi-disciplinary team and delivered by the author/volunteers

- 2. interviews with patient and family before and after the trial
- 3. functional assessments and data analysis of patients' functionality pre/post trial.
- 4. feedback sessions and end of trial information pamphlet

#### RECRUITMENT

The design is for a small sample size of 8-10 similarly affected stroke patients who would have the means to participate physically and mentally. They would participate in an intensive, structured art program over a two-month period (exclusion criteria: patients with receptive aphasia - can not understand language - or major visual deficits).

#### ART PROGRAM

The proposed art program will include:

- Participatory videos (learn by seeing/observing others doing tasks)
  designed and produced by the author (one prototype is completed)
- Sequential drawing and painting exercises/tasks beginning with gross motor skill line-work moving to finer motor skills and transitioning from B&W to colour shapes.
- o Mental practice
- o Interviews with survivors and family, volunteers
- Future design: instructional training videos for professional facilitators: artists /physiotherapists/occupational therapists

ART PROGRAM PRACTICUM ~ drawing, observing and visualizing tasks

The program is designed to commence with selected patients once released from acute care at Kingston General Hospital, and settled in long-term, rehabilitation at Providence Care. The shape/task sequences (Fig. 6) are designed to be delivered/attempted in a sequential order, beginning with simple and basic and progressing to more difficult. Each tasks targets different muscle groups and actions, exercising gross and then fine motor skills in the upper limbs.

Exercises would be introduced to patients as soon as possible after they are discharged from acute care and settled into long-term care for rehabilitation. Private training would be ideal, but some small group sessions would be used due to time and human resources limitations.

TASKS, LEARNING MODULES, ART SESSIONS



Figure 6: ART Tasks, modules and program prototype for sequential drawing sessions

#### FUNCTIONAL ASSESSMENT

A robotic arm device, (The KINARM) located at Providence Care Hospital will be used for the upper extremity assessment of sensory-motor functionality.

The clinical trial is proposed for the near future. At the time of submitting of this paper, Providence Care Hospital had just moved into a new modern building in Kingston, on the shores of Lake Ontario (April, 2017).

### CONCLUSION

The importance of this study is that it identifies the discipline of visual art for stroke rehabilitation as an under-researched therapeutic modality. It also identifies significant gaps in current services available for stroke survivors and various means to address those gaps. The author identifies the discipline of art as a potential future solution to enhancing rehabilitation science, and as an adjunct extension to present-day practice.

This study underlines the potential of visual art as a cognitive and physical rehabilitation tool and it's overall value as a beneficial and purposeful occupation for stroke survivors. The paper demonstrates a significant need to assess whether art activities benefit stroke survivors physically and cognitively. It should be stressed that there remains a need for evidence-based quantitative research to assess possible correlations between sensorymotor recovery and that of art-based interventions. The paper presents a unique opportunity to build upon scant research and conduct an in-depth investigation into artbased therapies in a small clinical trial. A credible assessment can only be achieved in clinical trials using scientific methods.

> "The Heart and Stroke Foundation recommends that Governments explore opportunities to enhance post-stroke rehabilitation services. " (H&S. 2014).

This issue is still not being fully addressed in Ontario's health care system. For several years it has been acknowledged that stroke care is lacking and patients are underserviced in Ontario. Individual LIHNs promote stroke awareness and quality care for staff through education seminars, conferences and networking yet the amount and quality of frontline service to stroke victims is lacking due to resource shortages and budget cuts. There are few stroke units outside urban centers. There is little funding available for stroke research.

Historically, the stroke patient has had little input into the design of their recovery process. The collaboration and co-designing (by physicians, therapists, survivors and professional artists) of holistically art-based programs, as adjuncts to regular recreational and physiotherapies and to be continued as self-directed - at home therapy, may be a valid consideration for future research. Implementation of an art-based rehabilitation program and more in-depth research in this field may have an impact on improving outcomes for stroke while affording patients autonomy and purpose.

It would be hoped that this research project is expanded upon in the future to make a difference for this population. This paper is a call for action.

# GALLERY OF ILLUSTRATIONS

Below are seven imaginary images that informed the Empathy Maps and Personas. Painted by the author  $\sim$  and not representational of any real person(s).



Illustration 1. Patient


Illustration 2. Patient



Illustration 3. Patient



Illustration 4. Patient



Illustration 5. Patient



Illustration 6. Patient



Illustration 7. Patient

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APPENDIX	Ϋ́Α	
EXPERT INT	ERVIEW QUESTIONS/RESPONSES	
Summary of Findings		
1 Profession & involvement in stroke/physical and cognitive rehabilitation	Findings: The 10 experts interviewed or sent questionnaires (same questions as interview) were: two physiotherapists, two occupational therapists, a speech therapist, a neuroscientist, a physical rehab physician, two learning specialist (one art therapist professor/one director of a school for learning disabled), a hospital 'volunteer services' director/coordinator. The learning specialists, the OTs, PTs, a director of volunteer services and the physician work directly with stroke patients. The speech therapist does not and the neuroscientist is a researcher.	
2 Any funding for visual art programs for stroke patients? Any volunteers running art groups?	Findings: All experts except two were unaware of any art programs offered in their institutions. The hospital volunteer coordinator offers a weekly, informal painting group run by a volunteer who initiates the activity. Only the OT was aware of paid staff funding for art therapy type of visual arts programming. Weekly, "open - no focus" sessions are run by a therapist and volunteers. The therapist gives the patients art supplies and they work in their rooms. This same OT said some other OTs use art to "help with gross and fine motor skills, regulating mood or helping with relaxation." This is a key finding and the sole indicator of art used for motor skill rehabilitation.	
3 Is it worth assessing potential physical and cognitive benefits from participating in art programs?	<ul> <li>Findings:</li> <li>All ten experts thought visual art for stroke is worth assessing quantitatively. The neuroscientist, who has developed clinical tests for stroke assessment, was supportive of this mode of therapy stressing, "the need for evidence-based medicine." The OTs were strong supporters of art for therapy:</li> <li>1. first OT: "more studies would allow more funding and resources to allow art based therapies to be incorporated into regular therapy."</li> <li>2. "absolutely, for regaining fine and gross motor skills."</li> <li>Both PTs said it is worth assessing because:</li> <li>1. "there are physical and cognitive benefits and (he/she) can't understand why this has not been done before? there are existing tools that can measure motor recoveryyou can measure art benefits."</li> <li>2. "art can stimulate the brain, physically and cognitively."</li> </ul>	
4 Foresee any short or long term positive outcomes to regular and /or structured art sessions?	<ul> <li>Findings:</li> <li>Neuroscientist said it would result in, "major enrichment in parts of the brain related to spatial and motor skills." Both PTs supported regular sessions.</li> <li>1. One PT said it would aid, "motor function, attention span, cognitive and motor planning, mood and social engagement."</li> <li>2. "historically a complaint of patients is that rehab is boring and they do not see the connection between the processes in rehab and real life. Patients need motivation."</li> <li>Volunteer services director, "I have witnessed several people benefit from art."</li> <li>OTs supported regular sessions:</li> <li>1. OT said, "knowing more about how art helps these conditions would valuable."</li> <li>2. "have worked in the States where art activities are more commonly used in OT."</li> <li>The learning disabilities specialist stated: "research indicatesthat active sustained engagement in a structured task can drive positive change." Art therapist suggested, " some structure is necessary but need for flexibility to do what the client wants."</li> </ul>	

5	Findings:
Would repetitive, sequential exercises be more/less beneficial than unstructured sessions?	OT said repetitive exercises are suitable, "only if the patient has identified certain skills they want to learn/goalsunstructured is much better for this population as the clients are very different in their abilities and would not likely be able to follow an art group protocol at the same level." Assumption that art has to be a group activity. "They may not have the ability to develop skills beyond that level, so the focus should be on enjoying and creating with the ability they currently have, versus trying to move to next level in sequence." Insight: not impetus to be challenging patients artistically. 2 <sup>nd</sup> OT: "depends on the goal of the session and motivation – benefits to both depending on whether client is hesitant to move on or motivated to explore." PT: I see the value of sequential and graded exercises. As a therapist, I think your audience will determine the necessity of the approach. There will be some who cognitively cannot follow more structure, some whose cognition will benefit from more 2 <sup>nd</sup> PT said this would be of benefit: "yes, repetitive, more guided, structured sessions encouraging use of both handseasy to ignore the affected handcalled learned disuse." Learning specialist: "identifying the starting point of the exercise so it is challenging but not too challenging – so it engages the brain in what research has identified as 'effortful processing' and then repeating the process. I would think these principles would apply to art therapy."
6 Aware of any negative outcomes for clients if they participate in art sessions?	<ul> <li>Findings:</li> <li>Eight experts said they were not aware of any risks or negative outcomes that might occur from participating in art sessions. Two mentioned "frustration as a key response to trying to do art.</li> <li>OT: "Frustration when it does not look the way they want it to look and difficulty accepting that it can be beautiful even if it is not 'perfect'. I see this with perfectionist personalities "versus</li> <li>2<sup>nd</sup> OT: no</li> <li>PT: had a frustrated patient - previously a professional artist - who "was very disappointed in quality of what (they) could produce. I think that would be rare however, and his was a special case in that regard. I can also imagine that some patients, if engaged too early may tire too easily. "</li> </ul>
7 When during recovery might art programs be most effective to a stroke survivor, early or later on in their recovery?	Findings: Physician: " early, intensive rehab leads to better outcomes overallexpect a role for (it) both early ar late, with different potential benefits (later may not improve motor skills, but may be better for mood/socialization." Neuroscientist: "the earlier the better and once they are stabilized leave acute care and are in rehab.""