



European Life After Stroke Forum 2023

Abstract Book

Containing all accepted abstracts by category



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European Life After Stroke Forum 2023

Scientific



Physical activity interventions and stroke. What do we know about terminology, mode, measurement, and the application across the stroke pathway?

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Abstract

Background

Stroke physical activity interventions are not consistently implemented across the entire stroke pathway of care. The lack of implementation and variation in both reporting of and the terminology used in this evidence warranted further investigation into the content of physical activity interventions.

Methods

A scoping review was conducted to identify and describe available systematic review evidence on physical activity in the adult stroke population. Retrieval was limited to systematic reviews; within those reviews there were no restrictions on primary study design. Included reviews had been determined to be within the field of physical activity and included adults 18 years or older with a diagnosis of stroke.

Results

50 systematic reviews were analysed. 33 of 36 reviews that reported ambulatory status were based on ambulant participants. The content of interventions is largely based on subsets of physical activity (n=31) where a measurement of physical activity is not consistent. In addition, a description of theories underpinning the interventions was lacking. Physical activity outcome measures were reported in 22 reviews. There is a lack of reporting and clarity in defining physical activity (n=11) and intervention dimensions and domains across the stroke pathway (including varying levels of physical capacities) and population demographics.

Conclusions

Better reporting of physical activity interventions is required to improve implementation. Research should include physical activity outcome measures across the stroke pathway. Determining which physical activity modes and parameters of each intervention would be useful in determining the optimal intervention for stroke survivors with different physical activity capacity levels.

How will this research improve life after stroke for stroke survivors

A risk factor associated with stroke reoccurrence is the lack of physical activity (PA) post stroke; yet PA levels, measured in steps per day, remain low post stroke. This research aims to understand why and implement changes that will impact secondary prevention, lifestyle, rehabilitation and long term support.

Employers' experiences providing support for employees with acquired brain injuries or mental illness to return to and stay in work: a thematic synthesis

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Abstract

Background:

Stroke survivors are often left with disabilities that restrict their ability to work. Alongside people with other types of acquired brain injury (ABI), they are at greater risk of developing mental illness which further restricts their work abilities. To date, reviews have focused on stroke survivors' perceptions of the return-to-work (RTW) process. This review aimed to explore employers' perceptions of factors influencing their support during the RTW process. To increase identification of relevant literature, studies with employers of ABI survivors, or people with mental illness were also included.

Method:

Five databases were searched for articles published in English from 2010 until August 2022. The results of twenty-three studies were synthesised thematically.

Results:

Employers' support was influenced by their awareness of the employee's condition/illness and support needs; their attitudes towards- and knowledge of the condition/illness and supportive strategies; opportunities for providing accommodations; and influence from employees and other stakeholders.

Conclusion:

Employers' support is influenced by various factors, involving different workplace actors. Stroke survivors and their employers may benefit from a standalone resource to guide them on planning and conducting a sustainable RTW. Useful content may include a disclosure decision aid, education for employers on supportive strategies, consideration of co-workers in RTW policies and planning, deployment of anti-stigma strategies, and support for employee self-advocacy. Further primary research is needed to investigate employers' knowledge requirements, and the influence of other stakeholders and contextual factors during the RTW process and beyond.

How will this research improve life after stroke for stroke survivors

The findings may increase health professionals' awareness of employers' experiences during the return-to-work process, and lead to health professionals providing guidance for employers to improve their support to stroke survivors. The findings are also being used to aid co-design of a self-guided, return-to-work toolkit resource for employers and stroke survivors.

Patient and Public Involvement in Stroke Research: The BEFORE Recommendations

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Abstract

Background:

Patient and Public Involvement (PPI) is the active partnership between researchers, patients and laypeople in the process of creating research. PPI aims to ensure equal opportunities for informed decision-making and guarantee the democratic representation of patient partners within the research team in order to improve the scientific quality of the research. Little is known about the factors that hinder and/or promote the autonomous involvement of people with stroke and aphasia in PPI projects.

Aim:

This study aimed to explore the views and perspectives of people who live with chronic stroke, with and without aphasia, with experience in research prior to the stroke, on their potential involvement as research partners.

Method:

Qualitative study. The research team included a PPI partner with chronic stroke-induced aphasia. Semi-structured interviews were conducted online with people with chronic stroke (n=8), four with aphasia and four without. Interviews were subject to thematic analysis following Braun and Clarke's 6-step framework.

Results:

Inductive thematic analysis generated four themes: (1) the kinds of Restrictions that make involvement in research difficult, (2) the preferred levels and ways of Involvement during the research process, (3) the Support required for active and collaborative involvement, and (4) the Impact of their involvement and how it benefits the study's outcomes.

Conclusion:

People experiencing chronic stroke and aphasia are willing to be involved as PPI partners if the research team provides the necessary support. Researchers need to consider the BEFORE recommendations prior to commencing co-produced research with people with stroke and aphasia.

How will this research improve life after stroke for stroke survivors

People living with chronic stroke and aphasia are willing to be involved in PPI stroke and aphasia studies, if researchers provide the necessary robust support environment. The findings provide new evidence about how patient partnership models can support people with chronic communication deficits to contribute meaningfully to co-produced research.

The PreventS-MD™ Webapp: The Translation and Adaptation of the Greek Version

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Abstract

Background:

The PreventS-MD™ Webapp is developed based on the Stroke Ristometer™ app. It is designed for health care professionals (HCPs) who can use it in conjunction with the electronic outpatient management system in clinics and hospitals. The PreventS-MD™ Webapp is a risk assessment, patient management and decision support system. It can optimize patient – specific risk factors management, monitor and control the risks of stroke and cardiovascular disease and facilitate discussions that can motivate patients to adopt a healthy lifestyle. PreventS-MD™ Webapp is part of a global initiative; the application has been translated in 10 languages.

Objective:

The objective of the current project is to translate and adapt the PreventS-MD™ Webapp in the Greek Language in to target Greek-speaking populations in Cyprus and Greece.

Methods:

To attain the objective of the project, communication with the developers of the application was initiated and backwards translation of the official PreventS-MD™ Webapp transcripts was conducted with the use of the Crowdin website.

Results:

This project presents the translated version of the PreventS-MD™ Webapp into Greek. This translation allows Greek-speaking HCPs to assess the patient's stroke and heart attack risk, in both primary and secondary prevention.

Discussion:

The wider community benefits from the use of the PreventS-MD™ Webapp by becoming aware of their own risk of stroke and the modifiable lifestyle changes that can be changed in order to reduce the risk.

Keywords:

stroke prevention, stroke risk factors, ehealth, primary and secondary prevention

How will this research improve life after stroke for stroke survivors

According to studies (references), 1 in 4 stroke survivors will suffer a second stroke and the problem is that many of those survivors aren't aware of such a risk. The PreventS-MD™ Webapp analyses the data of those survivors, increases awareness, provides personalised guidance and steps for preventing a second stroke.

The role of online support groups on the caregivers of stroke survivors

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Abstract

Aims

In Europe informal care is a mainspring of the chronic care provision systems and gains recognition as a cornerstone in welfare policy. Caregivers are taking on a role that requires a wide range of skills and capacities for which they are not prepared, but no appropriate training is offered during the rehabilitation phase. Support groups for stroke survivors and caregivers are considered to be a challenge key to recovering from stroke. The present study aimed to test and present the efficacy of a web-based intervention for alleviating burden of caregiving in stroke rehabilitation, which blends both peer and professional support.

Method

Data from adult stroke survivors were collected from the Hellenic Alliance for Stroke. A self-reported questionnaire was provided to the caregivers of adult community-dwelling stroke survivors and the answers were collected on google forms.

Results

Fifty adult family caregivers who used to join an online support group took part in the study (78% females, 38% males, ranging in age from 18 to 90 years, mean age 50). The main outcomes reported, after the participation in psychoeducation groups, were: “rising awareness about stroke”, “understanding the psychological effect of stroke”, “psychological support for caregivers” and “ideas for leisure activities”.

Conclusion

Caregivers benefit from psychoeducational programs that help them better understand both their emotional needs and those of the stroke survivors. The main benefits include skills building and psychological support, through the creation of a social support network that includes health professionals, stroke survivors and other caregivers.

How will this research improve life after stroke for stroke survivors

It provides data from an applied technique in supporting carers and the importance of using technology to fill the gap in the availability of appropriate support services

Coping Strategies and Quality of Life after Stroke. A scoping review

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Abstract

Background:

Physical, social, and cognitive impairment following a stroke may constitute a serious problem to the quality of life (QoL). A very important psychosocial factor that influence QoL after strokes is coping style, used by survivors to deal with disease state. Coping strategies are behavioral and cognitive modalities used by survivors to manipulate the negative impact of stressful situations.

Review question:

Which coping strategy is adopted by stroke survivors and is suggested to be most effective?

Method:

A descriptive review was conducted on the measures of coping strategies and quality of life, used by stroke survivors. Studies were extracted from two databases (Medline, Scopus). The search combined the terms: “stroke AND coping AND quality of life”. The inclusion criteria were identified as following: English full texts, data from the last 10 years, assessing the relationship between coping strategies and QoL after stroke.

Results:

Of the 260 studies identified, 5 studies met the inclusion criteria. Multiple coping strategies emerged through the research: Emotional –focused coping, problem-focused

coping, active coping, avoidant coping, accommodative and assimilative coping. Data from this review highlight the positive impact of active coping strategies concerning QoL and implication on the relationships between social support and coping, as well as adaptive coping that was associated with a better QoL. During acute phase after stroke, assimilative coping was dominant while accommodative coping replaced it gradually over time.

Conclusion:

Future long-term interventions studies with survivors after stroke, should investigate more thoroughly how coping strategies could improve QoL.

How will this research improve life after stroke for stroke survivors

Recognizing the appropriate and better management of difficulties arising after stroke is important.

The use of Coping strategies can be adopted and improve parameters related to the quality of life of survivors.

Unmet social needs in life after stroke – survey results from the German stroke foundation

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Abstract

Background

Social health restrictions caused by stroke contribute to depression and reduced quality of life [1]. However, insufficient information is available on unmet needs in Germany.

Method

The German Stroke Foundation developed a questionnaire oriented on the Greater Manchester Stroke Assessment Tool, to differentiate needs and the proportion of unmet needs. The instrument was sent out to 3,375 stroke survivors in May 2021.

Results

979 completed questionnaires resulted in a response rate of 29%. 56% of the respondents were male. Average age at the time of the stroke was 56 years ($SD=21.1$) and the stroke happened 9.2 years ($SD=8.4$) ago. 33.7% rated their impairment due to the stroke as light, 39.9% as moderate and 26.4% as heavy. 92.2% of participants dealt with negative stroke consequences. 69.2% wished for more support.

Regarding social health the highest proportion of unmet needs were difficulties in maintaining or making new social contacts (14.6% men, 14.2% women). 8.7% men, 9.0% women reported difficulties in relationship with family members. Significant gender specific differences could be observed in 'communicating with other people' (13.9% men, 8.6% women, $p=.011$) and 'being concerned about the relationship with their partner' (13.1% men, 7.9% women, $p=.005$).

Conclusion

Results indicate the need to develop appropriate long-term support for stroke survivors. To understand and identify gender specific differences more research is required.

Reference

[1] Northcott, S. et al. (2016): A systematic review of the impact of stroke on social support and social networks: associated factors and patterns of change. *Clinical Rehabilitation*, 30(8):811-831.

How will this research improve life after stroke for stroke survivors

With the survey of stroke survivors, the German Stroke Foundation wants to use a patient-oriented approach to determine and understand the needs perceived by stroke survivors. On this basis, we want to expand targeted support services, improve healthcare, and support the coping with life after stroke.

Cognitive impairment after stroke

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Abstract

Background

Cognitive impairment represents a major problem in the period after stroke. It may manifest as memory problems, impaired judgement, confusion, inability to recognize own problems and decreased executive function.

Aim

To analyze the frequency, associated risk factors and clinical correlates of cognitive impairment after stroke.

Material and methods

We included 62 consecutive patients 3 months after the initial stroke. Demographic data, vascular risk factors, stroke features and neurological examination were analysed. All patients were examined by a battery of neuropsychological tests for cognitive functions assessment.

Results

Mean age of patients was 67,5 years; male gender and ischemic strokes were dominant. Cognitive impairment was registered in 43 patients (69%). Associated factors were older age, male sex, low education, recurrent or severe stroke, leukoencephalopathy, severe cortical atrophy, diabetes mellitus and atrial fibrillation ($p < 0.05$).

Conclusions: Modifying vascular risk factors should be treated promptly in order to reduce the incidence of cognitive impairment after stroke.

How will this research improve life after stroke for stroke survivors

This research is related to cognitive dysfunction after stroke, and will help raise awareness and improve treatment in people living with this experience.

Perceived barriers to physical activity--stroke survivors in the community: A qualitative review of European studies

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Abstract

Background & Aims:

Stroke is the number one cause of disability in Europe yet, physical activity has been proven to improve disability, however it has been identified that stroke survivors fail to participate in even the minimal recommended amount of physical activity when in the community. Therefore, the objective of this review is to increase understanding relating to this important issue by taking perceptions of stroke survivors, carers and health professionals.

Method:

Electronic searches were carried out between August 30, 2019- September 16, 2019 using PubMed, CINAHL and PsychInfo. Data from eight included qualitative studies relating to the phenomena of interest of this review (why stroke survivors fail to participate in even the minimal recommended amount of physical activity in the community) was systematically extracted and synthesized using thematic analysis. Only European qualitative studies published after 2010 were chosen.

Results:

Barriers to physical activity participation from stroke survivors and health-care professional's perceptions were identified. These include; poor knowledge relating to physical activity, physical disabilities, fear, poor information provision, personal beliefs and social influence.

Conclusion:

A significant proportion of stroke survivors reported that their lack of knowledge on; their physical activity capabilities, the physical activity recommendations post stroke and the positive effects of physical activity acted as barriers to them not participating in physical activity. This review has highlighted the need for long-term education strategies to be considered in the stroke population living in the community.

How will this research improve life after stroke for stroke survivors

This research has identified many barriers to physical activity post stroke from first order construct data of European studies-- dtus increasing knowledge and awareness of these barriers, contributing to the improvement strategy of the deliverance of information to stroke survivors relating to physical activity.

The COMPEX-trial: Computer-assisted self-training to improve executive function versus unspecific training in patients after Stroke, Cardiac arrest or in Parkinson's Disease: A randomized clinical trial

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Abstract

COMPEX: Computer-assisted self-training to improve executive function versus unspecific training in patients after Stroke, Cardiac arrest or in Parkinson's Disease: A randomized clinical trial

BACKGROUND

Patients often experience working memory impairments after stroke, Parkinson's disease or cardiac arrest. This leads to decreased ability to live independently and decreased quality of life. There is a need for cost-effective rehabilitation methods to mitigate these symptoms.

PURPOSE

The purpose of this trial is to identify if Computer-Based Cognitive Rehabilitation (CBCR) is an effective method to mitigate working memory impairments.

HYPOTHESIS

CBCR can mitigate working memory impairments after stroke, resulting in increased ability to live independently and increased quality of life. Training with a specific emphasis on working memory has a significantly greater impact compared to generally cognitively stimulating activities performed on a computer.

METHOD

A Multicenter randomized clinical trial across four European countries: Denmark, Sweden,, France and Switzerland. At total of 700 patients: 400 stroke patients, 200 Parkinson patients and 100 cardiac arrest patients will be randomly assigned to specific or unspecific Computer-Based Cognitive Rehabilitation for eight weeks, five hours a week.

Outcome measures: 1) Primary outcome: ADL-functioning from MDS-HC-IADL, 2) Neuropsychological tests of working memory and related cognitive functions 3)

Measures of quality of life. Outcome measures are tested at baseline, directly after the training periods (eight weeks after inclusion) and at follow-up to assess long-term effects (five months after inclusion).

GAIN

If Computer-Based Cognitive Rehabilitation is effective, it can be implemented directly into clinical practice as a cost-effective rehabilitation method.

How will this research improve life after stroke for stroke survivors

If Computer-Based Cognitive Rehabilitation is effective, it can be implemented directly into clinical practice as a cost-effective rehabilitation method.

Exploring the return-to-work experiences of people who experienced stroke during the COVID-19 pandemic

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Abstract

Research background/aims

Around 25% of people who experience stroke in the UK are working age, yet fewer than 50% return to work (RTW). The COVID-19 pandemic detrimentally impacted the UK labour market, with disabled people particularly affected. Stroke survivors are among the 2.5 million people who are currently economically inactive.

Seeking to understand the impact of the pandemic and furlough on RTW (primary outcome) in the ReTurn to work after stroKE (RETAKE) trial, we explored RTW-related experiences of people who experienced stroke during the pandemic.

Method

To supplement the main trial's findings, 9 RETAKE participants (5 women, 4 men) were purposively selected to include employees in sectors impacted by the pandemic (e.g. hospitality, retail), regardless of intervention arm. Semi-structured telephone interviews were analysed independently and collectively using thematic analysis before agreeing themes.

Results

Participants experienced difficulties contacting GPs for RTW advice. Lengthy waits for medical interventions and driving assessments also delayed/prevented RTW.

Participants whose post-stroke abilities and job roles accommodated working from home (WFH) described how this facilitated RTW and enabled them to manage fatigue by avoiding commuting and working flexibly. Lockdowns and pandemic-related restrictions hampered RTW where WFH was impossible. Furlough delayed RTW plans but increased time devoted to recovery and facilitated phased returns.

Conclusion

The pandemic created a two-tier workforce for stroke survivors aiming to RTW. WFH and technology enabled RTW where post-stroke abilities, jobs, and employers facilitated it. Pandemic restrictions hindered people unable to work remotely and those awaiting medical interventions or driving assessments.

How will this research improve life after stroke for stroke survivors

During the COVID-19 pandemic, working from home (WFH) and online meetings, proved effective and became more acceptable. With support, WFH can help stroke survivors manage fatigue which is a common barrier to RTW. Stroke survivors in jobs unsuitable for WFH may benefit from retraining to avoid long-term unemployment.

The effects of physical activity on post-stroke fatigue: A systematic review

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Abstract

Background/Aims:

Fatigue is a damaging post-stroke symptom affecting 38-77% of patients. Physical activity improves physical fitness, improves quality of life and avoids subsequent strokes. The effects of physical activity (PA) on post-stroke fatigue (PSF) are unclear. The aim of this systematic review was to identify and summarise the most recent research to determine the effect of PA on PSF.

Methods:

Trials to be included for review were identified from the following databases; CINAHL, PubMed, EMBASE, MEDLINE, AMED, PsychINFO, HMIC, EMCARE and BNI from 2010-2021. The search strategy was based on terms and synonyms focusing on key concepts of fatigue, stroke, and physical activity. Studies included those in the English language, RCT's, and of >18 years of age.

Results:

6 studies from 402 were identified. Studies utilised a variety of different PA intervention approaches including home-based high intensity interval training, progressive task training, aerobic exercise, mobile apps, cognitive and graded activity training and graded task circuit training.

Conclusion:

The effect of PA on PSF is poorly researched. The absence of a clear definition of PSF makes it difficult to measure and compare outcomes and few studies used valid fatigue outcome measures. Studies with a population with high perceptions of fatigue at baseline are less likely to engage in physical activity limiting any potential benefits. Consensus on how to define and measure post-stroke fatigue is needed before the impact of PA can be measured.

How will this research improve life after stroke for stroke survivors

If physical activity has a positive effect on post-stroke fatigue this could help people to manage stroke as a long term condition and provide secondary prevention.

Impact of patient input on the study execution of a prospective, epidemiological study assessing the proportion of stroke survivors who develop problematic post-stroke spasticity

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Abstract

Research background and aims

It is increasingly accepted that people living with long-term conditions should be involved in the design, conduct and dissemination of research that affects them. The Epitome study is a prospective, observational, epidemiological study in participants with paresis (weakness) within 2 weeks of a first-ever stroke. Participants are monitored remotely to detect the onset of 'problematic' post-stroke spasticity (PSS) that would benefit from pharmacological therapy using the Post-stroke Spasticity Monitoring Questionnaire (PSMQ, Zorowitz et al, 2017).

Methods

Patient experts provided feedback on the study protocol at two virtual meetings.

Results

Based on patient feedback, the recruitment period was extended from 2 weeks to 1 month after the stroke event, reflecting the lack of time that patients had to consider PSS within the first two weeks. Patients emphasized the need for clear, jargonless explanations of the study objectives during the informed consent process, including clarification of the term spasticity (in terms of its manifestation as 'muscle stiffness'). Text edits were also recommended for the PSMQ to make it more lay-friendly. Importantly, patients recommended offering participants the choice of remote monitoring by telephone calls or electronic questionnaire completion (by themselves or with caregiver assistance), depending on their ability to use equipment and personal preferences. Patients will also receive regular updates by newsletter (digital and paper).

Conclusions

Following the patient consultations, the study design and plan was updated to reflect patient considerations.

How will this research improve life after stroke for stroke survivors

Patient consultation in study designs will make the studies more relevant to people living with the condition. The study will inform on the scale of the clinical problems caused by post-stroke spasticity.

Are co-designed breakfast group interventions acceptable and feasible for stroke survivors and health care professionals? (BISTRo Study)

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Abstract

Background:

Difficulties with eating and drinking after stroke negatively impact health and well-being (Klinke et al., 2013). Stroke survivors six months post-stroke said they wanted more opportunities to practice eating and drinking (Jones & Nasr, 2018).

Aims:

To co-design, a breakfast group intervention and implementation toolkit to improve the way eating and drinking interventions are delivered in hospitals. Healthcare professionals, stroke survivors and informal carers co-designed the intervention protocol and prototype implementation toolkit. This was initially tested for acceptability and feasibility in three hospitals in the United Kingdom.

Method:

BISTRo is a mixed-methods study, using participatory action research methods. Interviews with stroke survivors, focus groups with health care professionals and ethnographic observations were used to investigate the attitudes and beliefs of those delivering and receiving the intervention. Each data set was analysed separately with electronic software. A triangulation matrix explored which themes were converging or contradictory across all three data sets.

Results:

Sixteen stroke survivors, 9 female and 7 males were recruited to attend a 10-day programme of daily breakfast group interventions. They were supported by members of the stroke rehabilitation team to prepare and eat their breakfast in a social dining context. Stroke survivors and health care professionals described benefits, such as socialisation, peer support, and psychological support. They valued the experience of normality and feeling human.

Conclusions:

Breakfast groups were perceived to be acceptable and enjoyable to stroke survivors and seemed to increase their confidence to eat in front of others as well as gain greater independence.

How will this research improve life after stroke for stroke survivors

Stroke Survivors valued socialising over breakfast in a safe and homely environment. Making breakfast was helpful in preparation for leaving hospital. They valued the peer support and opportunities to try out aids and equipment. Stroke survivors believed they would be more confident to dine out with family and friends.

How do stroke survivors and their carers manage post-stroke fatigue? Nottingham Fatigue After Stroke Study (NotFAST2)

Dr Shirley Thomas¹, Dr Joanne Ablewhite¹, Dr Fiona Nouri¹, Professor Fiona Jones², Professor Roshan das Nair³, Dr Laura Condon⁴, Ms Amanda Jones⁵, Professor Nikola Sprigg¹, Professor Avril Drummond¹

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Abstract

Background

Post-stroke fatigue (PSF) affects almost half of stroke survivors and is an international research priority. Our aim was to gain insight into the management of PSF by exploring the experiences of stroke survivors living with PSF and informal carers, as these experts are often not consulted to inform clinical practice recommendations.

Methods

Qualitative, descriptive design. We recruited a purposive sample of UK stroke survivors, with current or previous PSF, and informal carers, primarily through social media. Semi-structured telephone interviews were used to explore the lived experience of PSF and management strategies. Data were analysed using framework analysis.

Results

Twenty stroke survivors (including 11 women and six individuals with aphasia) and eight carers (6 women, all spouses) were interviewed. Most participants developed their own strategies for coping with PSF. Strategies included: acceptance of having fatigue (which took time); pacing activities and rest periods; using a diary to plan timing of activities and identify triggers; educating others about PSF; using relaxation/meditation; and seeking professional advice and support. PSF also had negative impacts on carers who often played a key role in supporting the management strategies.

Conclusions

Stroke survivors and carers used a range of strategies to manage PSF. There was not one particular strategy that seemed to be effective for everyone. Most people described having to find their own ways of coping with fatigue and would have welcomed professional advice and support with management. Future research on PSF

management and evaluation should be centrally informed by those with lived experience.

How will this research improve life after stroke for stroke survivors

Post-stroke fatigue (PSF) is common and also impacts on carers. We found a range of strategies are used by stroke survivors and carers to manage PSF. Our findings will inform the development and evaluation of a PSF management programme which can be individually tailored and will inform clinical practice guidelines.

Development of a tailored intervention targeting sedentary behavior and physical activity in people with stroke and diabetes: a qualitative study using a co-creation framework

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Abstract

Purpose

Type 2 diabetes and sedentary behavior pose serious health risks in stroke survivors. Using a co-creation framework, this study aimed to develop an intervention in collaboration with stroke survivors with type 2 diabetes, relatives, and cross-sectoral healthcare professionals to reduce sedentary behavior and increase physical activity.

Materials and methods

This qualitative explorative study used a co-creation framework consisting of a workshop and focus group interviews with stroke survivors with type 2 diabetes (n=3), relative (n=1), and healthcare professionals (n=10) to develop the intervention. A content analysis was used to analyze data.

Results

The developed Everyday Life is Rehabilitation (ELiR) intervention consisted of a tailored 12-week home-based behavior change intervention with two consultations of action planning, goal setting, motivational interviewing, and fatigue management including education on sedentary behavior, physical activity, and fatigue. The intervention has a minimalistic setup using a double-page paper "Everyday Life is Rehabilitation" (ELiR) instrument making it implementable and tangible.

Conclusions

In this study, a theoretical framework was used to develop a tailored 12-week home-based behavior change intervention. Strategies to reduce sedentary behavior and increase physical activity through activities of daily living along with fatigue management in stroke survivors with type 2 diabetes were identified.

How will this research improve life after stroke for stroke survivors

A broader understanding of life after stroke and examples of how to handle fatigue, rehabilitation implemented into activities of daily living, and motivation for movement.

Self-management from the perspective of people with stroke – An interview study

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Abstract

Objective

Self-management support can improve the quality of life, mood, self-efficacy, and physical function of people following a stroke. Understanding how people perceive and experience self-management in different contexts is therefore crucial to the development of self-management support for people with stroke. This study aimed to explore how people with stroke understand and practice self-management during the postacute phase.

Method

Semistructured interviews with people with stroke, qualitative content analysis.

Results

Eighteen persons participated. Most participants interpreted self-management in terms of 'taking care of their own business' and 'being as independent as possible'. However, they encountered difficulties performing daily activities at home, for which they felt unprepared. Although interest in implementing self-management support models is increasing, participants did not recount specific advice and largely created own game plans for self-management without support from healthcare.

Conclusion

This study shows that people continue to feel unprepared to manage everyday activities after being discharged from acute stroke settings and must largely work things out for themselves. There is an overlooked opportunity to start the process of self-management support earlier in the stroke pathway, with healthcare professionals and patients combining their skills, ideas and expertise. This approach would give patients the confidence necessary to self-manage and to continue to flourish rather than allowing their self-management ability to decrease during the transition from hospital to home.

Practical implications

Individually tailored self-management game plans for people with stroke could be a way

to support successful self-management of health and daily activities in their new post-stroke situation.

How will this research improve life after stroke for stroke survivors

More focus on self-management support would give patients the confidence necessary to self-manage and to continue to flourish rather than allowing their self-management ability to decrease during the transition from hospital to home.

Utility of prolonged Holter-ECG for diagnosis in people affected with cryptogenic ischemic stroke

Nurse. Elisabet Ortiz Martos, Dr. Victor Augusto Vera Monge, Dr. Joaquin Serena Leal, Nurse. Joana Rodrigo Gil, Dr. Yolanda Silva Blas

Hospital Universitari Dr.Josep Trueta., Girona, Spain

Abstract

INTRODUCTION:

In an approximately the 30% of ischemic stroke, the etiology remains undetermined and it is classified as a cryptogenic stroke. In many cases the etiology can be a paroxysmal atrial fibrillation (AF), so other diagnostic tools are needed, such as the prolonged Holter-ECG (for 15 days) which facilitates the detection to adapt the treatment and reduce the risk of recurrences. In our centre, we have a specialized nursing consultation where this device is placed during 15 days. The main objective of this study was to analyse the incidence of AF in people with an undetermined stroke who had prolonged Holter-ECG.

METHODS:

We included in the study those patients admitted to our Stroke Unit, affected by an ischemic stroke of indeterminate etiology since 2018 to 2022. Sociodemographic variables, pathological history and presence of AF have been recorded.

RESULTS:

326 patients were included. In 36 cases (11,15%) a previously unknown AF was detected, being the female gender more prevalent (75%). Average age of women was 80 years and male 78 years. 91,42% of the cases had high blood pressure and 19,44% type 2 diabetes mellitus. When comparing sociodemographic data, among the cases where AF was not detected, it was observed a higher percentage of male gender (46%) with an average of 67 years.

CONCLUSION:

The placement of prolonged holter in people affected by stroke of unknown etiology allowed the diagnosis of previously unknown AF in 11.15% of patients, being more frequent in elderly women. This fact implies a therapeutic change and involves the initiation of anticoagulation therapy, if there is no contraindication, to reduce the recurrence of stroke.

How will this research improve life after stroke for stroke survivors

This research is useful to note that Holter is a tool to detect stroke's etiology, in case of cryptogenic stroke, so we can do a diagnosis and these implies a therapeutic change. It will also reduce the recurrence of stroke and avoid a worse quality of patient's life.

Stroke survivor, family carer and professional priorities for improvement of stroke services in Ireland: preliminary results of a stakeholder survey

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Abstract

Background and aims

Exploring the views of those impacted by stroke is important for service improvement. This survey examined care priorities among stroke survivors, family carers, and professionals working across community and inpatient stroke care, and stroke advocacy, in Ireland.

Methods

A survey was carried out with three stakeholder groups - stroke survivors, family carers and professionals working in stroke care. Participants selected five priority improvements to stroke care, from a list of 45 potential service improvements. This list was based on results from an earlier qualitative study, which involved in-depth semi-structured interviews and a qualitative survey, with the same stakeholder groups. Qualitative results were combined with policy document review and consultation with a stakeholder advisory group, to generate the list of potential improvements.

Results

Preliminary survey data was collected from stroke survivors (n=30), professionals (n=39) and family carers (n=14). Three priorities were common to professionals and the survivor/carer group: (1) specialised community neuro-rehabilitation (29/83, 35%), (2) long-term community support for meaningful and beneficial activities (26/83, 31%), and (3) improved information and support for system navigation (19/83, 23%). Survivors and carers also prioritised exploring ways to improve speed of access for atypical presentations (12/44, 27%), and improved access to high-quality specialist acute care (11/44, 25%). Professionals also prioritised specialist staff recruitment and retention (11/39, 28%), and specialist inpatient rehabilitation (10/39, 26%).

Conclusions

Stakeholders consistently prioritised community-based services and long-term support for life after stroke. This likely reflects the importance of these services to survivors, and the current gaps in provision.

How will this research improve life after stroke for stroke survivors

The information collected in this survey can help to ensure that the development of stroke services in Ireland, and future stroke research, are influenced by the priorities of relevant stakeholders, particularly stroke survivors and their family members. This ultimately has the potential to improve services and outcomes for stroke survivors.

Communication with healthcare professionals – the perspectives of people with aphasia

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University of Southern Denmark, Odense, Denmark

Abstract

Background and aims:

A growing body of evidence shows that communication partner training (CPT) of healthcare professionals (HPs) improves communication with people with aphasia. However, less is known about how people with aphasia perceive communication with HPs in acute/sub-acute care and rehabilitation. Hence, the aim of the study was to investigate how people with aphasia in acute/sub-acute phases perceive communication with HPs (trained and untrained). Furthermore, the presentation provides information of involvement of three co-researchers with aphasia making research with people with aphasia in early phases more feasible.

Method:

Qualitative semi-structured individual interviews with people with aphasia in acute or sub-acute phase were conducted. Fourteen (seven males, seven females, aged 49-78 years with mild to severe aphasia) participants from five Danish hospitals participated. Professionals from three of the hospitals had received CPT. Reflexive thematic analysis were conducted. Research questions, consent forms, interview guide and support materials for the research process was created in collaboration with the co-researchers with aphasia, who also took part in membership checking of the analysis and in aphasia-friendly dissemination.

Results:

Some of the generated themes are communication situations (e.g., care, training), communication topics (e.g., medicine, goals, future), communication support (e.g., staff supports very well, staff supports but not enough), experience of communication support and involvement. Overall, the participants expressed satisfaction with communication with HPs and differences between trained and non-trained HPs could not be identified. The collaboration with co-researchers with aphasia resulted in an accessible data collection with people with aphasia very early post-stroke.

How will this research improve life after stroke for stroke survivors

This study contributed to the sparse knowledge about how people with aphasia perceive communication with healthcare professionals early post-stroke. Eventually this knowledge can lead to better communication partner training programs that will improve access to healthcare for people living with aphasia in terms of decision-making related to own healthcare.

Post-stroke mood disorders: an underdiagnosed association

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Abstract

Introduction:

Post-stroke depression (PSD) affects 33% of patients who survive stroke and is associated with: increased hospital stays, poor functionality at discharge, lower therapeutic and rehabilitation adherence and increased mortality.

Aims:

To evaluate PSD and Post-Stroke Anxiety symptoms during the follow-up of patients who suffered stroke in our hospital and determine risk factors.

Methodology:

Observational, single-center, prospective study conducted at the Stroke Unit of Clínic Barcelona. Patients admitted with ischemic or haemorrhagic stroke who did not present severe cognitive impairment, active depressive syndrome at the time of stroke or use of antidepressants, extensive stroke with severe neurological involvement and severe aphasia participated in the study. Sociodemographic and epidemiological variables are evaluated. Anxiety and depression are assessed using the HADS-A/HADS-D scale at baseline (during the first week after stroke) and at two-month follow-up with a telephone call. All patients must sign an informed consent form. The study is approved by the ethical committee of our hospital.

Results:

Preliminary results-currently evaluated: N=42 (baseline) n=33 (follow-up).

85% (baseline) and 75% (follow-up) presented symptoms of depression.

71% (baseline) and 64% (follow-up) presented symptoms of anxiety.

19% (baseline) and 24% (follow-up) presented moderate depression.

43% (baseline) and 30% (follow-up) presented moderate or severe anxiety symptoms.

Women presented higher risk for post-stroke anxiety at baseline ($p=0.018$) but not at follow-up ($p=0.64$) or for depression ($p=0.11$)

Conclusions:

Depression and anxiety are common in patients with a stroke. Knowledge of risk factors may help to get early treatment and improve quality of life or even mortality.

How will this research improve life after stroke for stroke survivors

The project aims to improve the identification of mood disorders, the depressive syndrome and anxiety in subjects who have just suffered a stroke, both in the acute phase and during the follow-up. The aim of this early detection is to highlight the importance of mental health assessment in stroke patients.

Enriched Music-Supported Therapy for the improvement of upper-limb motor function and quality of life in patients with chronic stroke

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Abstract

Stroke is one of the main causes of long-term disability worldwide. Most stroke survivors still present motor deficits in the chronic phase, negatively affecting their autonomy and participation. Music-supported Therapy (MST) is an effective intervention to improve upper limb motor function and quality of life (QoL) post stroke. We designed an enriched version of MST (eMST) adapting it for home use and adding music therapy group sessions. The eMST aims to improve upper limb motor functions through musical training. Self-training and group sessions aim to promote autonomy and motivation, essential elements for motor recovery. We developed an app for electronic tablet to conduct the sessions with a MIDI-piano and percussion instruments. A randomised controlled trial was conducted to test the effectiveness of the eMST in improving motor functions and QoL of chronic stroke patients when compared to a conventional home-based motor intervention. Forty patients were recruited and randomly allocated to the eMST group or the control group, both consisting of a 10-week home-based intervention of 4 one-hour sessions per week. Upper limb motor functions and QoL were evaluated pre-, post-, and 3-months post-intervention. Patients from both groups clinically improved in upper limb motor functions post-intervention, but only patients undergoing eMST demonstrated enhanced QoL. The eMST showed to be an effective home-based intervention in improving not only upper limb mobility but also QoL of chronic stroke

patients. This intervention could have a medical and a social impact, trying to avoid a worrying health problem in people who face daily living limitations.

How will this research improve life after stroke for stroke survivors

The eMST aims to provide chronic stroke patients with the opportunity of continuing rehabilitation by themselves. The use of eMST could have a medical and social impact since it tries to improve physical and mental health of people with long-term disability while decreasing the burden on the health system.

Proictus Clinical Trial: A qualitative view compared to the use of PROMs

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Instituto de Investigación Biomédica de Lleida Fundació Dr. Pifarré, Lleida, Spain

Abstract

Background and aims

Stroke patients face important challenges in their daily lives. Although there have been many advances in stroke research, contributing to understand behaviour patterns is also necessary. Proictus clinical trial promote a care continuum, based on the collection of health information directly from stroke patients themselves so-called patient-reported outcome measures (PROMs). However, the qualitative data analyses can contribute to enrich the research and increase the understanding patient's experiences. The project aims to go further in the knowledge of patients concerns after stroke and compare this results with their PROMs.

Methods

Semi-structured qualitative interviews were conducted with 20 participants of the Proictus clinical trial. The interviews were recorded, transcribed verbatim and analyses using thematic analysis.

Results

After the stroke, patients describe physical and emotional consequences, and they are mostly validated in the PROMs questionnaire. Employment is one of their biggest concerns as well as having a recurrence and lost their independency. Patients report a lack of information after the stroke and they would ask for more follow-up sessions from the sanitary services. Regarding Proictus clinical trial, patients value positively the individual care.

Conclusions

Qualitative research is needed to learn through the patient's experience and offered them a better care. The PROMs questionnaire has the specificity of its domains, however, interviews offer a more open and free view of what patients want to express. Proictus combined approach is closer to patients, thanks to the combination of two analysis methods and its holistic view of each person.

How will this research improve life after stroke for stroke survivors

Proictus provides individualized care to patients, based on their needs, interests and concerns, offering more efficient and effective care. Putting into practice what we have learned through their voices is what will make the difference in trying to improve the quality of life of patients after stroke.



European Life After Stroke Forum 2023

Service Development



Development and Implementation of an Acute Management of Disorders of Consciousness Pathway for Therapies

Mrs Deborah Brown, Mrs Martine Balmir

King's College Hospital NHS Foundation Trust, London, United Kingdom

Abstract

Increasing numbers of people survive brain injuries due to medical advances. This results in more patients in disorders of consciousness who present with high and complex care needs, requiring early therapy management and discharge planning. A pathway was developed to improve quality of care, patient experience and to ensure delivery of a high standard, evidence-based and equitable needs-based service for this patient group.

A number of positive results have been noted through the development and introduction of a therapies Pathway for Acute Management of DOCS. The aims of increasing staff awareness, confidence and competency in managing this patient cohort and supporting patient flow within the hospital to facilitate timely and appropriate patient discharge to specialist rehabilitation facilities have been met. Initial Pathway training feedback showed significant improvement in confidence and competency self-ratings for all therapy disciplines. Improved confidence and competence in managing this patient group was evidenced by increased therapy sessions per discipline.

It would be worthwhile to share this Pathway with other countries so that patients, carers and stroke services could benefit from use of the Pathway.

How will this research improve life after stroke for stroke survivors

Implementation of this Pathway contributed to the reduction in hospital length of stay noted for this group of patients with high and complex care needs. Time to specialist rehabilitation service referrals were reduced as well as time to PEG placement which allowed for earlier transfer to appropriate inpatient rehabilitation hospitals.

Enhancing the competencies of community stroke coordinators in a non profit disability support organization: Development and use of a competency self assessment tool.

Mrs. Suzanne Smith-Bayley, Mrs. Nadia Troisi, Ms. Christina Sperling

March of Dimes Canada, Toronto, Canada

Abstract

Background:

Community organizations often employ staff with varying educational backgrounds to provide stroke recovery support to individuals and families impacted by stroke. March of Dimes Canada has created the role of After Stroke Coordinators who provide community based stroke support. Outside of healthcare settings, there are no widely accepted competency frameworks for this type of community-based system coordinator role.

Aim:

To create and validate a competency framework and performance indicators for a community stroke coordinator role.

Methods:

Published competency documents for corresponding roles were reviewed. A standard template of relevant competency domains was developed. Indicators of competency for each domain were identified. The competency framework was then assessed for content validity, piloted tested, revised and then deployed amongst all coordinators. Data was collected on the following: competency goals identified, learning and development opportunities recommended, ongoing feedback in use of the tool, challenges in the deployment and review.

Results:

The resulting competency framework has 13 domains; each with a set of corresponding indicators. Feedback resulted in several enhancements: the tool was made more concise, language was simplified, the number of indicators were condensed, and a manager rating scale was removed. Areas for staff training have been identified. Utility in use of the tool in the hiring process was demonstrated.

Conclusions:

Implementation of a competency framework demonstrates a commitment to provide consistent, high-quality service to clients and facilitates identification of staff learning and development opportunities. This novel competency framework developed for community-based stroke coordinators could be useful for other stroke support organizations.

How will this research improve life after stroke for stroke survivors

This research ensures that people living with the effects of stroke receive evidence informed care and navigation from personnel with specialized competencies.

NGO influence on Health Care and Social Services

Project Quality Health

Dr. Maja Bozinovska Smicheska^{1,2}, Assistant Professor Ljupcho Efremov³, Prof. Anita Arsovska^{4,5}

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Abstract

NGO influence on Health Care and Social Services

Project Quality Health

Background:

Stroke care in developing countries is obstructed by discoordination of services and limited access to care. Aim of this project was improving quality and accessibility of health care and social services and building of NGO capacity and self-sustainability.

Methods:

We implemented the project in Southwestern region of N. Macedonia that consisted of diverse activities appointed toward stroke education, prevention, self-management and data collection, targeting population at individual but also societal level, including people of lower socio-economic status and different ethnic groups; as well as procurement activities in order to improve public healthcare facilities. The main team consisted of stroke specialists, cardiology specialist, laboratory technician, social worker and researchers.

Results:

During the project, we managed to perform field and internet activities, consisted of education, individual clinical examinations, consultations and workshops. Project achievements: Significantly increased number of population having access to health and social services; Scientific study evaluating different levels of stroke risk and prevalence of risk factors in population in selected region; Procurement of medical equipment and specialized medical vehicle serving as mobile clinic; Promotion and

awareness- first Stroke risk calculator in Macedonian language, educational video infographic, massive media coverage.

Conclusion:

Our project was EU funded and it shows the opportunity for capacity building that enables NGO to develop competencies and skills that can make them more effective and sustainable, increasing their potential for to improve lives and solve societal most sensitive problems.

How will this research improve life after stroke for stroke survivors

Improving awareness of stroke etiology, secondary prevention, education on managing the hidden stroke effects.

Medical equipment will serve public health system in future.

Survey results considering stroke risk levels represent useful tool for medical professionals as well as for policy makers.

Building NGO capacity to help enrich survivor's lives.

Enabling physiotherapist with Remo: a digital AI empowered care model + medical device. We enhance the effectiveness, capillarity and the global sustainability of post stroke treatment.

PhD, CEO Paolo Ariano^{1,2}, CGO Felice Di Luca¹, PhD, Physiotherapist Giorgia Pregnotato^{1,3}, Evangelist, Physiotherapist Giuseppe Tedesco¹

¹Morecognition, Torino, Italy. ²Istituto Italiano di Tecnologia, Torino, Italy. ³SAN CAMILLO IRCCS S.R.L., Venezia, Italy

Abstract

In the world the majority of the 100 million stroke survivors after hospitalization cannot return to live independently because they are excluded from the necessary rehabilitation treatments.

REMO MODEL

We are evolving the physiotherapy treatment model for post-stroke patients based exclusively on face-to-face treatments (patients do not pay for the rehabilitation effectiveness but for the time spent by the physiotherapists during the sessions) towards a system that also includes remote treatment sessions.

We provide each patient with a Class 1 medical device (a bracelet with electromyographs and accelerometers) which measures muscle activity and generates immediate feedback on the correct execution of each exercise, through an App and an AI system. The therapists check remotely if and how the patients performed the prescribed personalized care exercises and

EFFECTIVENESS

Remo allows patients to perform at home the personalized exercises prescribed by the therapist, increasing drastically the number of sessions and consequently the results of rehabilitation (function of the number of well-done exercises and not of the time spent in front of a therapist).

CAPILLARITY

We clustered Italy in 1900 district (50K people per district) and we are selecting a therapist in each district to bring the Remo care model closer to all patients.

SUSTAINABILITY

Time, economic and environmental cost of the trip to the appointment are sensibly decreased for patients, care givers and therapists. Cost per session is halved per patient, time directly invested by therapist is valorised in term of type of activities and economical return.

How will this research improve life after stroke for stroke survivors

Our clinical studies demonstrate that using Remo patients reach an effective motor recovery of hemiparetic upper limb and a significant improvement in activities of daily living autonomy.

Understanding carers of the stroke survivors

Jelka Jansa¹, Tatjana Erjavec², Milan Cucek²

¹UMCL, Ljubljana, Slovenia. ²SSSS, Ljubljana, Slovenia

Abstract

Stroke affects the immediate and long – term Health related quality of life and also Well – being of the family. Since stroke onset, the family members are unexpectedly faced with many daily problems' unknown to them up till then. Culture and available support services also have an impact on the experienced burden of stroke care. The Slovenian Stroke Support Society, operating mainly via local clubs, and thus supporting stroke survivors and their families, has been aware of the importance of involving family members and/or carers for the lives of stroke survivors. In order to understand better the issues of caring and more importantly, the impact of caring on their own lives, two types of investigation were performed. First, by using focus group of main carers, members of local stroke club, we investigated about their perceptions of changes in their daily life. And second, by using the World Health Organisation Disability Assessment Shedule (WHODAS 2.0), we explored the long - term effects of stroke in terms of health and disability on main carers. WHODAS assesses following domains, namely: Cognition, Mobility, Self-care, Getting along, Life activities, Participation. Both investigations support the need for developing services to empower main carers while being in process of adaptation to life after stroke in the family.

How will this research improve life after stroke for stroke survivors

Ideally, stroke survivor, upon completing institutional treatment and rehabilitation, returns back to family and into familiar environment. Yet, it is accepted that the majority of functional improvement happens up to 12 months post stroke but family functioning could deteriorate for years. Understanding carers issues' is therefore important.

A stroke can be a new beginning

Mr Ivan Milojevic, mr Nenad Nikolic

Stroke Association Serbia, Cuprija, Serbia

Abstract

During 2018, we realized that in addition to the lack of a systemic solution for stroke survivors in our country, there is also a lack of opportunities for the public to hear the authentic stories of people who have survived a stroke. In order to raise the awareness of the widest possible public, we decided to start a project of making stories (interviews) with young people who survived their stroke when they were in the period when they were most active, when they were raising their children, when they were at the peak of their professional, personal, emotional and family aspirations. We did about 15 interviews with the idea of making a booklet with these stories. The stories of these young people are full of their dealing with this serious disease, and even more about how the beginning of a "new life" went. The emotions, authenticity, motivational messages of these people and the way their return to partnership and family relationships went, how they returned to their jobs, how they discovered new opportunities for their expression through sports and other activities, what challenges their families had are "lit up" pages of social networks and the website of our organization.

The honest stories of young people become "magnet" for many other stroke survivors to contact us and get direct contact with people whose stories were published. The number of these people is increasing day by day.

This project was part of the #BrainLifeGoals campaign launched by EFNA

How will this research improve life after stroke for stroke survivors

This project has given many stroke survivors great motivation for a better recovery and helped stroke survivors network. It also helps our organization get a better picture of the needs of stroke survivors.

Life After Stroke - An Aussie's Journey

Mr Ray Newland

N/a, N/a, Australia

Abstract

Life After Stoke - An Aussie's Journey

This presentation traces the journey of life after stroke of an active Australian man, Ray Newland, from age 68 in 2008 through to age 82 in 2022. It will show how one can proceed from stroke unknown, through initial fear of stroke to acceptance of stroke and through the difficulties and hard work of rehabilitation and recovery of stroke culminating in reaching a near normal life and offering life experiences to the improvement of stroke care and recovery in the health care community.

It will highlight some personal observations of how fear of stroke severely affected the mental mindset and limited the motivation and recovery aspirations of fellow stroke patients, how every stroke is different for each individual patient, how person-centred-care (or its absence) can advance or retard levels of recovery and how, in the opinion of the author, life after stroke can be enhanced through story telling for stroke patients and health service staff.

In conclusion it will show the scope and possibilities of including consumer first hand experiences with stroke to relevant executives, clinicians and allied health staff of public health services.

Relevance and Potential

The relevance of appointing stroke survivor consumer advisors to key health service committees and forums would be of great value in developing further understanding and improvements to care and recovery of stroke patients everywhere.

How will this research improve life after stroke for stroke survivors

The presentation will encourage self improvement for all stroke survivors present at the Life After Stroke Forum and those who read or view the presentation at a later time.

Stroke Association Connect - providing immediate post discharge support

DR Rubina Ahmed

Stroke Association, London, United Kingdom

Abstract

In April 2020, Stroke Association UK launched a new service called Stroke Association Connect, co-developed with people affected by stroke and key stakeholders at NHS England and NHS Improvement. The service provides immediate post-discharge telephone support for people affected by stroke.

The service offers essential reassurance, support with immediate questions or worries, and connects people to practical, social and emotional support at the start of the stroke recovery journey. The service also includes a 'safety check' component, enabling any clinical concerns that have arisen post-discharge to be identified and, through integrated working, addressed by the appropriate clinical team.

From April 2020 to January 2022 Stroke Association Connect received 9,281 referrals made by 104 NHS Trusts and teams.

Offering reassurance, accessing support with immediate questions or worries, and being connected to practical, social and emotional support right at the start of the stroke recovery journey are important for stroke survivors wherever they live. This service in the UK has demonstrated that an immediate post-discharge telephone support has played a key role in ensuring that people know that they are not alone after their stroke, they know about the support available, and importantly how to access it.

While health systems vary between countries, the Stroke Association has gained insights into the benefits of working in an integrated way across services and professions and how stroke support organisation services can contribute to the wider stroke pathway. These insights have the potential to inform the development of similar services in other countries.

How will this research improve life after stroke for stroke survivors

People told us the service has made them feel more reassured, well informed, supported and more emotionally able to move forward with hope and optimism. Our learnings include the need to develop processes to refer patients and the importance of calls being at the right time for the stroke survivor.

The Importance of Art Therapy for Stroke Recovery and Life after Stroke

Dipl.eng. Dorina Dobreva, Dipl.art therapist Evgenia Marincheva

Association for Stroke and Aphasia, Sofia, Bulgaria

Abstract

Over 5 years of hard work from art therapist with the stroke survivor Donka Dimitrova proved significant positive results in stroke recovery and even some progress in aphasia status towards improvement. Strategy and full program is created and tailor-made for each individual. One of the main goals of our Association for Stroke and Aphasia is to define how to make this therapy more affordable for most stroke survivors who might benefit from it. We also plan to expand art therapy services covering the unique needs of caregivers and family members of stroke survivors.

We plan to open Art Therapy Accademy globally accessible in order to share the positive experience and know-how.

How will this research improve life after stroke for stroke survivors

Arts-based therapies generally reduce psychological sequelae of stroke such as anxiety and depression. The cognitive sensuality and neuroplasticity of the brain are triggered continuously while all achieved results are stable. The art-therapy helps to keep positive attitude in everyday life, to gain self awareness and find new fields of self-affirmation.

Development of virtual programs to address the priority education, support, and participation needs of people post- stroke

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Abstract

Title:

Development of virtual programs to address the priority education, support, and participation needs of people post- stroke

Background:

After Stroke at March of Dimes Canada (MODC), a National non-profit organization, was required to pivot quickly to virtual programs due to the COVID Pandemic. MODC, had previously offered several in-person programs. The shift to virtual programming offered an opportunity to scale programs to reach participants at a national level.

Objective:

To respond to the needs of people living with stroke through the development of a suite of evidence informed virtual programs.

Methods:

Through formal and informal feedback measures (surveys), our team identified the needs of people living with stroke and their desire for stroke specific virtual programs. Programs were then developed to address the identified needs.

Results:

In response to identified needs for: 1. Greater understanding of the effects of stroke on domains of wellness we developed: Ask an Expert Monthly series, 2. Learning how to live better with the effects of stroke we developed targeted peer support groups, such as young stroke survivors and caregivers specific groups, 3. Skill development and self-management strategies, we developed GRASP upper extremity program and an 8-week Living with Stroke self-management Program in collaboration with Heart and

Stroke Canada, 4. Safe, structured opportunities to work on mobility, strength, aerobics, and mindfulness we developed adapted exercise classes.

Conclusions: The COVID 19 pandemic created significant barriers to in-person program implementation but created an opportunity to offer innovative programs through a video conferencing platform.

How will this research improve life after stroke for stroke survivors

This work supports the development of stroke specific, relevant, targeted, cost effective virtual programming that is easily replicable for other regions.

Here for you - helping to rebuild life after stroke

Dr Rubina Ahmed

Stroke Association, London, United Kingdom

Abstract

The Stroke Association's Here For You telephone support service connects stroke survivors and carers to trained volunteers to help combat isolation and offer peer support. Here For You provides beneficiaries with one weekly call from trained volunteers for up to eight weeks. A beneficiary can receive a second block of eight weeks if required. There are two types of volunteers:

- Lived Experience volunteers have experienced stroke first-hand. They understand the practical and emotional challenges, and can offer peer support.
- Connect and Chat volunteers provide support and offer someone to talk to about interests to help the stroke survivor or carer feel more connected with other people. This may be appropriate when people are feeling more alone at a particular moment, unable to take part in the usual activities they enjoy.

From its launch in April 2020 to 31 March 2022, Here For You supported over 1,500 people and recruited and trained over 600 volunteers. In November 2021, we carried out an evaluation and the majority of the feedback was very positive. Many said the regular conversations helped them understand how to cope better, reduced loneliness and improved their mental wellbeing.

The impact of stroke on mental well-being affects stroke survivors and carers across the world. We know that there are gaps in access to long term support in many countries. This service in the UK offers an example of how volunteers, including those with lived experience, can be engaged in life after stroke support activities.

How will this research improve life after stroke for stroke survivors

We received feedback that some people found it unsettling when the support ended. This highlights that for many people, longer term support is needed. We are looking at ways for people to carry on receiving other types of support. This learning may be of interest to organisations across the world.

The emerging role of the advanced practice nurse in stroke care

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Abstract

The advanced practice nurse (APN) in stroke care is a figure that has been developing for only one year in our hospital. This is a registered nurse with expert knowledge, complex decision-making skills and the necessary competencies for an extended practice. The functions performed by the APN in stroke are:

- Education and secondary prevention: health education is provided to patients and family members admitted for stroke and achievable goals are set in relation to secondary stroke prevention with post-discharge follow-up. This allows patients and family members to be empowered and enabled to make decisions, as well as to have a referral contact when needed.
- Interprofessional collaboration with the aim of establishing a continuum of care for the patient at the time of discharge. It also contributes to the development of protocols and clinical guidelines, as well as participation in quality improvement programs in stroke patient care.
- Research and evidence-based practice focused on improving the quality of care and quality of life of stroke patients.
- Professional leadership, being the reference nurse in the pathology in the hospital setting. In terms of teaching, the training and professionalization of stroke nurses is promoted.

The APN of cerebral vascular pathology is in process of development and the exchange of its own functions with other centers can improve excellence in the transversal care of stroke patients, their empowerment and secondary prevention of this pathology. Recognizing, empowering and externalizing this figure is considered fundamental for these purposes.

How will this research improve life after stroke for stroke survivors

The advanced practice nursing program in stroke care at Hospital Clínic of Barcelona aims to improve the quality of both acute care in the in-hospital setting, providing health education to the patient and/or family, as well as patient discharge follow-up, promoting adherence to secondary stroke prevention measures.