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The Bridges Stroke Self-Management program for Stroke Survivors in the Community: Stroke, Carer and Health Professional Participants' Perspectives

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Abstract

Objective: Self-management programs are considered to be one of the top priorities within health care and rehabilitation. Bridges is a stroke self-management program based on self-efficacy principles that supports survivors to develop effective strategies for managing life after stroke. This study aimed to explore with stroke survivors, carers and health professionals their experiences of using the Bridges stroke self-management program in addition to usual rehabilitation delivered by the community stroke team.

Methods: A qualitative study using a purposive sampling method was used to recruit participants following stroke, who had been included in the intervention arm of feasibility randomised controlled trial, their careers and the health professionals who had delivered the Bridges programme. Interviews were conducted with eleven stroke survivors and two carers. Three health professionals took part in two focus groups. Inductive content analysis was conducted to explore key themes.

Results: Five themes were identified: managing progress; personalised goal setting; greater understanding of recovery; ownership; and factors influencing Bridges such as timing; participant characteristics; and health professionals' skills in delivering Bridges.

Conclusion: This is one of the first qualitative studies to explore experiences of an individualised approach to supporting self-management. Support needs to be given to clinicians and patients' to create a more collaborative self-management approach. The Bridges program supports stroke survivors, and health professionals in providing more person-centred care. It was found to be beneficial and acceptable from the perspective of stroke survivors, carers and health professionals. Further evaluation of the Bridges self-management program is warranted.

Keywords: Stroke; Bridges self-management; Carers; Health professionals; Qualitative study

Introduction

Stroke is a neurological condition that is causing chronic disability worldwide [1]. The global burden of stroke suggests that one in six individual's world-wide will experience a stroke in their lifetime [2]. With an increasing ageing population, the number of stroke survivors and the overall global burden of stroke is increasing [2].

Despite developments in acute and rehabilitative stroke care in recent decades individuals are still reporting a broad range of unmet needs including: emotional support, involvement in decisions about care, rehabilitation therapy, support for everyday activities, information provision, access to services, and help to return to work [3, 4, 5]. Stroke survivors report they do not feel ready to manage themselves after discharge from the supportive environment of acute care [5, 6]. Therefore there is growing interest in the process of adjustment and interventions that may facilitate the stroke survivor's ability to cope with life after stroke.

Self-management programs (SMPs) are considered to be one of the top priorities within health care and rehabilitation [7]. Self-management support enables people with long term conditions develop the knowledge, skills and confidence to manage their own health [8]. Emerging evidence has shown that self-management support can impact patients' self-efficacy, knowledge about their condition, satisfaction, clinical and quality of life outcomes, and health and social care resources and costs [9]. Self-management interventions have also been identified as a way to support individuals coping with life after stroke [10, 11, 12].

The Bridges stroke self-management program is a UK developed program based on self-efficacy principles that supports survivors to develop effective strategies for managing life after stroke [13]. Bridges uses one-to one support from a health professionals and a patient-held workbook to support behaviour change, increase motivation and action through strategies such as problem solving and goal setting [13]. The Bridges workbook is used as a tool to facilitate a personal

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record of goals, progress and helpful self-management strategies. Bridges has been designed in consultation with stroke survivors and their families to reflect the range of challenges post stroke and solutions that recognising that stroke is a unique and complex event, it provides a mechanism for tailoring self-management support. It can be integrated into regular therapy or used after discharge from rehabilitation [14].

Research has shown preliminary proof of concept for the Bridges SMP, including the feasibility of delivery and acceptability to patients, carers and professionals [13, 15]. Promising results have also been reported regarding change in outcome following stroke [13, 16]. In a randomised controlled feasibility study, a greater change in functional activity, social integration and quality of life over a 6-week intervention period was shown for participants who received the Bridges SMP [16]. An important aspect of feasibility is the experiences of translating the intervention into practice and the exploration of the context, barriers and attitudes of those using and delivering the programme; this is the focus of this qualitative study.

Aim

The purpose of the qualitative study was to explore with stroke survivors, carers and health professional their experiences of the Bridges SMP to gain a greater understanding of: the outcomes experienced by stroke participants; the acceptability of the programme to all involved; and, any factors identified as barriers or facilitators to successful implementation of the programme.

Methods

Ethical approval was obtained from the Office for Research Ethics Committees Northern Ireland (ORECNI: 08/NIRO/67).

Participant selection

The carers and participants, who had experienced a stroke, who had been included in the intervention arm of feasibility, randomised controlled trial exploring the Bridges SMP and the health professional participants, who had delivered the program, were approached to participate in this qualitative study. Written informed consent was obtained from all participants.

Face to face interviews were conducted with each individual stroke participant in their respective homes following completion of the six weeks Bridges SMP. Telephone interviews with carers of stroke participants who had received the Bridges SSMP were conducted within three months of their relative having completed the Bridges SMP. Carers had requested that interviews be held by phone so that the interviews could be organised around their other commitments. These interviews were held in an enclosed office using a secure telephone system.

Two focus groups were conducted with health professional participants. A focus group design was chosen as group interactions can reveal more about clinicians' understanding of a difficult clinical problem and the reasoning behind clinical decisions than may be gained using other data collection techniques [17]. The first focus group was used to pilot the topic framework and identify emerging themes and issues, which were then clarified in a second follow-up focus group. Semi-structured question frameworks were developed for stroke and carer participant interviews based on a set of open ended questions that explored the issues and context relating to engagement in the Bridges SMP (see Table 1). The topics included were informed by the findings of previous evaluation work on the Bridges SMP conducted by Jones and colleagues [13], and by identifying common queries raised in work within the subject area [9,11, 12].

Table 1: Topic guide for interviews and focus groups.

Topics for interviews with stroke survivors (n=11)
Tell me about Bridges in your own words Tell me about your experiences of using the Stroke Workbook If you had to explain it to someone else how would you explain it? Is there anything that has changed as a result of Bridges? If you had the opportunity to change any aspect of Bridges what would you suggest? What do you think would be a good time to introduce Bridges? How do you think you might feel about Bridges in a few months?
Topics for telephone interviews with carers (n=2)
What do you understand about the Bridges process? Have you been involved in using the workbook? Is there anything that has changed for (name of family member) as a result of Bridges? If you had the opportunity to change any aspect of Bridges what would you suggest? What do you think would be a good time to introduce Bridges? How do you think you might feel about Bridges in the future?
Topics for focus groups with health professionals (n=3)
Key components 1.1 Tell me about your experiences of delivering the Bridges intervention. 1.2 What do you perceive to be the key components of the Bridges intervention? **Delivery of the intervention** 2.1 Which aspects of the intervention if any, work well? 2.2 Which aspects of the intervention, if any, work less well? 2.3 What do you feel could be done differently when delivering Bridges? 2.4 When do you think is a good time to introduce the intervention? 2.5 Which health professionals are most suitable for delivery of the Bridges intervention? 2.6 Describe a patient most suitable for the intervention, what would they be like? **Effectiveness of the intervention** 3.1 Please give an example of a patient or experience where you consider the Bridges intervention to have been successful. What do you think influenced the success of using the intervention? 3.2 What are the main barriers to implementing the Bridges intervention? 3.3 How do you think the success or failure of the intervention could be best captured or measured?

All interviews were conducted by two researchers who had not been involved in the delivery of the Bridges SMP during the feasibility RCT. The focus groups were co-facilitated by the lead author, and Jones who had developed the original Bridges intervention, and trained the community stroke team in the Bridges SMP; neither researcher was involved in the actual delivery of the Bridges SMP in the feasibility RCT.

Data analysis

All interviews and focus groups were audio-recorded, then transcribed by a research assistant, who was not directly involved in the study; participants were de-identified. Thematic analysis was used to analyse the qualitative data. The data collected from each set of participants was analysed separately to ensure comprehensive exploration of the themes arising from each group. The analysis focused on identifiable themes within the data, which came from direct quotes. The lead author was responsible for the primary thematic extraction. Two senior researchers independently analysed a sample of the transcripts themes from these transcripts. During a consensus meeting, each independent set of themes was compared to each other, and where there was disagreement, the original narrative transcripts were carefully examined to reach consensus.

Results

All eleven participants in the intervention arm of the feasibility randomised controlled trial (RCT) agreed to be interviewed in their own homes. The mean age of stroke participants was 62.18 years (SD: 13.57) with a mean time since stroke of 7 weeks (SD: 4.45). There were four females (36.4%) and seven males (63.6%). They were moderately disabled in terms of self care as measured by a mean Barthel Index of 14.09 out of 20 (SD: 5.30), and a mean Nottingham Extended Activities of Daily Living Scale of 26.00 (SD: 14.19).

Two out of six carers agreed to be interviewed by telephone. The three health professionals involved in the delivery of the Bridges program agreed to participate in the focus groups. One was a stroke specialist nurse, one was an occupational therapist and one was a social worker. The emerging findings from the three groups of participants were synthesised under five overarching themes: managing progress; goal setting; understanding recovery; ownership; and factors that influenced the Bridges SMP. Table 2 verifies the themes that were identified across each group. The Bridges program gave stroke survivors a sense of confidence in managing their own progress. Various components of the Bridges SMP, including: goal setting, collaborative interactions with the healthcare professional, the use of the workbook as a resource, and monitoring and reflecting on their progress; were associated with an increased sense of motivation. The Bridges goal setting approach enabled participants to think about setting personal targets, enabling them to take more control. The case studies included in the Bridges workbook were perceived to be an important resource offering stroke survivors an insight into other peoples' experiences which helped them better understand the process of recovery. The theme of ownership was unique to healthcare professional participants; the Bridges stroke workbook fostered empowerment of stroke participants by handing over control. The final theme identified the factors that influenced the delivery of the Bridges program from the participants' perspective. Each theme is illustrated with sample quotes from all three groups of participants below.

Theme 1: Managing progress

The theme of managing progress emerged strongly from the all three groups of participants. Participants following stroke appreciated the opportunity to use the Bridges stroke workbook identifying a sense of gaining confidence in managing their own progress. Carers also identified that the workbook helped their relative to reflect on what was happening, giving them encouragement to carry on.

"it's a tool to help you manage and see your progress . . . by seeing the changes, the motivation then gets better so that you can get on with life quicker and put the effects of the stroke and see that things can change and improve." Participant E

" … they need to start thinking about other things, normal stuff, as I said the goals you want to go for … I think it gets the process going a bit more rather than somebody saying to them do that or the other…" Carer B

Similarly, health professionals also believed that stroke participants' engagement in the Bridges SMP enabled them to better manage their progress which they related to self-discovery. They perceived that the processes involved in the Bridges SMP of problem setting, goal setting and reflection were the ways through which stroke participants' developed a greater appreciation of their abilities.

"Some structure I think, that she needed in that stage. She was just so confused about her abilities and I think it's proved to her that if she takes one bit at a time and works towards targets that are manageable instead of looking at the whole picture and becoming overwhelmed. She was able to take it little by little by little and see then on reflection, you know on week five we looked back to week one and even the targets then were like, not laughable but so simple, yet at the time when she set them she didn't know whether she was actually going to meet them or

Table 2: Overview of themes across participant groups.

Theme	Stroke participants	Carers	Health professional
Managing progress	A tool to help manage progress after stroke Gaining confidence A source of encouragement	Enables the person who has had a stroke to think about things, and what they have done	Developing a greater appreciation of their abilities
Goal setting	The personal nature of the Bridges goals Setting small, achievable targets	Increased incentive to work towards goals Supporting the family to let go	The difference between Bridges SMP and usual rehabilitation goals
Understanding recovery	Insight into others' experiences	Insight into what others would do	Insight into other stroke survivors' experiences
Ownership			Fostering empowerment by handing over control
Influential Factors on Bridges SSP	Need to be individualised		Need for reflective listening skills

not and it let her see on reflection how well she was progressing in not just physically but emotionally." Health Professional A

Theme 2: Personalised Goal setting

Stroke survivors, health professionals and carers noticed a difference in the construction of goal setting when using Bridges. There was a perception by stroke participants that the goals they set through the Bridges SMP were distinct from goals that had been set during usual therapy.

"*. . . I always felt that there was an awful lot more that could have been done with it* [research he had compiled], *basically a book, there's a lot more and it occurred to me half way through with* [the facilitator] *coming out that it would be an ideal way to both as therapy, and it actually would be a useful stimulating way to use time . . . I don't know if I had of thought of that if it hadn't been for the process of it."* Participant H

By engaging in collaborative discussion with the health professional delivering the Bridges SMP, participant H was able to problem solve and devise a course of action which commenced with improving upper limb movement so he could carry out tasks required to fulfil his goal. This participant felt that the processes of goal setting and problem solving involved in the Bridges SMP led to an important realisation of how rehabilitation activity could relate to meaningful activity.

"When you realise why you are doing the different exercises, what bearing they are having on getting to the chair or whatever, even moving around the bed "Participant H

The goal setting process involved in the Bridges SMP of setting small achievable targets was also perceived to provide stroke participants with a route map to work towards their overall goal or aspiration. Stroke participants perceived that the processes involved in the Bridges SMP provided them with the initiative to actively work towards achieving their goals.

"it's to set achievable targets and goals not too have a wish list but to have things that are manageable, not, sort of, too advanced I suppose. It's keeping things, I think, simple, rather than looking too far forwards" Participant E

Carers also observed that the Bridges SMP focused stroke participants and provided them with something to work towards by promoting active engagement of the stroke participant in goal setting; and through the role of the health care professional as a source of encouragement.

"When something like that happens to somebody they almost kind of go into themselves because it is such a big thing that's happened to them . . . they need something to take themselves out of that, to start thinking about . . . the goals that you want to go for and things that you want to aim for and I think it [Bridges SMP] gets the process going a bit more" Carer B

Health professional participants also perceived that the goals set as part of the Bridges SMP were more personal and comprehensive than those set as part of usual rehabilitation.

"…his targets were not necessarily physical, they were not necessarily related to his stroke, these were long term life goals, these were the dreams, then we were able to identify that hand and arm function was going to be able to help." Health Professional B

Theme 3: Understanding recovery

Stroke participants perceived that they had a greater understanding of their recovery post stroke as a result of engaging in the Bridges SMP. The processes involved in the Bridges SMP including the collaborative discussions between the health professional delivering the programme and the stroke participant, appeared to influence stroke participants understanding of their condition.

"It clarified my mind with the various things that would improve . . . If I hadn't had it and had just sort of been left after having had the stroke I would have been adrift and wouldn't have had the know how to approach it, the development of the different approaches to the different aspects of the stroke." Participant H

In addition, the case studies included in the Bridges workbook offered an insight into other peoples' experiences which helped them better understand their condition which encouraged them with regard to their own recovery.

"I would say it gives you illustrations of a case where people have had a stroke similar to yourself sometimes worse than yourself, and how they have recovered and got back to doing what they did before. In some cases in note people went on to do degree work even after it, you know. So it's encouraging to know how people can recover." Participant A

Some stroke participants felt that being able to relate to other peoples experience of stroke detailed in the case studies lessened the sense of isolation they themselves were experiencing due to their stroke.

"Well Bridges was very informative because it didn't make you feel as isolated, that you could see other people in the book that had the same sort of things that had happened to you . . . to know that you are not alone was very important, very informative." Participant J

Theme 4: Ownership

This theme of ownership was unique to healthcare professional participants. There was a perception by health professionals that the Bridges SMP fostered a sense of true ownership for stroke participants by focusing on their personal goals. Health professionals identified the importance of this section of the stroke workbook as a way they could empower stroke participants by handing over control in both a symbolistic and real way. They confirmed that this component led to an appreciation of the need to change the control dynamics in their usual practice.

"I think we should all be trained in this way because as a therapist we've got to get away from this, about what we want them to achieve, it's so wrong. We got to think about handing over to patients." Health Professional C

Theme 5: Influential factors

Both stroke participants and health professional participants identified three key influences within this theme: timing, stroke participant characteristics, and health professional skills.

Timing

Generally stroke participants reported that they were happy with

the time that the Bridges SMP had been delivered to them and that the home setting seemed the right place to be using the program as opposed to hospital which was not believed to be suitable. Overall there was a sense that that timing needed to be decided on an individual basis.

"I don't think after so many weeks this is what they do, I think you have got to use a bit of sensitivity that way and when you do, to me it worked well." Participant K

There was an emerging consensus that the length of the intervention should be decided on an individual basis to enable individuals to work at their own pace.

"Six weeks for me was fine but maybe for somebody else it could take ten, maybe twelve. That's what you really need to look at individual cases or how soon they have taken it up as well." Participant J

Health professionals also believed that the timing and duration of the Bridges SMP needed to be decided on an individual basis.

"I certainly feel that introducing it on Day 1 is not necessarily appropriate . . . ideally if it was running for every patient then every patient would just be getting it immediately that it was appropriate to introduce it." Health Professional A

Health professional participants also proposed that including a review for stroke participants could be strategy by which to encourage stroke participants to continue using the principles learned in the programme, and to act as an incentive to stroke participants to keep them motivated.

"Well it would be nice to review it with them . . . then you've a purpose whereas you can sort of become quite lethargic, just to keep the momentum going when somebody else is dipping in and out." Health Professional B

Participant characteristics: Who is it for?

There was a suggestion by some stroke participants that the Bridges SMP may be more relevant to individuals who had more significant problems post stroke. However, the contrasting point of view was also expressed with the suggestion that younger less affected individuals could benefit greatly from the Bridges SMP as they would have more capacity to progress.

"I think it's been a fantastic support mechanism for survivors of stroke especially at my age and at my time of life, I can only imagine that anyone younger than me would see extreme benefits because at a younger age they're more active and the impact is probably more severe than someone who is quite elderly who doesn't have the physical strength to progress." Participant E

Health professionals believed that engagement with the Bridges SMP could be influenced by stroke participants' attitude; in particular, greater motivation was identified as positively influencing engagement.

"She was brilliant for Bridges and she would have been in the older age group but yet her mindset was definitely not in the older age group it was young. She was so keen to try and great motivation." Health Professional C

Health professionals' skills

A number of skills were identified by the health professionals as being important for the delivery of the Bridges SMP the majority of which were personal characteristics rather than attributes associated with a particular professional discipline. These skills included: effective communication skills such as reflective listening which health professional participants defined as the ability to be able to listen to stroke participants and help them weed out the important points; being able to work at the stroke participants pace; and, the ability to guide stroke participants whilst promoting ownership...

"Is it important to work at his pace and . . . really listening to what they are saying even to be able to weed out with the patient what are the important points and identifying that." Health Professional B

Discussion

This study set out to explore with stroke survivors, carers and health professionals their experiences of the Bridges SMP in order to gain a greater understanding of: the outcomes experienced by stroke participants; the acceptability of the programme to all involved; and any factors identified as barriers or facilitators to successful implementation of the programme. The Bridges SMP was acceptable to stroke survivors, their careers, and health professionals. Stroke survivors perceived that the programme had enabled them to: manage their progress, set goals of a personal nature, and gain a greater understanding of recovery post stroke. One of the key emerging themes was the perception that engaging in the processes involved in the Bridges SMP such as working towards small goals and reflecting on progress increased their motivation and incentive to work towards their goals. The case studies contained in the workbook were valued as a source of encouragement which promoted an "if they can do it I can do it" attitude. The interactions between the participant and the healthcare professional were perceived as being positive by stroke participants who described how the health professionals provided support in goal setting and problem solving. In turn there was an understanding by health professionals that their role in the Bridges SMP was to empower the stroke participant to take control of their recovery by promoting ownership. The training received by the healthcare professional participants appeared to help them understand the potential influence they had during these interactions in supporting self-management. Similarly to our study, Kessler et al (2009) suggest that individuals after a stroke may adapt more successfully to their new lives when they can access required knowledge and take action to regain control in the presence of support [18]. Ch'ng and colleagues (2008) have also identified that information seeking, participation in rehabilitation; problem solving and engagement in activities have been highlighted by stroke participants as extremely helpful during recovery [19]. It would appear that the Bridges SMP was a successful intervention in providing stroke participants the opportunity to engage in various coping strategies.

The process of goal setting (theme 2) used in the Bridges SMP was perceived by both stroke and health professional participants as being distinct from that used in usual rehabilitation. Both stroke and healthcare professional participants also perceived that Bridges SMP goals were more comprehensive in nature than usual rehabilitation goals. This is in contrast to current ongoing discussion

in rehabilitation, where it has been identified that clinicians ultimately appear to have control in selecting which goals to work on even when the preference of the individual with stroke has been established, even though the concept of patient-centred goal setting is being promoted in stroke rehabilitation [20, 21]. Two components of the Bridges SMP were seen as enabling stroke participants to gain a greater insight into their condition and an understanding of the potential for recovery (theme 3): collaborative discussions between the health professional delivering the programme and stroke participants; and the case studies in the Bridges SMP workbook. Ch'ng et al (2008), has also highlighted the need for individuals to have an informed understanding of their condition so that the effort they invest in rehabilitation helps realise their goals. By promoting a sense of ownership for stroke participants through collaborative interactions it is possible that the Bridges SMP is an intervention that could be used to facilitate better communication between stroke participants and healthcare professionals [22]. In our study, the Bridges SMP provided a real way of handing over control to stroke participants.

The final theme referred to potential influences on implementing the Bridges SMP. The timing of introducing the Bridges SMP and the programme duration were acceptable to all participants in this study. However, there was the strong opinion that timing had to be decided on an individual basis so that an individual's readiness to participate was taken into account. Rollnick et al (2008) suggests that readiness to change is influenced by both the perceived importance to the participant and their confidence [23]. Informing stroke participants of the potential benefits of engaging in self-management and attempting to build their confidence by introducing some of the principles of the Bridges SMP may influence their readiness to engage with the programme. Essential skills required by health professionals delivering the Bridges SMP were identified as being: effective communication skills and the ability to work in a way which promoted ownership of the stroke participant. Similarly to our study, Jones et al (2012) have also found that when delivering the Bridges program, health professionals reflected on the need for effective communication and the concept of getting the balance of power between imparting advice and encouraging self-management and choice [24].

Limitations

This study was conducted in the UK with relatively small numbers participants.

As the impact of self-management programs are dependent on the context in which they are set these findings may lack generalisability to the larger stroke population. People who have received self-management training may quickly lose the confidence and motivation to self-manage when faced with unresponsive and unsupportive clinicians and services, therefore integration of self-management support into health care services is viewed as particularly important [8]. Our feasibility RCT and qualitative study evaluated the Bridges SMP as add on to usual stroke rehabilitation. Future evaluation of the feasibility of embedding the Bridges SSMP into practice is required.

Conclusions

Several national clinical guidelines recommend the provision of self-management support for individuals with stroke [1, 25]. It is not yet possible to determine which individuals following stroke may benefit the most from implementing a SMP. A recent discussion paper by Jones et al (2012) has highlighted that individuals who have experienced a stroke vary in their readiness to participate in SMPs [26]. A review by Lennon et al (2013) provides preliminary support for supported self-management after stroke, but concluded that the optimal timing, content, and mode of delivery remains to be determined [12]. This is one of the first qualitative studies to explore experiences of using the Bridges program, an individualised approach to supporting self-management. The most favourable way of supporting self-management involves empowering and activating people so they feel confident to manage their condition and therefore are more likely to alter their health and social behaviours [9]. Support needs to be given to clinicians and patients' to allow for change in the way they view their roles to create a more collaborative self-management approach [8]. The Bridges program supports stroke survivors, and health professionals in providing more person-centred care. It was found to be beneficial and acceptable from the perspective of stroke survivors, carers and health professionals. Further evaluation of the Bridges SMP is warranted.

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