An Environmental Scan examining the evidence supporting psychosocial care
and the adoption of hopeful care in stroke recovery

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Executive Summary

Overview:

The Toronto Stroke Networks has undertaken an Environmental Scan examining the evidence supporting psychosocial care and the adoption of hopeful care in stroke recovery.

Psychosocial Care - definition

Psychological and social services and interventions that enable patients, their families and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health. Institute of Medicine (IOM 2008)

For the purpose of this e-scan *psychosocial* is limited to psychological (e.g., anxiety, depression, coping, quality of life) components. It does not look at programs designed to address such issues as financial challenges, childcare, nutrition, and transportation.

A growing body of peer reviewed research and grey literature demonstrates that the psychosocial aspects of treating and managing illness (e.g., cancer, stroke, diabetes, chronic pain) are equally as important as biomedical care (Kirkevold 2014, Nicholas 2016, Turner 2011, 2017, Ho Yu Cheng, Teoh 2009, Hole 2014). Policymakers and health care institutions recognize this and include concepts such as hope, patient engagement and caring for the whole person in their guiding principles and mission statements. However, the paradigm shift that would see the critical responsibility for psychosocial care mandated across the entire health care team has yet to occur. Psychosocial remains primarily marginalized, siloed and relegated to social workers and psychologists.

Rehabilitation needs to incorporate perceptions of control over recovery, stress management, hope, understanding social identity, finding meaning and recovery expectations (Teoh 2009, Soundy 2014). It must also adopt an integrated approach to the management of post-stroke depression that includes psycho-education.

Translating this evidence into standards of practice and clinical treatment may seem resource and labour intensive, but there are aspects of it that are relatively simple to start. The key to promoting hope, reducing anxiety and depression and supporting wellness across the treatment experience starts and ends with communication and trusting relationships that can bridge the disconnect between patient and provider perceptions and expectations. Active listening, encouraging the telling of stories, seeing, hearing and treating the whole patient and not just the disease or disability – a collaborative vs prescriptive approach – contribute to better outcomes and quality of life.

The integration of hope and other psychosocial elements into post-stroke care represents a paradigm shift in how medical systems operate, what kind of care is rewarded, who is seen to be driving the care plan, and how we can expand the boundaries of everyone's role – patients, family and caregivers. The shift is already underway. We see the language of patient safety, patient engagement, patient-centred care and compassionate care at the highest levels of the system.

Methodology:

The search started with *hope, hopefulness* and *psychosocial* as related to stroke, cancer and chronic illness and applied to clinical practice by a range of health care providers, including physiotherapists, nurses, psychologists, physicians, social workers.

The search went on to examine what contributes to developing or increasing hope? What interventions/activities exist? How successful are they? Lastly, academics, clinicians and administrators in health care settings and leading rehab hospitals were contacted to discuss their institutional experience with psychosocial care and how they were training staff (see Appendix 1 contacts).

What the Research says ...

This e-scan summarizes the evidence supporting psychosocial care and the correlation between hope/hopefulness and health outcomes and quality of life. It highlights the communication-based contributors and detractors to hope. It defines terms and provides evidence supporting effective communication, the role of identity, sense of cohesion, perceptions of control, group membership, participation, narrative and storytelling, goal setting, motivational interviewing, patient engagement, patient/relationship-centred care.

The evidence supporting the power of hope and hopeful relationships and their correlation with adherence, self-efficacy and positive health outcomes has led to the development of a range of interventions by academics in such disciplines as nursing, physiotherapy, psychology and medicine. However, the evidence supporting their efficacy remains, in many cases, too statistically insignificant for a wholesale investment by single-payer systems and health care institutions in the changes and training required for health care providers to effectively implement them. That said, there are a number of training initiatives, interventions and tools that show promise and are being used in the field. A scan of institutions and research studies (see lists in appendices) across several jurisdictions highlights some exciting developments. Support materials are provided where applicable.

Assessment: The need and the tools

Research supports the need to evaluate psychosocial/psychological adjustment and well-being of patients early and regularly (Winstein et al 2016). Mental health is a moving target and issues can present themselves at any point. Patients are particularly vulnerable during periods of transition. Family and caregivers play an enormous role, particularly in post-discharge care and should also be evaluated for stress, anxiety, coping, wellbeing and how equipped they feel for the job they are now expected to perform. The literature also points to the importance of assessing health care practitioners. *Empathy fatigue*, burnout and a lack of understanding about the psychosocial impacts of stroke can impact the practitioner's own health, their ability to do their jobs, and their patients' ability to thrive. Health care provider hope has been correlated with patient hope. (Compassion training eases doctor burnout - Washington Post, August 22, 2017)

Challenges and Barriers

Challenges and barriers present themselves at all levels of health care. At the staff level they take the form of resistance to change, a not my job attitude, resentment towards early adopters, and anxiety about the expansion of job descriptions without compensation. At the institutional or department level, there is a reticence to invest time and financial resources in system/program/ training redesign based on relatively new and "soft" science, and a reluctance to rock the human resources boat. At a system level, despite changes in vision and mission statement language, psychological, communication and cognitive needs are still not a high priority (Read 2013, Nicholas 2016). Finding C-suite (CEO, CFO, CIO, COO) champions to lead the charge is imperative.

Next Steps:

The e-scan concludes with a set of questions and next steps the Toronto Stroke Networks must consider to move forward with a more strategic adoption of hope and psychosocial care.

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Active hope empowers us to think the unthinkable
yet act within the limits of the realistically possible – Eric Fromm

1.0   Introduction

Despite the fact that it has long been understood that depression is an independent predictor of poor recovery, lowered quality of life and more severe disability (Auton 2015, Ayerbe, Ayis, Wolfe, & Rudd, 2013), historically, the focus of health care has been largely on biomedical care – what's the disease/condition/injury doing to the body and how do we treat it? The care surrounding biomedical – psychological and social (psychosocial) contributors to disease and to health, were not, until recently, understood to be critical to healing and wellbeing.

A growing body of peer reviewed research and grey literature is now demonstrating that the psychosocial aspects of treating and managing illness (e.g. cancer, stroke, diabetes, chronic pain) are equally as important as biomedical care (Kirkevold 2014, Nicholas 2016, Turner 2011, 2017, Ho Yu Cheng, Teoh 2009, Hole 2014). Policymakers in government, health care think tanks and institutions are recognizing this and are embracing concepts such as hope, patient engagement and caring for the whole person in their guiding principles and mission statements.

But even with this revolutionary conceptual change, in practice the attitude often remains that it's someone else's problem. I do brains, I don't do minds… A form of medical NIMBY-ism. Psychosocial care for the most part remains siloed, un-championed and relegated to social workers and psychologists. The paradigm shift that would see responsibility for psychosocial care understood and shared by the entire health care team has yet to occur.

Resistance to change is one of our most deeply shared human traits, and in fairness, health care practitioners, institutions and systems are already overburdened and economically stretched. The changes required to see the evidence supporting the inclusion of and the shared responsibility for psychosocial translated into clinical treatment at the "bedside" or in clinic are likely perceived as resource and labour intensive.

But the positive news stemming from the research and the pockets of clinical change that are happening is that this kind of revolution can happen in smaller manageable chunks and the benefits are contagious. Evidence indicates that the key to better, more effective care across the treatment continuum starts and ends with communication and trusting relationships.

A consistent problem created by lack of open communication and active listening is the disconnect between patient and provider perceptions, expectations and measures of recovery. This can impact both the patient's and the health care practitioner (HCP)'s commitment to the process and thus the outcomes (Grypdonck 1996).

A collaborative vs prescriptive approach – active listening, encouraging the telling of stories, seeing, hearing and treating the whole patient and not just the disease or disability – all contribute to better outcomes and quality of life.

All research and science seeks to build evidence through measurement. The science of hope, hopefulness and psychological wellbeing is no different. However, here the primary measurement tool is perception – a hugely relevant yet subjective and often unexplainable element of health, health care and wellbeing. Hope, coping, struggling, inability to progress may all defy the biophysical circumstances. Measurement is as key to care planning and implementation as it is to science. Evidence points to the need to measure often. There are many recognized tools/scales used to measure such things as depression, anxiety, hope, quality of life. A number have been included here.

2.0   The key concepts and how they are interrelated

Defining psychosocial care is complex and made up of both services - what is needed (support groups, therapy, childcare, financial aid, information, mental health assessments – these have always been understood to be significant, yet remain under-funded) and the way we offer them how it gets delivered (how we listen, communicate, collaborate, empathize, support – this area is exploding as a new area of research).

The what is needed is particular to every patient and family and is best determined through active, ongoing, engaged communication. The how it's needed and delivered – the positive, whole-patient-focused communication is both universal (everyone needs to feel heard and respected) and particular (everyone's need for autonomy and style of taking in information is different).

In unravelling what comprises the psychological elements of psychosocial care, this e-scan begins by examining the inter-related pieces of hope and hopeful care, patient-centred care, patient-engagement and positive psychology.

2.1   Psychosocial

The IOM (2008) defines psychosocial care as…*psychological and social services and interventions that enable patients, their families and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health.*

Another definition of psychosocial wellbeing is (a) basic mood of contentment and the absence of pervasive feelings of sadness or emptiness, (b) participation and engagement in meaningful activities, (c) good social and mutual relations, and (d) a self-concept characterized by self-esteem, self-acceptance, usefulness and belief in one's own abilities (Kirkevold 2014).

In *Cancer Care for the Whole Patient* (2008), the term psychosocial health services has been adopted (rather than simply psychosocial services) to ensure their inclusion in health services broadly.

Both *Cancer Care for the Whole Patient* (IOM 2008), and *Psychosocial Care of the Adult Cancer Patient - Evidence-Based Practice in Psycho-Oncology* (Donald R. Nicholas 2016) reference the insufficient preparation of the workforce to deal with psychosocial. This includes lack of clarity around competencies, absence of curricula built around competencies, inadequate number of educators, trainers, mentors, insufficient specificity in accreditation and licensing standards.

Psychosocial care for cancer: a framework to guide practice, and actionable recommendations for Ontario (Macdonald 2012) has adapted the IOM report and set standards of care for psychosocial oncology in Ontario. There are 31 recommendations including screening patients, families and caregivers (P/F/C) for psychosocial needs at the initial visit, training and education for all staff in psychosocial care and assessment, the development of inter-professional collaborative care models and recommendations related to oversight and monitoring, workforce competencies and ongoing research.

2.2   Hope

A frequently cited definition of Hope is as a "multi-dimensional life force, which is always present to some degree and is characterized by a confident, yet uncertain, expectation of achieving a future good that is realistically possible and personally significant." Dufault & Martocchio (Bluvol 2002)

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Hope and hopefulness lie at the core of perceptions of quality of life, and are positively correlated with health outcomes, superior pain tolerance and less affects of symptoms (Larsen 2014, Soundy 2014, Berendes 2010). However, the search for what makes someone hopeful, for strategies and interventions that increase hope, for behaviors that decrease hope is a chicken and egg undertaking. Hope is positively correlated with less depression. But depression is known to remove hope (Gum 2004). More severely disabled stroke survivors have a higher degree and rate of depressive symptoms and a more difficult time setting and reaching goals. Does hope contribute to self-efficacy and improve outcomes? Does it increase a patient's ability to set and meet goals? Or do positive outcomes and achievements build hope? (Cross 2015) The answer to all these questions might be yes.

What has emerged from all the research reviewed in this scan, is that hope as it relates to health is complex and must be understood as such by all HCPs. Hope comes in different forms that serve different functions at different times. When a particular hope/actively hoping (related to a specific outcomes, or level of recovery from a condition) fails us we turn to generalized hope/simply having hope (a state that gives life meaning and protects against despair) to get us through (Lohne 2009, Bright, 2012). In patients with more complex cognitive impairments or communicative disorders like aphasia, generalized or simply having hope may be the entry point into hope, actively hoping can be much more difficult when faced with a lot of uncertainty (Bright 2012).

All members of a care team, including the P/F/C must bring their hope to the rehabilitation process. It is critical that P/F/Cs not see hope as something that can only be bestowed upon them by HCPs, leaving them dependent on the authority of professionals who have the power to decide when feelings of hope are legitimate or not (Larsen 2007).

Hope is a moving target that's continually being refreshed. It is both a cause of improved outcomes and an effect. Interestingly, the majority of studies indicate that patients continue to hope regardless of their prognosis (Soundy 2014, Hammer 2008). In his 2014 framework for hope that captures all types, Soundy places generalized hope at the centre.

Illustrating the framework of hope: courtesy Andy Soundy
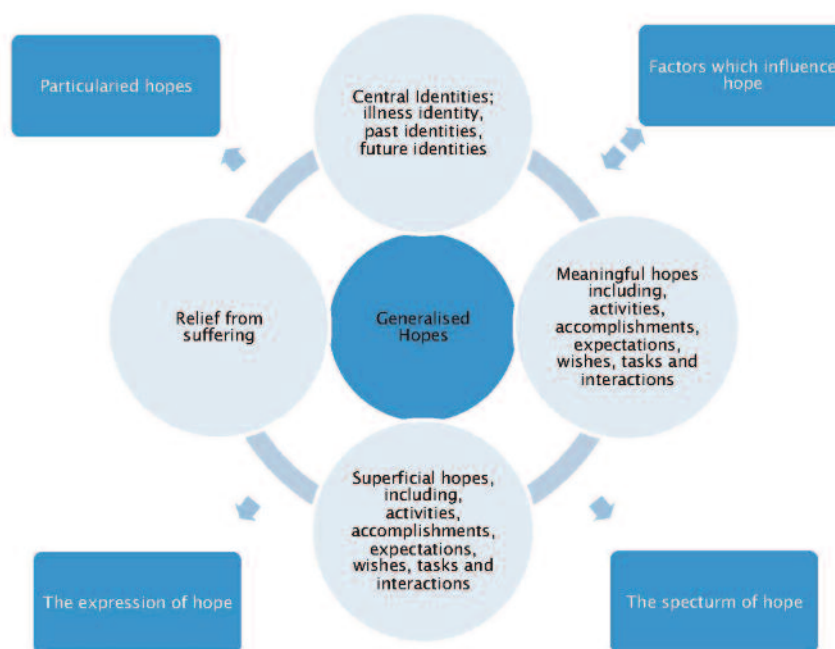
Hope Theories

C.R. Snyder whose theory shaped the field of positive psychology, defined hope as 'a positive motivational state that is based on an inter-actively derived sense of successful (a) agency (goal-directed energy), and (b) pathways (planning to meet goals). Rather than emphasizing the emotional aspects of hopefulness, Snyder conceptualized hope as a cognitive construct reflecting motivation and capacity to strive toward personally relevant goals. Hope depends on agency thinking and pathways thinking. Agency thinking refers to people's perceived ability to pursue goals despite obstacles. Pathways thinking refers to perceived ability to generate plausible routes toward goals.

K. Herth's hope theory has greatly influenced the fields of health psychology, nursing, and medicine. Herth is primarily concerned with people's future goals as they relate to coping with medical illness, interpersonal loss, or other psychophysical stressors. Herth identified three dimensions of hope that correlate with patients' psychosocial functioning.

• cognitive-temporal (similar to Snyder's notion of agency thinking) refers to individuals' beliefs that they can realistically attain desired objectives or outcomes (Arnau et al., 2010).

• affective-behavioral (similar to Snyder' s pathways component) reflects people's confidence that their plans or actions will lead to goal attainment (Arnau et al., 2010).

• affiliative-contextual refers to people's perceived social support, spiritual support, and sense of belongingness.

D. Webb's taxonomy divides Hope into five types (Eaves 2014)

• Realistic Hope: reasonable or probable based on current medical knowledge

• Utopian Hope: collectively oriented, a hope that group action can lead to a better future

• Wishful Hope: very high, but still possible hopes, anchored in the current world. Hope as a wish, want or desire" – like a cure

• Technoscience Hope – faith in the inevitability of scientific or medical breakthroughs

• Transcendent hope – general hopefulness not tied to a specific outcome, goal, or defined future. This can be hope drawn from religious faith

Bright et al (2011) depict the key features of hope as:
A) Developed through a range of factors: internal (attitudes, sense of self and personal history), stroke-related, and external (family and friends, spiritual beliefs, staff).
B) Having three attributes – an inner state, an outcome-oriented attribute, and an active process.
C) Yielding positive outcomes that affect a person's internal state and recovery.

Hope vs Optimism

Denise Larsen, Associate Dean and director of Hope House, University of Calgary has published widely on hope and hopefulness and its relationship to health outcomes. She emphasizes that hope is not an emotion, but a task or process that requires work. That work can be encouraged or discouraged by HCPs who have far more power (unrelated to their technical competence) to influence outcomes than they may realize.

A HCP's understanding or lack thereof of the complexity of hope and its importance to the patient can result in everything from great results to catastrophic ends. Larsen makes the important distinction between hope and optimism. Optimism is defined as feeling positive about the future when good outcomes are likely. Hope takes over in cases of unlikeliness or hardship, where work is needed to believe in and move toward positive outcomes (Larsen 2014).

In a study on optimism and hope in chronic disease, Schiavon (2017) discusses that when stressors are prolonged, optimists are more vulnerable.

"False" Hope, "Realistic" Hope

To destroy hope because it seems 'unrealistic' may be more psychologically damaging than leaving individuals to adapt to the 'reality' of their situation in their own time. HCPs must attend to patients' needs for hope and recognize the importance of exploring its meaning and the purpose it serves for them (Rose Wiles 2008, Eliott and Olver 2002, Thorne et al 2006).

In many medical settings and in the minds of clinicians, patient hope is associated with expecting a cure and if there is no cure, then hope is seen to be unrealistic or even false and gets mistaken for denial (Larsen 2014). Any discussion about hope can then slide quickly towards hopelessness.

The concept of false hope needing to be discouraged (or squashed) by HCPs, has fallen out of favour (although some HCP's still feel it's their job to keep people realistic). There's no evidence to suggest that false hope is counterproductive to recovery. These hopes may be better described as defiant (Soundy 2008, 2011) or audacious (Larsen).

The conflicts or negative interactions that arise when P/F/Cs have a different perspective on hope than their HCP, can remove hope (Bright et al. 2011). This risk can be mitigated by two things:
1) getting to know the patient and 2) having a broader understanding of the multiplicity of hope.

Also, the idea that HCPs must share their P/F/C hope is neither realistic nor useful. Larsen uses the term *diversified hope portfolio*. HCPs need to understand that people have many hopes. Of course it can be dangerous when a patient gets stuck on one particular hope. But the role of the HCP is not to extinguish that, but to help supplement it with additional hopes.

The question of whether two differing opinions on hope can co-exist remains key to the patient/HCP relationship. Client hope is often seen by HCPs as a barrier to moving forward.

This represents a mismatch of hope perspectives related to the viability of a certain hope. Not all patients are strong or autonomous enough to hold onto their "subjective" hope in the face of a physician's "objective/ expert knowledge" that holds firm despite the fact healthcare is not characterized by exact knowable truths. Hope rests on the possible not the probable. For patients it's often based on deep desire rather than perceived likelihood.

HCPs were found in the literature to be able to develop, destroy or restore hope. Tensions arose when therapy staff and patients did not share hopes for recovery although some studies found hope could still exist in this situation (Bright 2011). It is critical for HCPs and caregivers to understand that being attuned to one's own fluctuating sense of hope may be more important than never losing it (Larsen 2012). HCP hope and how they communicate their own hopefulness can dramatically influence patient hope (Hobbs 2012).

It is important to understand what an individual can accept about the loss they perceive and how it affects their identity. Further to this, it is critical to recognize that in some instances the hope of a possible recovery may be an individual's main agency for motivation and challenging the effects of the stroke. Removing this hope can leave a patient with a very negative view of the therapist. Rebuilding and restructuring one's identity relies on mastery of experiences, learning and self-development, where hope changes and adapts due to perceived success and the influence of others. Hole 2014

Hope and Adherence

Important to patients and caregivers, health care providers, institutions, health economists and insurers alike is the relationship between hope and adherence. K Herth states that "Hope requires a sense of control over one's destiny." Suzanne Makarem (2014) has studied why people don't always follow the doctor's orders.
She concludes that a patient's perception of control (POC) over their situation and what they can do to improve it, manage it or cope, is linked to hope which is in turn linked to compliance. Until recently health behavior models have paid little attention to emotions. But they are critical to motivation or demotivation.

The HCP plays a critical role in building the confidence and sense of control that lead to hope and adherence. Some patients are naturally more autonomous than others. They want to collaborate actively in all decisions. Others defer to their doctors/HCP, which places a greater burden of responsibility for positive outcomes on the provider. Regardless who holds the control, control is critical to hope.

The paradox. Hope as a dialectic

Soundy (2014) quotes Barnard (1995) who claims: *People with chronic conditions are impelled at once to defy limitations in order to realize greater life possibilities and to accept limitations in order to avoid enervating struggles with immutable constraints. This is the dialectical nature of chronic illness.*

Hope is closely linked to hopelessness and despair (Bright et al 2011). They are the flip side of the same coin. The central strategy of maintaining hope is a dialectic between dealing with illness as a threat, allowing an emotional response, managing uncertainty and gaining control, moving forward again until the next threat presents itself (Hammer 2008, Forbes 1999).

The paradox allows hope to be held and lost at the same time. The availability of multiple modes of hoping allow patients to report a continued feeling of hopefulness while also reporting a decrease in hope (Eaves 2014). A number of tangible psychosocial interventions – Motivational Interviewing, Cognitive Behavioral Therapy, support groups, tele-support, all raise hope by increasing knowledge, self-efficacy and control.

2.3   Patient/Provider engagement

Patient Engagement is a broad term referring to involving P/F/Cs in aspects of health care from partnering with HCPs in care planning and follow through, to influencing and helping set policy, program and research directions, to physical plant design, board membership and so on. The concept has seen a dramatic uptake and integration over the past decade and is now part of hospital accreditation.

On the patient level, engagement is often referred to as activation and is measured by how involved the person is in their own care. Playing an active role is correlated with perceptions of control which increase hope, compliance and outcomes.

Levels of engagement have been associated with increased functional improvement during inpatient rehab and levels of post-discharge function. Engagement is also associated with lower levels of depression and higher levels of affect, adherence and attendance (Bright et al 2014).

Post-stroke goals set by the World Health Organization (WHO), prescribe that rehabilitation be centred on the patient's own goals and planned in close cooperation with them (Bendz 2003).

In her conceptual review of engagement in rehabilitation, Dr. Felicity Bright, Auckland University of Technology, NZ, distinguishes between process and state of mind. This distinction challenges how clinicians view and work with the so-called "disengaged" patients. Disengagement (or failure to engage) is often depicted as the patient's "problem" and responsibility, thus ignoring the role of the HCP, the therapeutic process or the environment. Patient engagement, Bright argues, is co-constructed and requires connection. A patient cannot engage unilaterally. Clinicians are responsible for assessing engagement but are often ill-equipped to do so. Their assessments (and the tools they use) regularly conflate engagement with compliance (Bright et al 2014).

"Engagement is a co-constructed process and state. It incorporates a process of gradually connecting with each other and/or a therapeutic program, which enables the individual to become an active, committed and invested collaborator in healthcare."

Patients are not solely responsible for engagement, clinicians must engage as well. Patients perceive HCP interest through behaviors such as sitting with them to talk about their story, being present, respectful, attentive, going above and beyond, showing empathy – making the patient feel known, and not judged. These perceptions impact their own engagement. Collaborative patient/HCP relationships and consensual treatment decisions are key to the patient's belief in their ability to adhere to a plan (Makarem 2014).

Much of the literature on hopeful and successful psychosocial care (elements such as patient/provider relationships, active communication of information and storytelling) has engagement at the core. In conversations with health care institutions about how they address hopeful or psychosocial care, people went straight to discussing patient engagement. The work of supporting and enabling patients to engage, overlaps and often forms the necessary underpinning for effective psychosocial care.

Like engagement, patient/person-centred care or patients' first are now ubiquitous terms used to mean placing the patient/family/caregiver, their psychosocial wellbeing, their identity in the world and their physical health, at the centre of care and healthcare delivery system design.

The less-used term relationship-centred care (Beach, Inui 2005) may best capture the need for active, engaged involvement by all parties. Practitioner engagement influences how they work and how they perceive the patient. Their disengagement often arises out of lack of confidence in their work or positive impact on patient outcomes, or after emotional responses to a patient or interaction. Each party's engagement influences the other. Hope (hopelessness), which is posited to be both a driver and a byproduct of engagement, seems similarly co-constructed by patient and practitioner. It is rare that one can unilaterally sustain hope or engagement (Larsen 2014, Bright 2012).

Rosewilliam et al (2011) undertook a systematic review of the evidence behind patient-centred goal-setting in stroke rehabilitation. Despite indications that patients could and wanted to be involved in designing and managing their own care, goal setting for stroke patients remained clinician-centred, system-centred or population-centred, rather than patient-centred. Patients criticized HCPs for being prescriptive and inflexible while HCPs ascribed various reasons for limited engagement to patients – lack of knowledge, expertise, cooperation, confidence, unrealistic expectations.

HCPs generally see themselves as patient-centred, even though evidence indicates that patients' social and occupational needs were not explicitly incorporated into rehab plans. Regardless whether the goal-setting methods identified in the literature were problem-oriented, needs-based, impairment-based, patient-centred, therapist-controlled and therapist-led, the evidence demonstrated that current goal-setting practice is not largely patient-centred (Rosewilliam).

Barriers to patient-centred goals are summarized as:

1) Professionals' avoidance of conflict in goal setting situations by evading discussions relevant to the patients' perceptions of their goals

2) Family dynamics in situations where the family dominated the process for their own interests, shifting the focus away from the patient

3) Professional attitudes and system restrictions - scarce resources, the dominance of formal assessments

Therapists stressed skills such as listening skills, negotiation skills, ability to adequately guide patients, ability to think laterally, and seeking alternate methods of communication for patients with speech problems in order to develop patient-centredness in goal setting (Rosewilliam 2011).

(See Craig Hospital and Johns Hopkins below for models of implementing engagement.)

Positive Psychology

Positive Psychology is the scientific study of the strengths, conditions and processes that contribute to the flourishing or optimal functioning of people, groups, and institutions. The field is founded on the belief that people want to lead meaningful and fulfilling lives, to cultivate what is best within themselves, and to enhance their experiences of love, work, and play. Positive Psychology Centre

Positive psychology looks at building, reinforcing and extending people's strengths while not becoming slaves to the "tyrannies of optimism". Positive interventions should not be at the expense of disregarding human suffering, weakness and disorder. Many of the strategies outlined in this scan find their roots in positive psychology, focus on agency, pathways and social supports and prioritize making space for P/F/Cs to discuss what's hard, alongside the development of coping strategies.

3.0   Research and strategies for the enhancement of hope and psychosocial wellbeing

This section examines a number of approaches/interventions showing promising outcomes and a positive correlation to hope and psychosocial wellbeing in the context of significant threats and challenges to health.

The obvious place to start was with Hope Enhancement Strategies (HESs) designed specifically to focus on and increase hope. They are primarily psychotherapy-based and emphasize supporting clients/patients to find it in themselves and their personal histories and strengths to move from a can't do to a can do set of beliefs.

Only modest and statistically insignificant evidence supports these HESs, suggesting that hope may not be as malleable as some suggest. Additionally, the HESs focused on such things as gratitude, optimism, forgiveness and mindfulness, show greater success in lab/research settings than they do in clinical, real life settings (Sin, Della Porta 2010). They need to demonstrate effectiveness in human-service settings before they can be recommended for use in clinics and hospitals (Weiss 2011).

Weiss suggests that rather than using hope therapy as a first line treatment, clinicians may wish to use hope theory as a model from which to select evidence-based treatments and to guide their interventions. More traditional approaches like psychotherapy, cognitive-behavioral and coping skills approaches (Gum, 2004, Weiss 2011) are associated with much larger increases in life satisfaction and subjective wellbeing (Mazzucchelli, Kane 2010).

What underlies hope and contributes to increasing or maintaining it in the face of traumatic illness or events has been found to be broadly related to ones understanding of self – sense of coherence or cohesive identity, perceptions of control, social inclusion. Thus strategies have focused on influencing how P/F/Cs see themselves through simple improvements and adjustments over time, successfully meeting tangible rehab goals, respectful treatment and solid relationships, invitations to tell one's story, well-timed provision of information.

In his early career, Stephen Wegener at Johns Hopkins (see below) focused directly on hope as a proven critical variable in outcomes. But the lack of strong evidence supporting specific techniques and interventions for its enhancement, and the fact that it remains unclear whether it's a trait (static) or a state (changeable) turned his attention to engagement and communication which evidence does indicate are contributing factors to positive outcomes and to hope.

Denise Larsen's work on hope in psychotherapeutic relationships concludes that in fact the relationship (therapist/client or HCP/PFC) IS the intervention. The HCP is often one of the primary sources of hope. The manner in which they communicate and manage the patient's pathways directly influences their agency or sense of control (Soundy 2014).

"Viewing therapeutic connection and engagement as an intervention differs to routine practice where (a) efforts to strengthen the therapeutic relationship and facilitate engagement appear to be seen as secondary to other supposedly more active ingredients considered to be the domain of disciplinary-based interventions; (b) the development of a good therapeutic relationship may be more due to chance than design; or (c) the skills needed to optimize connection and engagement are considered unteachable, instead developing intuitively through experience over time, eventually marking out the expert from the average practitioner." (Bright 2015)

At the health care delivery end, hospitals, rehab centres and funders must examine the research and what P/F/Cs and HCPs are saying works for them, and determine how, where, and in what to make investments. Despite this scarcity of strong evidence, some healthcare facilities and providers are willing to go with intuition and promising interventions.

This e-scan sought to examine areas to expand the role of a range of HCPs in hopeful care and psychosocial support. Some studies and onsite training in engagement, communication and Motivational Interviewing techniques (see Rehab centres interviewed below) do involve physiotherapists, occupational therapist and other team members in their training and interventions.

The Role of Nurses

Much of the work on hopeful care and psychosocial support is driven by nurse academics and focusses on an expanded role for the already well-positioned and trained stroke nurses in education and support (Burton 2005, Hartigan 2010, Kirkevold 2014, Grypdonck 1997). De Sales Turner 2006 recommends that nursing curricula, training and professional development and in-service education place hope-facilitation on their agenda. She also suggests that each nurse inventory the attitudes and beliefs that inform their practice on a regular basis.

Collaborative Teams

Critical to the provision of psychosocial care, is effective interdisciplinary collaborative or integrative care. HCPs must function as a team that knows, shares and discusses the physical, emotional and personal circumstances of their P/F/Cs and understands their respective roles in relation to each other. This includes being aware of what happens when a patient is transferred back to the community. However, as Donald Nicholas points out in Psychosocial Care of the Adult Cancer Patient 2016, while the need for collaborative care has been widely recognized (Institute of Medicine 2001, 2008, 2011, Institute of Medicine and National Research Council 2008) it is far from routine, the path to achieve it is unclear and in most settings it remains an aspirational goal. The barriers to achieving effective inter-professional work are found at the individual, team, institution and systemic levels.

Aphasia

Existing research is inconsistent in its inclusion, or more often than not, exclusion of people with common stroke sequelae such as aphasia, communication disorders or cognitive impairment. This may mean that key information about hope after stroke is missing (Bright et al 2011, Mumby 2013). Additionally, the research that does focus on aphasia often neglects the distinction between people with post-acute vs. chronic aphasia. Much of the intervention-focused research (eg. narrative, Motivational Interviewing, patient perceptions of care) notes in the limitations section that patients with aphasia or other severe cognitive impairments have been left out. Some researchers (Bronken 2012, Bright 2014, Simons-Mackie 2007, Winkler 2014, Cruice 2007, Mumby 2013) have focused on aphasia as it relates to hope, access, adjustment. Only a few (Bronken, Kirkevold, Bright) adapted or ran studies specifically for aphasia patients. The interventions required approximately 40% more time over a longer period and with shorter more frequent sessions.

Mumby and Whitworth (2013) researched the adjustment process in people with chronic aphasia and note the importance of inclusion and participation. However, they observe that participation in itself is not enough. It must be meaningful in terms of personal goals and societal roles. This understanding has implications for HCPs and caregivers who may think they are being supportive by encouraging or facilitating patients to simply "get out more often".

3.1 Sharing information actively

Active and tailored sharing of information comes up repeatedly in the literature as an important element of hope-inspiring care (Lohne and Severinsson, 2005). It enables shared decision-making, which enhances perceptions of control that in turn increase hope. Information or resources cannot simply be handed over. It must be conveyed in a way that supports patient and caregiver emotional progression through recovery. Timing of the provision of information is as important as the information itself. When can it best be made sense of (this relates to patient's sense of cohesion), assimilated and followed? Is it accompanied by lists of resources, contacts or info helplines where follow-up questions can be dealt with as they arise (Tutton 2011)? In her work related specifically to nurses, Hammer (2008) discussed the importance of knowledge and its relationship to fear and anxiety reduction.

This can play itself out for both HCPs and P/F/Cs. HCPs require adequate knowledge and understanding of the disease (Tutton et al, 2011; Cross and Schnieder, 2010) and the potential for a cure or improvement (Smith and Sparkes, 2005) in order to feel confident in their work and help patients and caregivers to set goals and equip them for the dramatic changes to come (Brown et al. 2013). HCPs who express a lack of confidence or knowledge (eg. by Googling in front of a patient) can cause uncertainty and loss of trust for the P/F/C which in turn causes anxiety and reduction in adherence (Makarem 2015).

Post-discharge, the role of the family/caregiver changes dramatically and many stroke survivors and caregivers feel they have nowhere to go for the information and supports necessary to take on the new role. The information deficit creates anxiety and can lead to poor outcomes (Sabari 2000, Cameron 2007, White 2014). (See Supporting family and caregivers below)

3.2 Goal setting

Goal setting has always been at the core of rehabilitation, but its success is contingent on patients driving, collaborating, or at the very least buying into it. And it must be built around an understanding of who that person is and what's important to them – ideally things the HCP has learned not by looking in a file, but through conversations with the patients or their caregivers. Thus at its best, goal setting must be done in tandem with sharing information actively, treating the whole person, encouraging a sense of control, storytelling. Tools like Motivational Interviewing that are now widely used (see below) are designed to lead the patient to understanding the need for and setting the goal themselves. Unless a patient is very self-motivated, generic goals set by someone else are less likely to be reached.

Patients differ dramatically on the scale from passive to active, in how involved they want to be and how much control they want to take. It is important for HCPs to understand that things like culture, language barriers or severity of disability could initially look like passivity or resistance. Not all P/F/Cs can or will be moved from passive to active, but research demonstrates that HCPs can influence patients' perceptions of control, degree of engagement and self-efficacy. All these things are correlated with hope, compliance and outcomes.

As discussed above, goal-setting in the form of agency (believing in your ability to achieve something) and pathways (envisioning a new route or goal when one doesn't work) thinking is at the core of both Snyder and Herth's hope models. The HCPs role is to become the expert in highlighting patients' pathways through rehabilitation, guiding a patient to see what is possible and realistically achievable (Soundy et al, 2010).

Brown et al 2014, studied patient perceptions of goal-setting after stroke. How patients should be involved in goal setting, the relationship of goals to treatment plans, and managing conflicting views between HCPs and P/F/Cs on the objectives of rehabilitation, are sources of ongoing debate and little consensus. Bendz 2003 also flags the disconnect between P/F/C and HCP perceptions and understanding of need. Patient uncertainty about their condition, about potential for recovery and about the rehab process itself creates difficulty in selecting goals. The authors suggest the answer lies not with the usual health education for patients, but with comprehensive education and training for HCPs about the physical and psychological stroke experience and its role in shifting patient perspective and understanding (Brown et al 2014).

SMART goals

SMART goal setting has received a lot of attention.

S - specific, significant, stretching,
M - measurable, meaningful, motivational
A - agreed upon, attainable, achievable, acceptable, action-oriented,
R - realistic, relevant, reasonable, rewarding, results-oriented,
T - time-based, time-bound, timely, tangible, trackable

Theoretically this approach makes sense, but imposing it as a requirement for all goals set by rehab HCPs (as was done in one major western Canadian rehab hospital), can become both an administrative burden and an artificial paper exercise divorced from the patient, their circumstances and capabilities. In the case of this hospital, an institution-wide investment in SMART training was made, not enough staff supports were put in place, and within a year the practice came to a "grinding halt".

The Brown at al 2014 study concludes that rather than one-size fits all (e.g SMART approach), clinicians require more nuanced goal-setting tools that match the patient, their psychological profile and personal preferences. Similarly, Bright suggests a needs-focused vs impairment-focused goal-setting process. She is examining the use of a 5-point scale of incremental goals toward the ultimate goal, where 5 is the highest desired outcome and 1 is the first step towards it. The P(F/C) is thus working on goals and hopes at many levels. The work is proving challenging for HCPs. It requires regular team discussions and case conferences, and can raise professional identity issues and limitations for less experienced therapists or therapy assistants who have the most direct patient contact, but are the least empowered. Additionally, organizational infrastructure and culture create barriers.

Critical to the process of goal setting is the ability to effectively measure outcomes. Goal Attainment Scaling (GAS) was developed for this purpose.

GAS measures outcome data from different contexts set out on a 5 point scale of -2 to +2. The quantitative measurement scale addresses the problem of how to adequately identify and measure qualitative goal impact and attainment. It enables measures to be linked across all levels of an organization from the frontline to senior management.

Level of Expected OUTCOME 3 months after the course	Rating	Behavioral Statement of EXPECTED OUTCOMES: - GOAL 1	Behavioral Statement of EXPECTED OUTCOMES: - GOAL 2
MUCH *MORE* Than EXPECTED	+2		
MORE than EXPECTED	+1		
EXPECTED Outcome	0		
LESS than EXPECTED	-1		
MUCH *LESS* Than EXPECTED	-2		

3.3   Identity, Sense of Coherence, Participation and Group Membership

Identity – the sense of who a person is and believes themselves to be in the world is profoundly threatened and often ravaged by stroke. Acceptance and rebuilding and revising ones identity and sense of coherence is often identified by stroke survivors as an unmet need (Hole, 2014). Identity is deeply social and relational. Stroke survivors are parents, children of older parents, husbands and wives, teachers, members of athletic clubs or religious congregations, team leaders, coaches. All these identities create what is referred to as Social Identity Continuity and a Sense of Coherence (SOC) promoted by experiencing life events as comprehensible (cognitive), manage-able (instrumental/behavioural) and meaningful (motivational) (Antonovsky 1987; Eriksson and Lindström 2005, 2006).

Identity is also shaken by a lack of control or understanding of what the physical body is or is not doing. That inseparable connection of mind/body where physical and mental actions requires no active thought or will, is often severed by stroke. In addition to the fact that this effort now becomes the patient's primary preoccupation, HCPs are often incapable of explaining why it's happening, which is a huge source of patient frustration. The psychological ramifications of this disconnect go far beyond the end of formal rehabilitation. Stroke victims express the need for extended services to support this rebuilding process (Ellis-Hill 2000).

One of the greatest post-stroke tasks for the P/F/Cs and HCPs is to recreate that SOC. Subjective quality of life is determined as much or more by (re) engagement with social life as with physical function (Haslam 2008). Having multiple identities and group membership is seen to be a buffer and a source of physical, emotional and social support that can help override functional limitations (Dorsett 2010). However, the incidence of perceived cognitive failures was also negatively correlated with participants' reports of their ability to maintain pre-existing group memberships after their stroke (Haslam 2008).

The role for HCPs is to know who the patient was before diagnosis/onset, consider the importance that person attaches to returning to the activities, relationships and identities associated with their past self, and determine how to help the patient retain and rebuild a new way of seeing themselves.

While the process of acceptance is key to this rehabilitation and many HCPs see getting the patient to that point as central to their job and to moving forward, it's not a generic term for adjustment. It's multi-dimensional and individual. Every patient gets to acceptance in a different way at a different pace (Soundy 2014).

Research indicates that women experience stroke differently. Female identity and the loss or impairment of the female role of housekeeper, mother, wife (in addition to the loss of other identities) might create a deeper sense of loss (Cross 2010). While this broad distinction between men and women is interesting to flag, the answer to addressing and rebuilding identity and a sense of cohesion lies not in generalities but in treating each patient as an individual with a history, a sense of identity, roles, and goals.

The research assumption that participation (seeing people, remaining a part of groups they once belonged to, joining others) contributes to hope was also found to be reversed. As hope increased, people were more likely to undertake participatory activities (Gum 2004). However, peer support/connecting with others who have been through the experience of stroke, was also found to be a contributor to hope (Sabari 2000). The WHO's conceptual framework for disability (Understanding Psychosocial Adjustment to Chronic Illness and Disability 2009) has participation - the need to return people to active productive life – as the ultimate goal of rehabilitation. However, there is no agreed upon definition of participation which makes it challenging to operationalize.

3.4   Narrative, storytelling, making space for pain

Narrative theory emphasizes that human beings create meaning, direction, identity and value in their lives through the stories they tell (Taylor 2007; Kraus 2007). Research suggests that telling one's story is a fundamental need following a traumatic event and may promote health (Bluvol, 2004, Aranert 2006, Tutton 2011, Wiles, 2008, Kirkevold, 2011, 2014, Larsen 2012, Hammer 2008). Related to storytelling and to treating the whole patient (see below), is recognizing the value of P/F/C subjective experience of stroke. Many studies have been devoted to understanding what is happening from the P/F/C (subjective) perspective (Prigatano 2011, White 2014, Brown 2013, Sabari 2015).

Larsen and others point out that hope cannot be imposed. Statements like, "You just have to be more positive" only serve to shut down the discussion of what is painful and hard that must happen in tandem or even before hope can emerge. People need to come to hope themselves. The technique of helping recreate and adapt narratives or to "re-story" takes stroke survivors through their own experiences with a focus on hope and dealing with adversity (Edie et al 2016).

Rose Wiles (2008) importantly discusses the need to resist the social sanctioning of appropriate narratives that encourage certain (positive) responses and discourages others. Charon (2001) discusses narrative competence in medicine – as a tool for empowering the P/F/C, a therapeutic act for all involved, a key to building trust, and, particularly in situations where there are no clear answers an act of courage and generosity to tolerate and bear witness to unfair loses and random tragedies.

In her research on work-aged stroke survivors, Randi Martinsen discusses the importance of supporting stroke survivors through co-construction and guided self-determination. Having a dialogue partner was seen to be essential (Martinsen 2014). Guided self-determination (GSD) is a theory and evidence-based problem-solving method designed to overcome barriers to collaborative care. It is based on life skills theory, dynamic judgement building and theories about behaviour change. GSD promotes patient autonomy, participation, skills building and intrinsic motivation to recreate meaning.

Listening to patient stories is critical to understanding their hopes and fears. This provides the opportunity for HCPs to support and drive the patient in their ongoing re-evaluation and reframing of their story and their future (Tutton 2011). A lot of the research supports enhancing the capacity of nurses to provide this supportive narrative or guided self-determination care (Turner 2009, Aranert 2006, Kirkevold 2014).

Key to enabling P/F/Cs to share their stories is a person-centred interviewing style comprised of a willingness to listen without interruption, sustaining respect and interest, making eye contact, allowing the patients to talk freely about aspects of their story that move beyond their symptoms, and inviting elaboration through open-ended questioning. Active listening is considered a therapeutic tool rather than a means to an end for assessment and prescription (Bright 2012, 2015).

Through her intervention using narratives and guided self-determination, Marit Kirkevold found that the very invitation to tell their story, initiated reflection processes the patient had not thought of on their own.

3.5   Supporting family and caregivers

HCPs must consider the impact of stroke on both partners and family members. The experiences, the needs for support and the burden of responsibility will be different for all involved. HCPs must assess the caregiver/family's emotional state and understand the role that uncertainty plays. How can they plan and support the P/F/C in ways that reduce that uncertainty? A different QoL tool should be used to assess caregivers. HCPs need to identify the families/conditions in which stroke survivors are most at risk post-discharge (White 2014, Cameron 2007, Ellis-Hill 2009).

Bluvol (2003) found the most important predictors of stroke survivor QoL are 1) degree of functional independence at discharge 2) Hope, 3) spouse's employment (better if partner is not working). This suggests that care plans must be designed around the particular family/caregiver circumstances.

The role of caregivers in post-stroke care shifts. Studies find that to maximize benefit, supports and information must be matched to current P/F/C needs. Additionally, information should be provided when the P/F/C is ready and able to understand and make use of it. During acute care and in-patient rehabilitation, caregivers commonly provide emotional support, assistance with activities of daily living and communication, and advocacy. Once home, the caregivers have primary responsibility for patients' recovery and rehabilitation.

Changes in caregiving experience and roles across the care continuum mean changes in education and support requirements. While research and discharge care planning acknowledge transitions as particularly challenging times that require special attention and information, to date, little research has focused on all the post-stroke phases and associated needs. Care plans should reflect the diversity of needs across time. (See Table 1 "Timing it Right" model for family caregiver intervention research pg 308/9 Cameron 2007).

In a small qualitative study of patients and caregivers who have just transitioned home (Ellis-Hill 2009), concerns were raised by P/F/Cs that services were developed and implemented by HCPs based solely on their own understanding of needs and abilities, and focused primarily on environmental factors and risk management, rather than a holistic psychosocial understanding of what is needed. Additionally, leaving the care of the physiotherapist is in itself emotionally charged, particularly for more passive patients and caregivers (Ellis-Hill 2009).

Solutions to this disconnect include keeping P/F/Cs informed and ideally involved in post-care planning – what services are being set up, when they will begin and who to contact if they've not heard by a certain time. Lack of information and support contribute to loss of momentum and lack of continuity that lead to stalling of progress and psychological distress.

Ho Yu Cheng (2014) discusses how the amount and duration of care, the responsibility to stroke survivors, and the lack of time to devote to their own health behaviors and social activities drain the physical, psycho-logical and social resources of family caregivers.

The Effectiveness of psychosocial interventions for stroke family caregivers and stroke survivors reviews the best available evidence on the impact of caregiver psychosocial interventions on the wellbeing, physical health and QoL of family caregivers, and the use of health care resources by the stroke survivors.

Counselling was found to have the greatest positive impact. Psychoeducation and the social support groups demonstrated a significant effect on reduction of the survivors' use of health care resources. The review suggests three-months of psychoeducation with eight sessions might improve the caregivers' family functioning, psychological wellbeing and sense of competence, and also enhance the chance of the stroke survivors remaining at home. There is a trend that psychoeducation, consisting of training in problem solving and stress coping, offered by telephone, reduced the depression level and improved the sense of competency of caregivers, although the summary of the effect was not statistically significant.

3.6   Treating the whole person

The broad acceptance that psychosocial ramifications of illness are as significant as the biomedical ones, translates in almost all the psychosocial literature, into the need to treat the whole person. (Narrative and storytelling above, is an important mechanism for achieving this.) Listening to patients and knowing who they are beyond their disease/illness/ physical abilities or limitations (including understanding their caregiver, family or social circumstances is key (Hole 2014). How stroke survivors see themselves, their fears of relapse and worries for the future, determines what improvements would have the greatest meaning to them and thus what type of goals should be set and supports put in place (Smith and Sparkes 2005, Bendtz 2003, Hammer 2008, Kirkevold 2014, Larsen 2014). Stroke survivors emphasize the importance of therapeutic interventions that incorporate their life interests and goals into rehab (Sabari 2000). They often perceive that they are not acknowledged as individuals in that process (Hole, 2014).

This final point has no clear home in the e-scan but is well worth mentioning and should be shaped by the HCP's understanding who the patient is. Light heartedness and laughter were important to keep patients positive and hopeful (Bays, 2001; Barker and Brauer, 2005; Lohne and Severinsson, 2005).

Work-aged stroke survivors

One has only to look at the literature related to work-aged stroke survivors and the threats they face – marginalization/being forced to leave work, failure to meet family or work expectations – to understand why the concept of treating the whole person, of knowing who they are and what's important to them, is so critical to designing care (Martinsen et al 2013).

Tools:

Psychosocial care of the adult cancer patient, Nicholas 2016 includes a chart: Adult Development and Theoretical Potential Disruptions to Life Tasks (p121) – A helpful tool for HCPs that broadly lays out stages of life and potential impact of illness re: altered relationships, dependence, achievement, body image, existential issues. Some concerns remain consistent across the life-span and others are particular to roles and stages.

Dialogue-based nursing interventions, accompanied by patient work sheets have shown a lot of promise (Kirkevold 2014) in increasing perceptions of QoL. The research has yet to be completed so the intervention details, resources/support materials cannot yet be shared (see below).

3.7   Perception of control, self-efficacy and shared decision making

Preparing patients to be autonomous and creating a perception of control is essential (Bays, 2001; Smith and Sparkes 2005). Patients need to feel in control in order to facilitate the independence required post-discharge (Wiles et al, 2002). Self-belief, confidence and the restoration of meaning are significant to patients in gaining a full recovery (Hartigan et al 2010). Shared Decision Making (SDM) now plays an important role in the treatment of chronic illness. Published SDM studies report improvements in patient satisfaction, treatment adherence, quality of life and well-being (Joosten 2008).

SDM has been defined as: "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences".

At its core, SDM rests on accepting individual self-determination as a desirable goal, and clinicians supporting patients to achieve this goal, wherever feasible. Self-determination in the context of SDM does not mean that individuals are abandoned. SDM recognizes the need to support autonomy by building good relationships, respecting both individual competence and interdependence on others (Glyn Elwyn 2012). Despite much attention to principles and competences, there's a lack of clear guidance about how to accomplish SDM in routine practice.

In Hole's metaethnography of the patient's experience of the psychosocial process that influences identity after stroke rehabilitation (2014), key dimensions of self-efficacy were identified as the need for verbal persuasion in the form of encouragement and feedback from HCPs, a sense of momentum, increasing expertise, progress to goals and expectations of oneself. Do I believe that I can do this?

It is also critical for HCPs to understand how much control patients want or need to take. Suzanne Makarem refers to this as the locus of control (LOC). Where patients are more passive the LOC lies with the HCP, who must then work to both encourage self-efficacy where possible while cultivating the belief/trust that their care can influence health outcomes. Faith in one's ability and faith in one's HCP can both lead to hope and adherence. But placing the LOC in the hands of the HCP is more precarious. Herth says that hope requires a sense of control over one's destiny. Higher perceived control leads to decreased distress, positive self-image and the expansion of coping mechanisms (Makarem 2014).

See above for the role that goal-setting, patient engagement, story-telling can play in developing perceptions of control and self-efficacy.

Placebo effect

Eaves 2014 examines how different types and combinations of hope influence the magnitude of the placebo effect. Hope serves as the unifying framework in psychotherapy. Often the only factor that sets apart patients with successful outcomes from those who don't thrive or improve is hope. The well-documented effects of placebo are in fact the effects of hope (Larsen 2010).

3.8   Supporting Health Care Providers

HCP hope is critical too ... In today's health care environments, the increased pace, pressures and demands for monitoring and surveillance placed on HCPs can compromise their job effectiveness and their own hope.
If HCPs are to develop communication, empathy and listening skills to create hopeful environments, they must be given the supports to do so (Tutton 2011).

No HCP has a bottomless bucket of hope and support to bring to all their clinical interactions. Providing care to P/F/Cs who've experienced traumatic illness and events where depression and anxiety is constant and high, will have a significant impact on practitioners. Trust in the HCP is at the core of hope. HCP hopefulness and belief in their patients is key to patient and caregiver hope, sense of control, adherence and outcomes (Larsen 2013, Makarem 2014). Employers must be cognizant of maintaining HCP hope.

In examining the hope that psychologists bring to their practice, Larsen concludes that a sense of self-competence (generally tied to experience) helps them sustain hope. Inexperience and uncertainty can threaten that hope. Training on how to attend to one's own hope should come early in career development and continue throughout.

Compassion Fatigue

Many HCPs experience what is called "compassion fatigue" which can result in a loss of empathy for patients, emotional numbing and a sense of no control. Studies have found that higher levels of burnout correspond to more medical errors, and that patient perceptions of HCP empathy improve compliance.

Burnout, loss of productivity, absenteeism, demoralization, substance abuse, turnover rates are a huge burden to the health care system and to society as a whole. Investments must be made in the mental health and well-being of practitioners.

James Doty, a Stanford University neurosurgeon and director of the Centre for Compassion and Altruism Research has established an eight-week program Compassion Cultivation Training. Similar programs are being developed for medical students, nurses and other practitioners.

The need for a range of supports for HCPs – psychological, time, proper training, follow-up was raised in many of the research papers and in conversations with administrators and HCPs (Marit Kirkevold, Caroline Watkins, Dr Jennifer Yao – GF Strong, Toby Huston–Craig Hospital).

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Relational Care

Felicity Bright's current work on engaging HCPs represents a philosophical shift from practical to relational care. Rather than physical rehab tasks being the main focus of treatment, the relationship is now primary. Autoethnographic methods that involve HCPs making assumptions, beliefs, and attitudes visible, considering their influence on practice and sharing them with other practitioners; as well as more active, targeted approaches to changing behavior, are needed to affect this shift. These techniques, including motivational interviewing should be used with HCPs and not just with patients (Bright et al. 2012; Mudge et al. 2014).

Bright posits that it can't simply be practitioner experience that contributes to best outcomes. Therapists can use the same rehab techniques with different results. Two growing bodies of relevant research are exploring (a) the role that practitioner's thoughts, feelings, and attitudes may have in influencing outcome; and (b) the practitioner's approach to practice or way of working. There is mounting evidence over the last decade arguing that who and how we are with our patients may have a potentiating effect on rehabilitation outcomes.

Yet despite growing evidence supporting this, in clinical settings the practitioners are rarely the focus of attention as a positive or limiting factor of rehabilitation processes or outcomes. Failure to achieve expected results is attributed to the patient, using descriptors such as unmotivated, not ready, noncompliant, or difficult.

3.9   Peer support

Peer support research and initiatives were not a focus of this e-scan, however the literature points to its effectiveness in areas like perceptions of quality of life, increased hope, social connection and sense of inclusion. It is important and encouraging for stroke survivors to see others living life and to share struggles and accomplishments (Cross 2015).

In terms of relevance to HCPs, research suggests that in order for peer support groups to function as effectively as possible, staff involved with in-patient and out-patient rehabilitation should make themselves available to community peer support group facilitators.

Additionally, in their role as active sharers of information, HCPs should be aware of what's available within the community and plant the seeds early for post-discharge exploration and participation.

4.0   Assessment: The need and the Tools

Research supports the need to evaluate adjustment, depression and psychosocial wellbeing of patients early and regularly (Chan 2009, Teoh, 2009). Mental health is a moving target and issues can present themselves at any point. Patients are particularly vulnerable during periods of transition. Nicholas 2016 reviewed a number of stress assessment tools and found them all to be moderately accurate – none stood out as best. Patient willingness, simplicity and time required to complete are all factors. There are a number of Assessment of Quality of Life (AQoL) tools available from the Centre for Health Economics at Monash University that measure a range of broad dimensions and take between 1 – 5 minutes to complete.

Family and caregivers play an enormous role, particularly in post-discharge care and should also be evaluated for stress, anxiety, coping, wellbeing and how informed and equipped they feel for the job they are now expected to perform.

Bright believes that current tools designed to measure patient engagement are neither useful nor comprehensive, and measure only compliance, adherence or attendance. Her team is working on a more comprehensive measurement tool.

The literature also points to the importance of assessing health care providers for hope, wellbeing and depression (see above). Empathy fatigue, burnout and a lack of understanding about psychosocial threats to health can impact their ability to do their jobs, and their patients' ability to thrive.

See appendices for a selection of assessment tools.

5.0 Interventions in the field - Introduction

Applying Randomized Controlled Trial (RCT) research techniques to assessing psychosocial interventions is complicated (Toby Huston, Craig Hospital, Marit Kirkevold, Caroline Watkins). There are challenges to isolating factors contributing to quality of life or wellbeing, ethical considerations regarding withholding support for patients in the control groups, as well as questions of who participates and physical, cognitive or geographical circumstances precluding their involvement (eg. aphasia patients). While the evidence may not be as statistically significant as needed to drive broad adoption, qualitative and anecdotal evidence plus trusted gut instinct have been compelling enough for hospitals and rehabilitation facilities to begin adopting certain interventions.

5.1 Stepped Care approach

There is a level of psychological need and care that can be assessed and offered by all HCPs. The Stepped Care model provides a broad guideline for what interventions require what level of professional expertise, and when issues are more acute and need to be bumped up to a new level of care.

The National Institute for Clinical Excellence (NICE) in the UK, advocates the stepped care approach for the identification and alleviation of mood issues following stroke. The aim is for the whole team to be skilled enough to understand and assist with alleviating psychological difficulties. A hierarchy of possible solutions to assist with mood issues guides how we support patients, beginning with the simpler solutions and reaching the more complex solutions as required.

Level 1 All staff to demonstrate: Core listening skills, Activity scheduling, Motivational interviewing, Problem solving

Level 2 Specialist staff trained in: Cognitive Behaviour Therapy, Interpersonal therapy, Family therapy

Level 3 Psychiatry, Psychodynamic therapy

5.2   Motivational Interviewing

Motivational Interviewing (MI) is a specific talk-based therapy designed to build the motivation to adjust and adapt. It was developed to help people with addictions and is now being used successfully with a wide range of health issues in a range of health care settings. By working with patients' dilemmas and ambivalence and through supporting and reinforcing optimism and self-efficacy, therapists enable patients to identify their own solutions.

Behavior change theories like this one have moved away from information and advice-giving to motivation, self-efficacy, activation and readiness to change. MI after stroke was found to have a beneficial effect on mood and self-reported depression, although it was not found to have an effect on function.

MI principles can be used to increase the client's awareness of the importance of changing what they make of their situation (adjustment), through sensitively highlighting the discrepancy between a patient's current concerns and their goals or personal values. The approach is intended to reduce ambivalence and strengthen personal motivation for, and commitment to goals.

Watkins MI Intervention

Caroline Watkins et al. in the UK developed a post-stroke MI intervention through an RCT that is offered (currently by nurses) within the first four weeks after stroke. The goal of their MI intervention is not related to compliance (as MI often is), but to supporting patient adjustment. The study was undertaken in a single rehabilitation centre and the positive outcomes (fewer depressed at three and 12 months post-stroke and fewer dying) resulted in MI being incorporated into the Royal College's National Clinical Guidelines for Stroke.

Patients in the intervention group received up to four individual sessions of motivational interviewing, one per week, with the same therapist. Sessions lasted between 30 and 60 minutes.

Therapists received four days of training in MI by a specialist followed by up to 10 practice sessions until competent and confident with the technique. They were supervised by a clinical psychologist through team meetings and one-to-one clinical supervision sessions on a monthly basis with additional informal support throughout the study. Debriefing was built into the supervision process to deal with the impact that issues (eg. abuse and trauma) had on the therapists themselves.

In an interview, Watkins said that the intervention is not yet shareable. The concern is that the training tool be applied in a "half-baked way," discrediting the value of MI altogether.

While Watkin's research on MI post-stroke has shown clear promise in helping stroke patients adjust and develop cognitive strategies to address new concerns, they must now determine how much of the success is attributable to attention and how much to MI. This requires a new research study with an MI psych support group and an attention control group in order to isolate the change agent. They are also seeking funding for a multi-centre site study prior to a broader roll out of the intervention. A training manual has been developed and once the research is complete (end of 2018), it will be shared.

MI – A Brief Guide

Drs Gary Latchford and Alistair Duff at St James's University Hospital in Leeds UK, have developed MI – A Brief Guide that was designed to increase compliance in patients with Cystic Fibrosis. While not designed for use with post-stroke patients, the guide is a clear, practical, engaging and adaptable resource. It covers the principles, practice, theory and techniques of MI and includes the keys to effective communication – active listening, empathy, open questions and summarizing and reframing.

"Many of the techniques that may be helpful here are designed to raise awareness of the problem, and to focus on the discrepancy between beliefs and goals - what they would like to be doing (or what they think they should be doing) and what they actually are doing. People often know this already, but try not to think about it."

5.3   PAAST - Psychological Adjustment After Stroke Training

The emotional impact of stroke. The UK National Stroke Strategy (2007) recognizes the central importance of a pathway that addresses the psychological changes that occur after stroke. The National Institute for Health and Clinical Excellence (NICE) and the Royal College of Physicians' national guidelines recommend routine assessment and management of mood and cognition after stroke. Assisting people with psychological issues following stroke is everyone's role within a stroke team.

PAAST has made publicly available two valuable PDF documents that outline the components of successful interpersonal skills and psychological care after stroke.

1) Interpersonal Skills: addresses therapeutic communication:
• rules for effective communication, hope, barriers to effectiveness
• core counselling skills – active listening, dealing with one's own discomfort, goal setting
• motivational interviewing, cycles of change, resistance.

2) Psychological Care After Stroke: covers these core competencies and includes reflective exercises that
 enable staff to think about their own experiences and how they might enhance the ward environment
• Understanding the person's experience of the stroke and assisting them psychologically in the early stages (acute and rehabilitation)
• Assisting with distress and adjustment post stroke, incorporating psychological models on adjustment
• Awareness of types of psychological problems following stroke
• Screening methods and tools to measure mood and other psychological problems, including reference to clinical guidelines for measurement of mood
• Understanding and assisting with psychological problems after stroke: depression, anxiety, anger
• Pathways for referral for more complex presentations

The PAAST website is password protected with member only access to the toolkits that include communication tools to use with aphasia patients. Multiple attempts to contact PAAST have failed as the site appears dormant. Academics currently doing work on psychosocial and MI work post-stroke in the UK are not aware of the initiative. However, the two documents outlined above provide useful, accessible information that could form the basis of new training materials.

5.4   Montreal Neurological Institute

Nurse clinician Heather Perkins, Montreal Neuro Institute (MNI), reported they focus on patient engagement according to provincial guidelines. MNI has developed a resource booklet for patients encouraging them to be involved up to their comfort level, including goal setting. The booklet is quite generic and also covers non-psy-chosocial topics related to post-stroke care.

Perkins says that MNI is very psychosocial-focused. While specific training for the rehab team on communication techniques, engagement and MI are not in place, it is expected that the team approach should focus on and track psychosocial issues. Monthly information sessions on reflective practice are held. Nurse clinicians are expected to participate in regular team discussions that focus on cases with psychosocial challenges. This work is valued and expected within MNI, and staff is given time to do it.

They have instituted white boards by the bedside where notes are updated regularly for team and P/F/Cs to view.

5.5   Outreach education and support (Norway)

Marit Kirkevold et al. have been working on an intervention promoting psychosocial wellbeing using narratives (dialogue-based encounters) and guided self-determination. The RCT, expected to be analyzed and ready for publication in October 2017, tested two formats - individual dialogues and group sessions. Those participating in the group sessions also received two individual sessions. The intervention builds on Narrative theory (see above) and constructing a Sense of Coherence that is correlated with hope and quality of life.

The facilitators (Nurses and OTs) received 16 hours of training and were supervised throughout the intervention. Individual encounters lasted an hour. Group sessions were two hours. The intervention started as soon as possible after stroke (between 4 – 6 weeks) and lasted until approximately six months post-stroke. Aphasia patients participated only in one-on-one sessions and their intervention lasted significantly longer (40% longer overall, double the number of visits, but half the time for each). Recruiting of participants was done through acute care hospitals. Work sheets were handed out prior to each encounter so participants could review content and identify priority issues.

Participants were generally positive about the intervention and highlighted the value of sharing experiences and ideas. Those in one-on-one highlighted the importance of the relationship with the HCP.

This is not a change-focused intervention, but a sense-making one, empowering the patients to believe in themselves, to clarify values, to identify the problem and how to solve it.

Participants felt that telling their stories enabled them to better understand their situation, the issues at stake, the possibilities and opportunities for formulating realistic goals and movement towards acceptance. It helped them cope by clarifying their actual coping challenges. There were no systematic differences in responses based on degree of physical or emotional challenge. Most participants expressed that their existing services did not address psychosocial issues.

The demand for the intervention across Norway is growing. Clinicians have seen positive outcomes. The research is supported by the stroke associations, including the association for people with Aphasia. However, as already stated, doing classic RCT research with this kind of intervention is a challenge. Adequate preparation is critical to doing it right. It's difficult to find valid, reliable tools for measuring psychosocial wellbeing. Kirkevold asks whether RCTs are really the "gold standard" in this kind of research.

Results to date have been unclear. Financing for uptake of the intervention requires evidence of proven effectiveness. Anecdotal evidence points to it being very promising, but it has yet to be tested on a large scale. To date nurses and physiotherapists have been trained to do the work. Myriad questions remain unanswered: who can deliver the intervention? Can volunteers do it? Can it be pulled apart so different people can do different components?

Researchers envision a workbook, worksheets and a training kit on how to support dialogues and invite conversation.

5.6   Expert Patient Involvement

Jennifer Read (2013) evaluated the impact of an inter-professional staff training course (nurses, OTs, PTs, technical therapists) involving expert patients addressing the psychological, communication and cognitive needs of stroke patients. Staff were interviewed six years after participating in the training and indicated that its lasting impact on holistic thinking and clinical development was largely due to the involvement of expert patients.

• Holistic thinking: HCPs thought of the stroke patient as a 'human being' rather than a 'job'. They identified with them as people with a past, present and future, empathized with their thoughts, feelings, experiences, wants and needs.

• Clinical development: The data suggest participants felt that the course helped their clinical development. They gained:

• the ability to communicate effectively with post stroke patients experiencing communication, cognitive and psychological problems

• the ability to identify less visible, more subtle needs and adapt treatment plans accordingly

• more flexible problem-solving approaches and understanding the importance of spending time with them and explaining things fully

• increased confidence working with this patient population

• the capacity for professional self-reflection

Despite the success of the intervention, data revealed barriers to broad uptake:

• Systemic barriers: The system did not prioritize the psychological, communication and cognitive needs of stroke survivors. Tasks reducing length of stay and cost improvements were the priority.

• Team barriers: Untrained colleagues and managers restricted participants' opportunities to instigate change.

The training continues to be offered but requests for additional information have not been answered.

5.7   PROMPT study

Jane Turner (2011, 2017) conducted a stepped-wedge cluster RCT to evaluate the feasibility and effectiveness of a brief psychosocial intervention for depressed cancer patients. It was delivered by trained front-line health professionals in routine clinical care.

Twenty-seven HCPs were trained to deliver the psychosocial intervention consisting of up to four sessions, tailored to patient symptoms and distress. Patients with disease progression who received the intervention experienced significant benefits in unmet practical needs including care and support, information, and physical and daily living.

Turner discusses the reluctance of patients to volunteer emotional concerns and the need for nurses and other HCPs to be trained to deliver psychosocial care in less severe cases. Embedding this care in routine clinical work makes it both accessible and timely for patients and caregivers, as well as cost-effective. She found simple behavioral activation to be as effective as more complex interventions. The telephone-based intervention showed success.

The core elements of the training included 1) supportive expressive – encouraging and validating the expression of emotions 2) cognitive behavioral 3) dignity conserving.

They aimed to determine if frontline health professionals without psychosocial expertise could be trained to provide psychosocial care. In addition to enhancing capacity, the embedding of psychosocial care into routine clinical practice was likely to improve patient access and reduce stigma, thereby increasing acceptability of the interventions by patients. Training was based on a model previously demonstrated to improve knowledge, skills and confidence of oncology nurses.

Participating HCPs self-reported changes in confidence, skills and attitudes which they considered enhanced their clinical practice beyond the scope of the study. However, it appears that the skills developed in the study were insufficient for them to remediate depression. This may be because the training was broad in focus with insufficient attention to alleviation of depressive symptoms. It is also likely that the HCPs were more focused on practical problem identification and support, consistent with their background training. This finding is also consistent with findings that better results in therapy are noted with more experienced therapists.

5.8 GF Strong Rehabilitation Centre Vancouver, British Columbia

Dr Jennifer Yao reports that the topic of hope comes up in team discussions (OT, PT, speech and language therapists, social workers) around goal setting. Staff can distinguish between hope and expectations. It is understood that hope should never be squashed. Overall, the team focusses on goal setting using agreed upon expectations.

A number of years ago a centre-wide training was undertaken on SMART goals (see above). Staff was expected to apply them to care plans for all patients. The new approach was not well implemented. While theoretically SMART goals make sense and there was senior level commitment to the training required for their adoption, challenges related to patient communication, cognition and level of understanding made across-the-board use impractical. In the end the exercise became labour intensive and artificial. Ultimately, there was no evidence that it translated into savings such as reduced length of stay.

An educator has provided sessions on Motivational Interviewing techniques for therapists, but GF Strong has no formal training around effective communication techniques. It is expected that most learning happens over the course of one's career.

That said, psychosocial (depression and anxiety, coping, problem solving, financial issues) aspects of care post stroke or brain injury, and mechanisms to connect biomedical and psychosocial care represent a large part of what gets done at GF Strong. There are no one-size-fits-all solutions. Patients can be anywhere on the continuum from totally passive, to actively engaged, and who they are as individuals will always determine the approach they need.

Dr Yao observed that it's interesting that hospital length-of-stay is only weakly correlated with severity and more significantly correlated with psychosocial supports.

5.9   Craig Hospital, Denver, Colorado

"At Craig Hospital, we believe in empowering patients to fully participate in their program of care, from plan-ning and scheduling to working hard to progress. There's no passive-patient model of care at Craig. It takes teamwork, and the patient is the most important member of the team."

Toby Huston, Rehab Psychologist and Director of Psychology at Craig Hospital was interviewed for this scan. Craig Hospital deals with some stroke patients – mostly younger or work age, but only as a second tier population. The primary focus is on Spinal Cord Injury (SCI) and traumatic brain injury (TBI). Craig has an egalitarian and flexible culture that has allowed for the implementation of new approaches. A commitment to valuing and operationalizing patient engagement is demonstrated by the interventions described below as well as patient membership on the hospital and research boards.

Two interventions are underway 1) Patient Engagement (PE) 2) Motivational Interviewing (MI). Although they have not found significant RCT evidence to support it, Craig trains all disciplines in PE and MI. Huston says there's enough anecdotal and experiential knowledge to know it's the right thing to do. As Marit Kirkevold identified, it is hard to apply the same research techniques for RCTs in the psychosocial realm.

Based on principles of positive psychology, the interventions focus on strengths, not deficits. The research project (a six week group intervention run as an RCT study) facilitated by two clinicians focusses on goal setting and inventory of strengths. The end point is to measure if a positive psychology intervention can impact self-efficacy and how perceptions of control make a difference. The Moorong Self-Efficacy Scale is used (see appendix 5).

The *Reinventing Yourself After SCI Project* (appendix 3) focusses on stroke survivors out six months and one year. A separate study uses the same intervention with caregivers. Respite care is funded so they can participate in the study. Ongoing effort is made to focus on patient engagement with a strong MI component. The concept is to engage patients where they are. Rehab lends itself to this. "Acute care does for the patient, rehab does with the patient"

The goal is to partner with the patient. To move beyond the model where only psychologists offer MI, Craig offers a full-day MI session facilitated by staff psychologists. This voluntary training attracted 150 participants from across disciplines: PT, OT, SLP, pharmacists, physicians, dietitians. Craig engaged Steve Wegener and Nicole Schechter from Johns Hopkins to handle training on patient engagement (see below).

Wegener and Schechter worked with the physician-led interdisciplinary teams that follow a patient from admission to discharge. A champion was identified on each team. Team leaders met with psychologists and also had monthly meetings with the Johns Hopkins folks who provided team exercises to overcome resistance within their group.

This is not a speedy process. Culture and behavior change takes time. This is a two to three-year project. They are trying to determine change through patient satisfaction surveys that ask patients to rate statements such as "My therapist understood my goals" "My HCP partnered with me to develop my treatment plan." See MI cheat sheets provided to staff (appendix 4).

Anecdotally, Craig has witnessed an embracing of the intervention by HCPs, an expressed ongoing desire for involvement, and fewer sessions where HCPs are feeling stressed-out and inadequate.

5.10   Nicole Schechter, Steve Wegener, Patient Engagement, Johns Hopkins, Baltimore, MD

The comprehensive Patient Engagement program offered by this team from Johns Hopkins sees engaged HCPs as the key to engaging P/F/Cs. Their two-pronged program focusses on 1) improving communication skills, decreasing the burden for HCPs and supporting them to activate patients and, 2) more engaged, prepared and confident activated patients. The dominant perception is that all this training requires HCPs to spend a lot more time with patients. In fact, the goal in teaching these skills is to make them more efficient and effective with their time. One of the evaluation measures is provider self-efficacy.

The duo's starting point is the Wagner Model of Chronic Care that sees all aspects of health care institutions, community (resources, policies, system design) as driven or operationalized through productive interactions between informed activated patients and prepared proactive practice teams (appendix 5).

The PE program has four phases.

1) Planning with leadership: This begins with defining the goals. What's driving the decision to train? Engagement? Show rates (patients turning up for appointments)? Patient satisfaction data? (At Johns Hopkins alone $17 million is now tied to performance and patient satisfaction outcomes.) Schechter and Wegener suggest placing the emphasis of the training on HCPs or administrators who have the most direct contact with patients – therapists, case managers. Leadership must be involved and attend all training sessions. Measurable outcomes (pre and post intervention) regarding learner (staff) and P/F/C outcomes (health and psychosocial) must be set.

2) Training: Depending on time and resources available a 60-90 minute grand rounds style motivational and interactive lecture is held. This is followed by a two-day, one-day or ½ day Motivational Interviewing training.

3) Maintenance program: This requires a minimum of one year working with the teams. Teams can be a staff group (all nurses or physicians) or a clinical team (stroke, traumatic brain injury) Each identifies a champion who receives extra training. There is quarterly coaching, a maintenance plan and activities designed for champions to do with their team to reinforce and strengthen the learning.

4) Evaluation/Outcomes: a) Standardized pre/post testing for learners – self-efficacy, knowledge and attitudes, behavioral skills. b) Satisfaction with training c) Evaluation of patient outcomes in collaboration with practice leadership.

Schechter and Wegener have started working with primary care physicians and nurses who bear the heaviest burden for managing chronic illness. Johns Hopkins materials are proprietary.

5.11   Shirley Ryan Ability Lab – Chicago, Illinois

Although hope is in their mission statement, it has yet to be operationalized. There is no training provided specifically on communication skills, hopeful language, encouraging storytelling etc, related to psychosocial aspects of care. However, changes in the language that defines the work being done at Shirley Ryan, reflect concepts from positive psychology. The shift to ability from disability and the concept of what is being gained as opposed to what is being lost. On a practical level, all therapists are required to ask about patient needs and goals.

5.12   Becoming Complex Capable – Guelph Community Health Centre

The Guelph Community Health Centre deals with complex clients with multiple unmet physical, mental, emotional or societal needs. They do not deal specifically with stroke patients. In 2015 they published a report on the importance of hope when working with their clients.

Guelph implemented a set of practical strategies to increase hope for both staff and clients. These include staff training on increasing understanding of hope, developing strong staff-client relationships and using implicit and explicit strategies. They use 'walls of hope' where people can post messages, and have implemented the development of welcoming plans.

6.0   Challenges and Barriers to uptake

Challenges and barriers to system transformation and the uptake of proven interventions present themselves at all levels of health care. At the staff level, they take the form of resistance to change, a not my job attitude, resentment towards early adopters, lack of encouragement or support for champions and innovators, and concern and anxiety about the expansion of job descriptions without compensation. In addition, the medical profession has traditionally been built on stoicism and maintaining emotional distance. Physicians are not taught how to have a healthy connection – there are no rewards or disincentives. However, evidence is suggesting that mental health and job satisfaction are the rewards.

At the institutional or department level, there is a reticence to invest the necessary time and financial resources in system/program/training redesign based on relatively new and "soft" science. Yet the research as well as the academics, clinicians and senior managers interviewed for this report all emphasize that to get results in the form of true transformation, requires time and ongoing oversight and support. C-suite (CEO, CFO, CIO, COO) champions need to lead the charge.

At a system level, despite changes in vision and mission language, psychological, communication and cognitive needs are still not a high priority. Currently there is insufficient preparation of the workforce to deal with the psychosocial. This includes lack of clarity around competencies, absence of curricula built around competencies, inadequate number of educators, trainers, mentors, insufficient specificity in accreditation and licensing standards.

Support services and follow-up post-discharge is lacking. Creative strategies are needed to provide access to professional advice and interventions through the course of the stroke survivor's life.

Recovery is still defined in physical terms and the cut off is generally 6 months, leaving survivors and caregivers with no funded access to ongoing critical psychosocial (or physical) rehabilitation services. Very lengthy out-patient waiting lists mean that many people will never get the support they need.

The current funding model is based on the false assumption that the further out you are from stroke, the less care you require. In fact, the opposite is often true. It is unlikely that the necessary expansion of publicly-funded, community-based post-stroke resources will be in place any time soon. But around the globe and across the continuum of post-stroke care there are pools of innovative and exciting change that are improving the quality of life for patients, family, caregivers and health practitioners. Watch and listen for them!

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7.0   Questions and issues to consider

• How much willingness is there to invest in a culture of inter-professional collaboration across the continuum of care?

• What's already going on formally or informally within the Toronto Stroke Networks?

• Can strategies to improve communication, active listening, understanding of the complexity of hope, be integrated into existing training?

• Are RCT and statistically significant findings necessary for the adoption of interventions?

• Is the TSNs ready to break down silos? How has that happened successfully already?

• Is there 'buy-in' from senior leadership? What would that take? Who can champion this?

• Where are the quick wins and low hanging fruit?

• If an intervention is selected for implementation, what resources are required and where will they come from? Where could it be piloted first? The need for training, continued oversight and freed up staff time to build confidence with the material and the process is critical to success.

• What would incentivize TSNs HCPs to adopt new skills and knowledge?

• How can the PFAC/expert patients be used effectively?

• What is the role for communication technologies? Tele-rehabilitation and emerging virtual technology tools are cost-effective ways of delivering ongoing rehab services post-discharge that show enormous promise (Saywell, 2014, Putino 2014)

• Everyone needs to be hope educated. How are HCPs trained and supported to attend to their own hope and psychosocial needs?

• How must the diversity of the P/F/C population be considered in planning for broad psychosocial interventions?

8.0   Next Steps:

• Consider developing a concise and inspiring presentation that encapsulates the e-scan research and current direction related to hope, hopefulness and psychosocial care.

• Inventory current formal and informal activities, initiatives, programs or components of programs that currently address or include psychosocial and related work (patient engagement, communication).

• Select one or two interventions/training sessions that could be piloted and measured.

• Seek 'buy-in' to develop a psychosocial care framework for adoption by Toronto Stroke Networks members. TSNs should lobby provincial and federal heart and stroke bodies to adopt a psychosocial framework similar to CCO and IOM.

9.0   Appendices:

Appendix 1 - Contacts

Appendix 2 - Bibliography

Appendix 3 - Reinventing Yourself After SCI" Project

Appendix 4 - Craig Motivational Interviewing – Cheat sheet

Assessment tools:

Appendix 5 Mooron Efficacy Scale

Appendix 6 Herth Hope Scale (appendix)

Appendix 7 The Adult Hope Scale (Snyder) (appendix)

Appendix 8 The Sense of Wellbeing Inventory (appendix

Appendix 9 Connor-Davidson Resilience Scale (CD-RISK) (appendix

Appendix 10 GAD (Generalized Anxiety Disorder) 7-item scale (appendix

Appendix 11 PM-PAC Participation Measure for Post-Acute Care

Appendix 1 Contacts

• Toby Huston, Director of Psychology, Craig Hospital, Colorado

• Rebecca Brashler, Director of Global Patient Services, Assistant Professor, Feinberg School of Medicine, Shirley Ryan Ability Lab, Chicago, Illinios

• Jennifer Robinson, Patient Navigator, Hamilton Health Sciences

• Raechelle Deveraux, Executive Director, Guelph Community Health Centre

 • Dr. Jennifer Read, School of Health and Related Research, University of Sheffield, UK

• Dr. Denise Larsen, Director of Hope House, Associate Dean, Professor, Counselling Psychology, Director of Research, Hope Studies, University of Alberta

• Tim Redman, Executive Director, Stroke Recovery Association of British Columbia

• Professor Marit Kirkevold, University of Oslo, Norway

• Gail Snelling, Executive Director NSSRC, North Shore Stroke Rehab Centre

• Professor Suzanne Makarem, Virginia Commonwealth University, School of Business

• Heather Perkins, Nurse Clinician, Montreal Neurological Institute

• Professor Dame Caroline Watkins, Director of Research and Innovation
Faculty of Health and Wellbeing, University of Central Lancashire

 • Dr. Andy Soundy, School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham,

• Dr. Felicity Bright, Auckland University of Technology Engagement Health and Rehabilitation

• Dr. Nicole Schechter and Dr. Steve Wegener, Patient Engagement, Johns Hopkins, Baltimore, MD

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