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Health Education and Training Institute (HETI)

“Back in the usual normal world”

Barriers and enablers to exercise and community participation after stroke: the role of community health and support services

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ABBREVIATIONS

FG – Focus Group

SS – Stroke Survivors

TACP – Transitional Aged Care Program

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ABSTRACT

AIM

To describe stroke survivors and carers experiences of services after discharge and explore the role of these services as an enabler or barrier to exercise and community participation.

METHOD

A qualitative methodology employing a post positivist framework was utilised. Semi structured in depth interviews and a focus group were conducted with fourteen stroke survivors and two carers. Key themes were derived from interpretive analysis of transcripts by two independent researchers.

RESULTS

Four main themes characterised participant's experiences of services after stroke. *"I suppose it depends who you are dealing with"* - the lucky dip of service provision, *"Getting back to the usual normal world"* - enablers to exercise and participation, *"We're all in the same boat"* - the benefits of group interaction and *"There's obviously no coordination"* - barriers on the long road to recovery. Case management or coordination was perceived as an important component of a stroke service and related to improved access to services. Community based rehabilitation programs were associated with positive experiences of services. They provided benefits in terms of practical assistance, opportunities for getting out in the community, carer support and general satisfaction. They positively influenced feelings of self efficacy, independence and social integration. Exercise opportunities after stroke were highly valued by participants. There were many social and motivational benefits derived from being in a group environment with other stroke survivors. A younger age at time of stroke was a significant barrier to accessing services.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

The experience of stroke survivors demonstrates that community health and support services can enable exercise and community participation after stroke. However their experiences highlight that there are a number of barriers to accessing these services. Stroke survivors identify coordination or case management and increased opportunities for exercise and community based rehabilitation programs as key ingredients of a long term support model for stroke. Service providers should consider interventions that increase opportunities for social and community participation. The provision of encouragement, information, transport facilitation and accompanied outings are strategies that might enhance exercise and community participation after stroke. Early referral after discharge to stroke specific exercise groups led by health professionals is a potential strategy for increasing exercise participation in this population.

KEY WORDS: Stroke, Community Integration, Services, Participation, Exercise

EXECUTIVE SUMMARY

CONTEXT

Research has found that residual disability after stroke has a profound impact on all aspects of life(1-4). This includes high rates of social isolation and depression(1). Literature suggests that satisfactory longer term care after stroke is lacking and that the current configuration of services do not reflect stroke survivors experiences of adjustment after stroke(1-3). Inadequate hospital discharge planning processes and poorly coordinated services have been reported to contribute to a situation where stroke survivors often “fall between the gaps” of service provision(2, 5, 6). Despite a number of generic and stroke specific services existing in the community, stroke survivors and carers report low satisfaction with services, related to both accessibility and services ability to meet their needs(1).

The evidence supporting the benefits of exercise in a chronic stroke population is compelling(7-14). These include functional, social participation and prevention of secondary complications of immobility. Despite this evidence and recognition by stroke survivors of the value of exercise(1), long term participation in exercise after stroke is low(15, 16). Stroke survivors experience reduced social and leisure participation which impacts negatively on health related quality of life(17-21). Recommendations from studies of follow up services after stroke argue the need for strategies to stimulate return to social and leisure activities in this population(2, 18, 21). However interventions to facilitate community participation have largely fallen outside the domain of current rehabilitation models.

The aim of this study was to describe stroke survivors and carers experiences of services after discharge in a rural Australian community and explore the role of these services as an enabler or barrier to exercise and community participation.

APPROACH

A qualitative research methodology employing a post positivist framework was adopted. Face to face semi structured interviews and a focus group were carried out with fourteen stroke survivors and two carers. Participants were recruited from a medical record audit that identified consecutive stroke admissions over a 12 month period and subsequently further participants were recruited from the local stroke recovery association. The time since stroke varied from 6 months to 11 years. Interpretive analysis was undertaken by two independent researchers to identify key themes.

FINDINGS

Participants experiences of services after stroke were mixed and characterised by four main themes: *“I suppose it depends who you are dealing with”* - the lucky dip of service provision, *“Getting back to the usual normal world”* - enablers to exercise and participation, *“We’re all in the same boat”* - the benefits of group interaction and *“There’s obviously no coordination”*- barriers on the long road to recovery.

Case Management or Coordination was viewed as a central component of a stroke service. The absence of coordination led to the greatest perception of dissatisfaction, as well as meant missing out on knowing what might be available. The role of coordination was information distribution, referrals, advocacy and improving access to services through a single point of contact.

Community Based Rehabilitation Programs were associated with positive experiences of services. Programs delivered early after discharge provided practical assistance, opportunities for early community integration and carer support. These programs positively influenced feelings of self efficacy, independence and social integration. Programs delivered much later after discharge provided socialisation opportunities and carer support.

Stroke Specific Exercise Groups were viewed as enabling social support, increased confidence, improved mood, motivation, reinforcement and an opportunity for knowledge acquisition. Opportunities for exercise were highly valued by participants. Goal setting, the relationship with the therapist, transport assistance and a stroke specific group setting were perceived as enabling factors.

The provision of encouragement, information, transport facilitation and accompanied outings were associated with enhanced participation. The main barriers to participation perceived by stroke survivors included a lack of coordination, unavailability of appropriate services, a younger age (less than 60 years) at time of stroke, a lack of encouragement, perceptions of health professionals and personal characteristics.

IMPLICATIONS

The experience of stroke survivors demonstrates that community health and support services can enable exercise and community participation after stroke. However their experiences highlight that there are a number of barriers to accessing these services. This study has demonstrated that key ingredients for a long term support model for stroke include case management or coordination, increased opportunities for exercise programs and community based rehabilitation programs. The role of coordination is to improve access to services. Community based rehabilitation programs should consider interventions for social and community participation, aligned with recommendations from the National Stroke Guidelines(22). Providing encouragement, information, facilitating transport and accompanying stroke survivors on outings are interventions which may enhance exercise and community participation after stroke. Exercise and education schemes using Chronic Disease Management principles(23), with early recruitment after discharge, may be one strategy for increasing exercise participation in this population. Interventions that increase exercise and participation have the potential to reduce the cost burden of chronic stroke. Consideration of strategies to address barriers to accessing services for younger stroke survivors with significant disability is warranted.

RECOMMENDATIONS

- Further qualitative and audit investigation into the experiences of stroke survivors on other transitional aged care programs (TACP) and generic community based rehabilitation services.
- Further investigation into methods of enabling increased exercise and community participation after stroke.
- Improved opportunities for access to coordinated transitional and community based rehabilitation services for younger stroke survivors (less than 60 years) with significant disability.
- Development of assessment tools and educational programs for generic community and aged care rehabilitation services to improve adherence to evidence based recommendations for stroke.
- More widespread implementation and evaluation of community based exercise programs for stroke in health care settings using a chronic disease management model.
- Inclusion of stroke survivors in existing community chronic disease management programs

INTRODUCTION AND LITERATURE REVIEW

There is increasing awareness of the need to develop longer term support models for stroke (1, 3-5). However there is limited consensus as to how best to achieve this. Studies have identified the considerable disability experienced by stroke survivors(1, 3) as well as revealed reduced participation levels(17, 19, 24) and poor health related quality of life(18, 24). Recent studies have highlighted the low satisfaction experienced with services after stroke(1, 25).

Growing evidence suggests that functional abilities can improve with exercise and task specific interventions even years after stroke(7, 11, 13, 26, 27). Participation in regular exercise and broader community participation after stroke has implications for reducing social isolation, improving health outcomes and quality of life(19, 24). Aside from personal benefits, this poses the potential for reducing the cost burden of chronic disease.

Strategies to achieve increased engagement of stroke survivors in exercise pursuits, beyond the initial rehabilitation period, have to date presented enormous challenges(15); and interventions to facilitate community participation, though advocated in stroke guidelines, have largely fallen outside the domain of current rehabilitation models(22).

This study aimed to describe stroke survivors and carers experiences of services after discharge and explore the role of these services as an enabler or barrier to exercise and community participation.

BACKGROUND

IMPACT OF STROKE

Improvements in stroke related mortality and morbidity have been brought about through improvements in acute care, such as the advent of Stroke Units and thrombolysis. Despite this stroke continues to be a disabling and devastating condition. In Australia there are an estimated 346 000 stroke survivors with more than 280 000 of these living with a permanent disability(28). There is a large body of literature detailing the longer term impacts of stroke(1, 3). The most common impairments are memory, mobility and communication(1). Other issues encountered include falls, continence, sexual activity, fatigue and pain(1, 3). Stroke survivors experience high rates of social isolation with at least one third suffering from depression(1, 3). The burden of carer strain is high(1, 2). Further problems include return to work and driving and loss of family and social roles(2, 4). Stroke survivors experience reduced community participation levels which adversely affects health related quality of life(18, 19, 24). Participation restriction results from a complex interaction of personal and environmental factors, with reduced mobility being a major contributor(15, 29).

POST DISCHARGE SERVICES

1. DISSATISFACTION

There are a number of generic and stroke specific services and programs that exist in the community that could be accessed by stroke survivors(5). The National Stroke Foundation “Walk In Our Shoes” (2007) report exposed an overwhelmingly poor satisfaction with services after stroke(1). Dissatisfaction was related to both accessibility of services and their ability to meet stroke survivors needs(1). These findings, which painted a grim picture for stroke survivors, have been replicated worldwide(25). National Stroke Audits have exposed often poor discharge planning processes which contribute to a picture of ad hoc and poorly coordinated service provision(6).

Despite dissatisfaction, stroke survivors identified a number of services and programs that they considered valuable after discharge(1). Follow up and phone access to an allied health professional ranked highly, as well as self management, education and exercise classes. For carers, support groups and counselling were also considered important services. In a UK study, lack of access to therapy post discharge was a major source of dissatisfaction(25).

2. STROKE SPECIFIC SERVICES

Stroke rehabilitation services delivered in the home have been shown to have numerous benefits for stroke survivors(8, 30, 31). In particular early supported discharge has been shown in a meta analysis to reduce disability, length of stay and costs of care(30). While most rehabilitation services delivered in the home occur in the early post stroke period, later home based rehabilitation services have been shown to result in benefits for function, continuity of care, carer respite and emotional support(2). Qualitative investigations suggest that home based rehabilitation services have the potential to be more aligned with the contextual and unique needs of each individual stroke survivor(2, 22, 32). Despite these benefits stroke specific community rehabilitation services are not widely available(22).

A number of novel interventions have been trialled to address the needs of stroke survivors after discharge. These have included community based multidisciplinary stroke teams(8, 31, 33), telephone follow up services(34) and nurse led case management models(35, 36). Community based rehabilitation models have varied in their target population, the timing and duration of interventions and the outcome measures used(37). Various models have had positive outcomes for functional, emotional support, reducing carer strain and providing information and practical assistance(8, 31, 33). Others have been found to have no benefits with respect to function or health service utilisation(35). In the instance of a specialist nurse intervention, despite generally negative trial results qualitative analysis was able to highlight positive outcomes and experiences resulting from some of the “less tangible” aspects of care(2). Recently, a Home Follow Up (HFU) Program was developed and trialled for a Tasmanian stroke population(34). The program principally involved telephone contact at set time frames post discharge, in conjunction with information provision and linkage with services. The study found that most stroke survivors perceived the service as helpful, providing a clear identification of a contact and referral points. However, several participants

did not recall the intervention and the authors concluded that access to and timeliness of community services was concerning.

The Classic program was another novel intervention that combined exercise, education and social support carried out once a week for seven weeks in a group environment(38, 39). This study found trends towards improved health related quality of life and physical functioning but was limited by a small sample size. This program is characteristic of well established and validated models which are the cornerstone of community based management for other chronic disease populations such as cardiovascular and pulmonary disease. In a qualitative analysis participants derived motivational, social support and self efficacy benefits(39). A similar program “Master Stroke” encompassing secondary stroke prevention and aligned with chronic disease management principles has been piloted in Newcastle with promising early trends for improvements in function, fitness, quality of life and participant satisfaction(14).

3. EXERCISE

Many of the services described above have emphasised an exercise component. There is high quality evidence that exercise can improve functional and walking capabilities after stroke(40). Contrary to longstanding and commonly held beliefs, growing evidence is emerging that these physical and functional benefits brought about by exercise can occur even years after stroke(7, 9). There is empirical support that engagement in exercise interventions in a chronic stroke population can also increase satisfaction and participation levels(10, 11, 13). There is a further rationale for promoting exercise in this population. Deconditioning brought about by mobility impairments associated with stroke increases the risk of cardiovascular disease, osteoporosis, falls and fractures(7, 11, 41). Exercise is an essential component in modifying and managing risk factors for cardiovascular disease(23).

Despite this evidence and recognition by stroke survivors of the value of exercise, long term participation in exercise after stroke is extremely low(15). Exercise programs for community based stroke survivors are not routinely available and there is very limited uptake of those that do exist(15). Trials cite poor sustainability beyond the intervention period and poor carryover of functional gains after the intervention(15). The most effective strategies to facilitate stroke survivor participation in community based exercise programs are not well known. A recent study of stroke survivor’s experiences in Scotland found that participants who accessed public leisure facilities did so only with encouragement from their health care professional or carer(42). The vast majority of exercise programs in trials are carried out by physiotherapists. A recent Australian study that recruited community dwelling stroke participants to an exercise program through Stroke Recovery Clubs struggled to obtain recruitment targets and reported low compliance and sustainability(15). By contrast several of the previous programs described, such as the Classic and Master Stroke have reported high attendance, citing the motivational benefits of a group setting(14, 38, 39).

The most common barriers to accessing exercise services reported by stroke survivors include cost, awareness of programs/centres, transport and knowledge of how to exercise(43). In theory many of these barriers are modifiable through flexible services, responsive to stroke survivor needs. Whether the elimination of these barriers increases

uptake of exercise in a chronic stroke population is unknown. Health professional's beliefs about stroke survivors capabilities has also been shown to impact on the delivery of community based rehabilitation services(25, 44). Another barrier described in accessing community based services is a dissonance between health professionals and stroke survivor's definitions of recovery. One viewpoint describes a limitation to recovery and need for acceptance of disability verses the goal of resumption of meaningful activities within the stroke survivors own social context(2, 25).

4. PARTICIPATION

Related to the objective of engagement in exercise and improving function is the concept of participation. Multiple factors including reduced mobility, transport issues, reduced confidence, fear and environmental access issues are all limiting factors to community participation after stroke(15, 29). Even after a mild stroke evidence highlights reduced rates of participation and high social isolation(17). Restriction in both leisure and social activities after stroke has been well documented(20). Engagement in leisure activities has been shown to be an independent predictor of well being in this population(20, 45). Participating in meaningful activities after stroke increases life satisfaction and is considered an important determinant of health related quality of life(21).

Recommendations from studies of follow up services after stroke argue the need for strategies to stimulate return to social and leisure activities(19, 20, 46, 47). Targeted occupational therapy interventions have been shown to increase leisure participation after stroke(47). Despite this interventions to facilitate increased participation have largely fallen outside the domain of current rehabilitation models. Exercise interventions that improve mobility, carried out in a controlled environment, may not counter some of the other barriers associated with participation(15). There is evidence that supported journeys with a therapist can increase community access after stroke(48). However there is evidence to suggest that in practice even amongst community rehabilitation teams, adherence to evidence based recommendations for participation interventions such as outdoor journeys, occurs for as little as 17% of stroke survivors(49).

5. LONG TERM SUPPORT MODELS AFTER STROKE

There is no scarcity of literature examining the impact of stroke on survivors and carers. The process of adjustment after stroke has been described as long and slow(2). The early post discharge period is reported consistently by stroke survivors and carers as a difficult time(22). The literature suggests that services as currently configured do not adequately reflect stroke survivors experiences of trying to adjust to the effects of stroke and many studies argue that satisfactory longer term care is lacking(1-3). A picture of poorly coordinated services has also been reported, contributing to a situation where stroke survivors often "fall between the gaps" of service provision(2, 5). Studies investigating the impact of stroke commonly draw out implications for service delivery, but relatively few have focused on community services themselves(2).

RESEARCH QUESTION

The primary aim of this study was to describe stroke survivors and carers experiences of services after discharge in a rural Australian community and explore the role of these services as an enabler or barrier to exercise and community participation.

The study aimed to gauge community and exercise participation levels, service utilisation and to examine any relationships between these factors. The intention was that insights gained will assist with the development of future local service models to support the long term needs of stroke survivors.

METHOD

STUDY DESIGN

A qualitative study design underpinned by a post positivist theoretical perspective was utilised. A post positivist approach asserts that reality is constructed by individuals and is influenced by context(50). The interactive process between the researcher and participants emphasises meaning and understanding of the phenomena under examination and strives to establish evidence that is valid for the existence of the phenomena.

SAMPLING

Eight semi structured, in depth interviews were conducted. Participants for interviews were recruited using convenience sampling. Potential participants were identified from a medical record audit of stroke admissions to a rural hospital over a twelve month period. Individuals discharged to an aged care facility, who were since deceased or who resided outside the local area and were travelling at the time of stroke were excluded. Thirteen potential participants were identified, contacted by phone and invited to participate. From this sample nine stroke survivors volunteered to take part in an interview. One participant later withdrew due to health reasons. The interviews took place at either the stroke survivors home or at the local hospital according to the participant's preference. The time since stroke for participants ranged from 5 – 12 months.

Subsequently, purposive sampling was used to recruit participants for a focus group. The local stroke recovery group and a local community stroke exercise group were approached in person and eight participants, six stroke survivors and two carers were recruited. The focus group took place in a meeting room at the local hospital. One participant recruited in this manner took part in an interview as they were unable to attend at the time of the focus group. This population was deliberately chosen to capture a greater range of experiences from a more chronic stroke population. The time since stroke in this group varied from two to 11 years.

All participants who expressed an interest in taking part in the study were provided with a letter and participant information sheet outlining the details of the research project (Appendix 1-2). All participants completed a consent form at the time of the interview or focus group(Appendix 3).

Participants with communication or cognitive impairments were not excluded from the study. Several participants with expressive aphasia participated in the research project. In one instance, the participant's carer contributed to the focus group with the stroke survivor present and another stroke survivor was able to write comments as well as express agreement or disagreement with comments made by other participants. This was documented in the transcripts.

DATA COLLECTION AND ANALYSIS

All data was recorded on an audio device and transcribed verbatim by the principal researcher. The interview duration ranged from 35 minutes to an hour and the focus group duration was 1 hour 10 minutes.

Prior to the interviews, participants were asked to complete a UAB Life Space Assessment tool (Appendix 4) which provides a profile of the stroke survivor's mobility within their home and community(51). At the onset of each interview basic demographic and mobility characteristics were obtained. Open ended questions were formulated to gauge and explore participant's experiences of services after discharge. This included any positive or negative aspects they encountered plus any services they felt would have been useful to them. Participants were asked about their involvement in exercise, social and leisure pursuits and about the factors that enabled or prevented participation. Finally participants were asked to comment on the aspects of a long term stroke support program that would be most essential to them. A full list of interview questions can be found in Appendix 5.

REFLEXIVITY

The principal researcher on this project is a physiotherapist and the project was funded as part of the HETI Rural Directorate Research Capacity Building Program in 2010. The researcher had previously been involved with a community based rehabilitation service which she perceived had strong benefits for stroke survivors. The research question evolved to explore the varied and collective experiences of this population in a geographically discrete area with a population of around 18 000. The study took place in a rural Australian community with an ASGC remoteness classification of "Inner regional" and ARIA classification "Accessible".

The principal researcher had a previous service provider relationship with 14 of the 16 study participants. Therefore measures were taken to reduce coercion and improve rigour. All initial approaches to recruit participants were made by an impartial third party. Participants were informed at recruitment as to the identity of the principal researcher. Data was coded independently by the principal researcher and an independent coder and themes derived from the data were checked for inter rater consistency. The sampling method was able to achieve data saturation.

ETHICS APPROVAL

Ethics approval was granted by the North Coast Area Health Service Human Research Ethics Committee (NCAHS HREC) on the 11th February 2011, with Site Specific Assessment approval received on the 14th March 2011.

FINDINGS

Fourteen stroke survivors and two carers participated in the interviews and focus group. The sample characteristics of this population are outlined in Table 1.

Table 1: Sample Characteristics

Criteria	N (14)
Age:	
< 60	3
61-70	4
71-80	6
80+	1
Gender:	
Male	5
Female	9
Aboriginal or Torres Strait Islander:	1
Time since Stroke:	
< 6months	1
6-12 months	7
1-2 years	1
> 2 years	5
Length of hospital stay:	
< 1 month	2
1-3 months	8
> 3 months	4
Living Situation:	
Alone	4
With partner or family member	10
Dysphasia:	
Severe difficulty with expression	2
Minor to Moderate difficulty with expression	2
No communication problems	10
Self Care:	
Independent *	9
< 50% assistance	3
> 50% assistance	2
Mobility:	
Requiring no aid	5
Requiring aids but no assistance	8
Requiring aid and assistance	1
UAB Life Space Assessment**:	
< 20	2
21-30	1
31-40	5
41-50	2
50 +	4

* Independent if able to complete with use of equipment and assistive devices

** From Peel C et al, Assessing Mobility in Older Adults: The UAB Study of Aging Life-Space Assessment, Physical Therapy, 85(10), 2005.
Number = total score over the last week

Four main themes emerged from analysis of the data (Table 2).

Table 2: Major Themes

Theme 1	<i>I suppose it depends who you are dealing with:</i> The lucky dip of service provision
Theme 2	<i>Getting back in the usual normal world:</i> Enablers to exercise and participation
Theme 3	<i>We're all in the same boat:</i> The benefits of group interaction
Theme 4	<i>There's obviously no coordination:</i> Barriers on the long road to recovery

Theme 1: *I suppose it depends who you are dealing with* - The lucky dip of service provision

Participant's experiences of services after discharge were polarised. Within the same rural area, there was large variability in the amount, type and satisfaction with services. One group of participants expressed an overwhelming lack of any services or help after discharge.

"I was just left without any help whatsoever." (FG participant #1)

"We survived... we battled along. " (Interview #6)

"There was no follow up." (FG participant #2)

"I didn't know it was available actually...I wrote a letter to the administrator of the hospital and she's the one who told me about physio." (Interview #6)

"He (carer) didn't have a clue what to do... now we survived... the poor fellow must have been frantic, he didn't know where to get help."(FG participant #1)

"She couldn't get in to the bathtub...she couldn't get into the shower...I stuck her in a chair in the middle of the bathroom and we did that for 6 months." (FG participant #3)

For this group, seeking out information on services in the community was usually through concerted efforts of family members or by pure luck or chance.

"My neighbour was down at the community centre and they saw this thing about a stroke group and thought that I should go along" (FG participant #7)

"I heard about it from someone at the pool" (FG participant #1)

These types of responses echo previous studies that have exposed "the poor deal" generally afforded to stroke survivors(1). In contrast, numerous participants described benefits and positive satisfaction with services they received after discharge. In particular participants described their experience of a Transitional Aged Care Program (TACP) and a local Council run program called "Up and About". Six and two participants respectively had been exposed to these programs, with a further participant having been involved with both. The duration

of the intervention for these programs ranged from 5 to 18 weeks. All participants expressed benefits in the areas of practical assistance, getting them out in the community and general satisfaction with the care received.

"I didn't really know what to expect. Really I didn't expect it to be so good a help." (Interview #8)

"The fact is that most people don't know it exists and it's wonderful to think that there is these things." (Interview #2)

One participant described receiving almost too much assistance after discharge. This was associated with a thorough discharge planning process from the hospital that involved multiple community based service providers.

"They all came to us when we got home, to the point that I thought it was happening quicker than I could control" (FG participant #5)

There was only one participant who felt that they didn't require any further external supports after discharge from a rehabilitation hospital.

Theme 2: Getting back in the usual normal world - Enablers to participation

Participants described the aspects of services they found useful or that they felt would have been of benefit to them. Participants enrolled in the Transitional Aged Care (TACP) and "Up and About" programs described the benefits of receiving practical assistance. Participants described practical assistance that included help with showering, dressing, cooking, transport, catheter management, equipment provision, home modifications, domestic assistance, personal alarm systems, carer support and respite. Practical assistance with housework and transport was viewed as reducing carer strain.

"It took a bit of pressure off my carer... I didn't have to rely on them so much... it probably kept us together." (Interview #3)

"Last year when (Stroke Survivor) did the "Up and About" program they got me (carer) into some counselling and stuff... they thought I could do with it... because I moved country and it was such a big change for me and I lost all my friends." (FG participant #3)

"It was of great benefit to my husband because he's not used to doing housework and he had to learn to do the cooking... I think they gave him the confidence to be able to help me with the cooking and with dressing me and things." (Interview #8)

"TACP told (carer) about the carer's allowance and that's very important...because a lot of people don't know about it."(Interview #9)

In addition, the nature of assistance with activities such as showering and kitchen duties was seen as enabling enhanced function and independence for the stroke survivor. They described individualised solutions to practical problems.

"they (TACP) worked with the shower... they put a black mark on the taps ... So I can turn it properly to that spot... and only have to adjust it a bit..." (Interview #3)

"I didn't think I'd be able to do much but I could peel the vegetables. They showed me how to use a different peeler and move about in the kitchen." (Interview #8)

"... (She) cut up the front of the bra and put elastic in the back and Velcro at the front so now I can do it up myself." (Interview #9)

Participants described these services as providing opportunities for getting out and about and participating in the community. They described various activities they had been engaged in such as shopping and golf and the benefits derived from this. Getting out and about improved feelings of confidence and several participants remarked that having an external presence to encourage and force them out and about meant they found themselves back in the community faster than they had thought themselves capable.

"It proved that I could get on the golf course. I wouldn't have tried it otherwise.... I thought I was pretty good." (Interview #3)

"Well it was a chance to get out again because I hadn't been out for months and I could do my little bit of shopping and we could have coffee and it felt like you were back in the usual normal world" (Interview #8)

"Then the council got this Up and About program and they came and asked me what I liked doing and that's how we got these games happening." (FG participant #7)

"We went to the shopping centres, we went to the stroke support group, we went to the library and we went to Bunnings... so I think wherever I wanted to go I was taken."(Interview #9)

"Because I know meself I wouldn't have walked up there without them" (Interview #1)

Participants involved with these services also described general satisfaction with the care they received and five participants described how the service had positively impacted on their confidence and motivation.

"I'm much more confident. I wasn't confident doing anything before. I was just sort of a bit depressed thinking oh well I'm buggered but you're not necessarily buggered are you...there's still a bit to go." (Interview #3)

"It was a very personable service... it just gives you the will to keep going." (Interview #2)

"They would come and see me at home and you know sit down and talk to me and it was the little things." (Interview #2)

Theme 3: We're all in the same boat - The benefits of group interaction

There was widespread consensus among participants about the importance of exercising after a stroke. Eleven out of fourteen participants had been involved in a community stroke exercise group led by a physiotherapist in their local area. Eight continued to take part in this weekly exercise group at the local hospital. Those who had discontinued with the group cited reasons such as older age, "laziness" and managing to do exercises more independently at home. One participant described feeling out of place because of her older age. Another participant with mild residual impairment described participating in community based yoga and walking. Several participants reported doing hydrotherapy after discharge and one participant reported doing up to four hours of exercise daily. One participant

described involvement in cardiac rehabilitation program after discharge with stroke and another described referral to a chronic lung disease service. Most of these had come through interaction with allied health professionals and particularly physiotherapists.

Numerous participants reported the difficulties with maintaining motivation to exercise over a longer term on their own. Participants derived enormous benefits from exercising in a group setting with other stroke survivors who were “in the same boat”. These benefits included companionship and social support, motivation, improved mood and encouragement brought about by “an atmosphere of hope”. Opportunities for information exchange and knowledge acquisition in an informal setting were also mentioned. Participants described benefits of the relationship with the physiotherapist in terms of guidance with doing exercises correctly, goal setting and positive reinforcement.

“There’s no one the same and I don’t know everyone’s story and they’re all at different places in their recovery but it’s good if you can help each other and encourage each other” (Interview #6)

“I just feel that after being up there and doing the exercises that I’ve achieved something and I always have a good night’s sleep so I think that says something.” (Interview #9)

“Makes you feel better that you’re not by yourself. I look around and think I’m very lucky I didn’t have a stroke like some of them” (Interview #1)

“It gets me out of my laziness.”(Interview #3)

Participants described the profound impact of stroke on the social sphere of their life and the importance of groups and opportunities for socialisation.

“Your whole world changes... All the people you related to previously are running their own lives and your whole social world contracts down to SS and me.”(FG participant #5)

“It’s an important aspect of your life and if you ignore it sooner or later you are just going to withdraw crawl into a box and that’s it.” (FG participant #5)

Participants described various socialisation preferences from stroke specific support groups, to families and groups found through community organisations that engaged in activities participant’s enjoyed.

“You know because I’ve slowed down a lot I kind of need something each day to motivate me to do something.” (FG participant #7)

“I find when I’m in a group with other people who have had a stroke I feel at ease... just because my hand shakes they won’t look at it and think what’s her problem sort of thing... it doesn’t matter if I spill a little bit of cake or tea on my lap.” (Interview #9)

Theme 4: There’s obviously no coordination - Barriers on the long road to recovery

Coordination or case management was described by a number of participants as being essential to their concept of a stroke service. A lack of coordination was associated with negative experiences and dissatisfaction and also meant individuals missed out on knowing what services were available. Participants described several other barriers to accessing

services. The TACP and 'Up and About' programs described in this study are both aged care initiatives. The age criteria for entry to these programs is 70 years or over. A younger age at the time of stroke was one barrier echoed by numerous participants. This was particularly evident for those less than 60 years of age at time of stroke. Participants expressed that the provision of information by health professionals in the form of contact numbers or websites was often not an enabler to accessing services. Difficulties included accessing technology, sifting for relevant information and negotiating and justifying needs with service providers. Poor carer support and training was also highlighted along with assumptions from health providers that the carer or changes in roles should be intuitive.

"they would go here's a website... and I'm sitting here thinking my computer's in another country and my sister's is in Moree and my brother's is in Brisbane and you are giving me a website"
(FG participant #3)

There was extensive agreement among participants that their mobility, function and independence had all improved since they returned home from hospital. Both carers described how stroke survivors were more independent now, several years after discharge. They described this improvement as a gradual process, brought about by time and effort but particularly effort. Two participants described how their experience of recovery had differed from the expectations of health professionals they had encountered.

"Personally I'm not academically qualified but personally from our experience the business of putting a time frame on recovery of individual things is not our experience. It's not the case" (FG participant #5)

"(Health professional) If you don't get this in the first month or in the first three months then you'll never get it" (FG participant #3)

Tables 3 and 4 outline the factors identified by SS and their carers as enablers and barriers to participation and exercise.

Table 3: Enablers to exercise and community participation

Service	Components	Benefits
1) Coordination Case Management	* Referral to services * Single point of contact * Information distribution * Advocacy	→ Improved satisfaction with services Improved access to services
2) Community based rehabilitation and transition services	* Practical Assistance * Therapy * Opportunities for getting out in the community * Carer Support	→ Improved self efficacy Improvements in function and Independence Earlier community integration Reduce carer strain Improved satisfaction with services
3) Community Based Exercise Groups	* Group setting * Stroke specific * Goal setting * Relationship with Health professional * Transport	→ Increased confidence Social support Encouragement Motivation Improved Mood Knowledge acquisition

Table 4: Barriers to exercise and community participation

- Lack of coordination “the lucky dip”
 - Availability of appropriate services
 - Exercise Programs
 - Community and transitional rehabilitation programs
 - Younger age at time of stroke (less than 60 years)
 - Lack of encouragement
 - Perceptions of Health Professionals
 - Personal Characteristics eg “laziness”
-

DISCUSSION

This study aimed to increase our understanding of stroke survivors lived experiences of services and how these experiences related to engagement in exercise and community participation. Three distinct service types were revealed in the findings: a stroke specific exercise group, community based aged care rehabilitation programs and case management or coordination.

COMMUNITY BASED AGED CARE REHABILITATION SERVICES

Previous research has highlighted the benefits of stroke specific community based rehabilitation teams(2, 8, 30, 31, 33). The timing, duration and emphasis of these programs have varied. The TACP program described in this study is a generic aged care rehabilitation program. For a stroke population this program could fit into two categories of community based rehabilitation as described by Geddes and colleagues(2001) early supported discharge and post discharge rehabilitation providing additional rehabilitation and aiming for seamless transfer from hospital to home(37). The “Up and About” program described in this study fitted a model of late community rehabilitation providing patients with the opportunity of an autonomous service, unconnected with hospital or GP referral.

Participants in this study described an overwhelmingly positive experience with these types of services. These findings support existing literature about the benefits of home based rehabilitation services after stroke(40). In this study community based coordinated services delivered in the transition period after discharge from hospital provided practical assistance which enhanced independence for the stroke survivor and reduced carer strain; provided opportunities for getting out in the community which improved confidence with accessing the community and enabled earlier community integration. In this study community based coordinated services provided later after stroke provided socialisation opportunities and carer support. The “Up and About” service described was provided without any health professional involvement. An implication of this may be that effective interventions can potentially be provided over the long term to SS even if there are limited health resources.

COORDINATION

Case management or coordination was viewed as a central component of a stroke service by participants. In particular, instances where coordination was absent led to the greatest perception of dissatisfaction. Previous research investigating coordination or case management models after stroke have reported conflicting findings(22). Aside from having a negative experience, a lack of coordination often meant the SS just missed out on knowing what might be available. This finding is consistent with the literature pertaining to experiences of services after stroke(1, 25). The findings of this study suggest that referral to a coordinator has a pivotal role in improving access to services after stroke and that this role would need to include referrals, information distribution and advocacy. The findings of this study suggest that coordination alone would not be sufficient to meet SS needs but play an essential role in liaising with responsive community services.

STROKE SPECIFIC EXERCISE GROUP

Research supporting the benefits of stroke survivors engaging in long term exercise is compelling(7-14). SS report a desire for exercise opportunities and yet research to date highlights the challenges of recruitment and sustainability(15). This study supports the notion that exercise opportunities post stroke are perceived as highly important by SS. This study also supports that of Reed and colleagues (2010) who found that a group exercise intervention increased confidence, provided social support, encouragement, opportunities for socialisation and knowledge acquisition among SS(39). Several programs have started to emerge in the literature that support the potential benefits of a stroke exercise and education scheme delivered using well established Chronic Disease Management principles(14, 38, 52). This study supports the early engagement with physiotherapists and other health professionals after discharge as having a positive impact on recruitment to exercise interventions.

ENABLERS AND BARRIERS

Addressing long term exercise and community participation after stroke is a complex issue. Despite indications for better long term support models after stroke, little is known about what can be achieved practically in the community(39). Several existing services described above were perceived by stroke survivors as enabling participation. A number of elements within these services emerged in the data that may have promoted participation. These included encouragement, information provision regarding the existence of social and exercise groups, facilitating transport and being accompanied on outings by a therapist or support worker. The existing literature suggests that encouragement and repeated verbal instructions alone are ineffective at increasing physical activity levels after stroke(53) whereas a combination of escorted journeys and provision of information is effective at increasing outdoor mobility after stroke(48).

A strategy for improving exercise uptake rates after stroke may be early referral after discharge to stroke specific groups led by health professionals utilising chronic disease management principles. The positive social benefits of these groups may have carry over

benefits for transition to community based options. Further research that looks at multiple sites providing such schemes is recommended.

One of the biggest barriers for accessing a number of community services was a younger age. The community based rehabilitation programs described in this study are both aged care programs with an entry criteria of 70 years or older. Given the potential benefits and in view of the profound disability often experienced by younger stroke survivors and the lack of equivalent services for people under 60 years, this warrants further consideration of entry criteria for such programs by policy makers.

STRENGTHS AND LIMITATIONS

One advantage of this qualitative study design is that benefits described by participants in terms of increased independence would have been unlikely to have been detected using typical quantitative measures. Another advantage of these findings is that the participants positive experiences of community based rehabilitation services comes from two generic programs and not a stroke specific rehabilitation service. This has implications for being more accessible to a greater number of stroke survivors, particularly in rural areas. To the author's knowledge limited research has been carried out that specifically explores stroke survivors experiences of transitional aged care programs which are now widely available in Australia.

There are several limitations to these findings. Although the characteristics of this population are heterogeneous, their experience of the programs described may not be representative of stroke survivors in general. Generic community based rehabilitation programs have varying structures, resources and geographic challenges which may limit the transferability of findings. In addition research has highlighted the gap between evidence based recommendations and actual practice in delivering stroke interventions, which has been evident amongst community rehabilitation teams.

The principal researcher undertaking this study had been involved in delivering some of the interventions described and had prior knowledge of many of the participants. This familiarity served to put participants at ease during the interview process and enabled in depth exploration of their experiences. However this may also have prevented participants from discussing some of the more negative aspects of the various interventions and prevented discovery of certain assumptions that went unexamined. This may also have contributed to self selection bias among participants making findings less generalisable.

CONCLUSIONS

The experience of stroke survivors demonstrates that community health and support services can enable exercise and community participation after stroke. However their experiences highlight that there are a number of barriers to accessing these services. This study has demonstrated that key ingredients for a long term support model for stroke include coordination, increased opportunities for exercise programs and access to community based rehabilitation programs. The role of coordination is to improve access to services. Community based rehabilitation early after discharge has the potential to enhance

stroke survivors feelings of independence, self confidence and satisfaction through the provision of practical assistance and supported community participation. Community based rehabilitation and support services should consider interventions that promote opportunities for social and community participation. Providing encouragement, information, facilitating transport and accompanying stroke survivors on outings are interventions which may enhance exercise and community participation after stroke. Early referral after discharge to stroke exercise groups led by health professionals is a potential strategy for increasing exercise participation in this population.

RECOMMENDATIONS

- Further research into the experiences of stroke survivors that have been involved with transitional aged care programs (TACP) and generic community based rehabilitation services in other regions.
- Further investigation into methods of enabling increased exercise and community participation after stroke.
- Improved opportunities for access to coordinated transitional and community based rehabilitation services for younger stroke survivors with significant disability.
- Development of comprehensive assessment tools and educational programs for generic community and aged care rehabilitation services to improve adherence to evidence based recommendations for stroke.
- More widespread implementation and evaluation of community based exercise programs for stroke in health care settings using a chronic disease management model.
- Inclusion of stroke survivors in existing community chronic disease management programs

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APPENDICES

Appendix 1

Participant Information Sheet

Appendix 2

Letter to Participants

Appendix 3

Consent Form

Appendix 4

UAB Life Space Assessment tool

Appendix 5

Interview Questions

APPENDIX 1



Participant Information Sheet

Barriers and Enablers to Physical Activity and Community Participation after Stroke in a Rural Area: the role of Community Health and Support Services

You are invited to participate in a study looking at the experiences of people and their carers living in the Clarence Valley who have had a stroke. The study will involve discussing:

- your ability to access your local community, participate in physical activity and leisure pursuits that are important to you
- the supports that have enabled you to increase your capacity to participate in physical activity and leisure pursuits important to you
- the barriers that have prevented you from engaging in physical activity and leisure pursuits that are important to you
- your experiences of community health services and other local services that you or your carer have received since your stroke

The study is being conducted by Amanda Tutty, physiotherapist for Grafton Base Hospital. Amanda is a novice researcher participating in a program run by CETI – Clinical Education and Training Institute Rural Division.

Before you decide whether or not to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information to assist you in your decision.

1. ‘What is the purpose of this study?’

The purpose of the study is to provide information to health service providers about the experiences and journey of stroke survivors and their carers after they leave hospital. The study wants to explore the supports and barriers you have encountered in trying to achieving your goals.

2. ‘Why have I been invited to participate in this study?’

Stroke survivors and their carers are being invited to participate in the project.

3. ‘What if I don’t want to participate in this study or if I want to withdraw later?’

Participation in this study is voluntary. You are free to decide whether or not you would like to participate. If you decide not to participate it will not affect your ability to receive any health or community services now or in the future.

You do not have to provide a reason if you choose not to participate and if you wish to withdraw from the study once it has started, you can do so at any time without having to give an explanation.

4. ‘What does this study involve?’

If you agree to participate, you will be asked to take part in a focus group. The focus group will be recorded on an audio device. The focus group will last about 1 hour. Your carer or a family member is invited to participate in the interview/focus group with you.

Prior to the focus group you will be asked to complete a one page questionnaire that asks you about your journeys outside of your home in the last month. A carer or another person can assist you to complete this form.

5. ‘Will I benefit from this study?’

This study aims to improve our knowledge of the experiences and needs of stroke survivors in the Clarence Valley.

There are no likely immediate benefits to participating in the study however you and other people living with stroke may benefit in the future from improved services to people living in the community with stroke.

6. ‘Are there risks to me taking part in this study?’

There is no known or likely risk to you if you do agree to participate in this study.

7. ‘How will my confidentiality be protected?’

Any information collected from you will be added to the data collected from all the participants of the study and will be presented in a way so that you cannot be identified.

Only the researcher will have access to your details and the content of the information that will be held securely at Grafton Base Hospital.

8. ‘What will happen with the results?’

It is intended that the results of the research will be written up into a paper that may be used for the following purposes:

- publish results in a health journal
- present results at a conference or other professional forum
- discuss results with other health service providers in the Area Health Service
- present results to CETI – Rural Division

9. ‘What happens if I suffer harm, injury or complications as a result of this study?’

If you suffer any stress as a result of participating in the study you should contact the researcher as soon as possible. Assistance in providing appropriate care and/or counselling will be provided.

10. ‘How is this study being paid for?’

The research is being funded by CETI – Clinical Education and Training Rural Division as part of the Rural Research Capacity Building Program.

11. ‘Will taking part in this study cost me anything, and will I be paid?’

Participation in this study will not cost you anything apart from your time and effort to attend the interview/focus group.

12. ‘What should I do if I want to discuss this study further before I decide?’

When you read this information sheet, the researcher is available to discuss with you any further questions you may have. Please do not hesitate to contact her.

Amanda Tutty
Physiotherapy - Grafton Base Hospital
Arthur Street
Grafton NSW 2460
Tel 02 6640 2235 / 0402 624 526

13. ‘Who should I contact if I have concerns about the conduct of this study?’

This study has been approved by the North Coast Area health Service Research Ethics Committee. If you have any concerns about the conduct of this study please contact the committee through:

Research Ethics Officer
NCAHS Human Research Ethics Committee
PO Box 126
Port Macquarie NSW 2444
Telephone: (02) 6588 2941 Fax: (02) 6588 2942
Email: EthicsNCAHS@ncahs.health.nsw.gov.au

Thank you for your time in considering participating in this study.

The information sheet is for you to keep.

APPENDIX 2



Amanda Tutty
Grafton Community Health – Aruma
PO Box 368
Grafton NSW 2460
Tel 02 6641 8280 / 0438 356 343

DATE

Dear,

Thank you for expressing an interest in participating in a research project that is looking at the experiences of stroke survivors and their carers. The project aims to explore the barriers and enablers to physical activity and community participation after stroke in a rural area and to explore the role of health and community support services.

Enclosed is a Participant Information Sheet. Please take the time to read it as it will explain everything to you.

If you decide not to participate or withdraw from the project you do not have to give a reason.

The project is being funded by CETI – Clinical Education and Training Institute as part of the Rural Research Capacity Building Program.

I will contact you soon by phone to answer any questions you may have and to confirm the date and time for the interview.

Please do not hesitate to contact me at any stage if you have questions.

Yours sincerely,

Amanda Tutty
Physiotherapist

APPENDIX 3



CONSENT FORM

Research Project:

Barriers and Enablers to Physical Activity and Community Participation after Stroke in a Rural Area: the role of Community Health and Support Services

I (your name)
have had the purpose of the research and any related benefits and risks explained to me by the researcher and I have a copy of the Participant Information Sheet.

I am aware that the research will involve:

- Participating in an interview with the researcher that may last 1 -2 hours. The interview will be held at at a time and date that is convenient to both parties.
- Completing a one page form about my journeys outside of the house

I understand that the interview/focus group will be recorded on an audio device and that my personal information will remain confidential at all times.

I understand that I am free to withdraw from the study at any time and I do not have to give a reason. If I do withdraw this will not affect my relationship with the researcher or with the healthcare organisation where the study takes place, nor will it affect any health care treatment or services that I receive now or in the future.

I have read and understood the written explanation provided to me on the participation information sheet and have been given a copy to keep.

I am aware of who to contact if I have any complaints about the conduct of the research and that these contact details can be found on the participant information sheet.

I agree to participate in the above named study

Name: (Print)

Signature:Date:

APPENDIX 4

UAB Life-Space Assessment™

ID Number			Date				
LIFE-SPACE LEVEL			FREQUENCY			INDEPENDENCE	
During the past week, have you been to . . .			How often did you get there? <i>(please circle)</i>			Did you use aids/ equipment? Did you need help from another person?	
<i>Life-Space Level 1. . .</i> Other rooms of your home besides the room where you sleep?	Yes	No	Less than 1 /week	1-3 times /week	4-6 times /week	Daily	
<i>Life-Space Level 2. . .</i> An area outside your home such as your porch, deck or patio, hallway (of an apartment building) or garage, in your own yard or driveway?	Yes	No	Less than 1 /week	1-3 times /week	4-6 times /week	Daily	
<i>Life-Space Level 3. . .</i> Places in your neighbourhood, other than your own yard or apartment building?	Yes	No	Less than 1 /week	1-3 times /week	4-6 times /week	Daily	
<i>Life-Space Level 4. . .</i> Places outside your neighbourhood, but within your town?	Yes	No	Less than 1 /week	1-3 times /week	4-6 times /week	Daily	
<i>Life-Space Level 5. . .</i> Places outside your town?	Yes	No	Less than 1 /week	1-3 times /week	4-6 times /week	Daily	

Source:

1. Baker et al., (2003). Measuring life-space mobility in community-dwelling older adults. *Journal of the American Geriatrics Society (JAGS)*, 51, 1610-1614.
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APPENDIX 5



Interview / Focus Group Questions

BASELINE CHARACTERISTICS

Age and gender

Time since stroke?

Length of hospital stay?

Attended rehabilitation? Inpatient? Home based?

Living arrangements? (alone, carer etc)

Functional ability (mobility – aid used? Assistance required? Distance? & self care (shower / dressing) – independence / assistance required?

SERVICES AFTER DISCHARGE

After your stroke, did you go home from hospital with any services or follow up?

Can you describe to me the type of assistance or help you received?

If you didn't have any services OR with the services you had....was there any other assistance or information that you felt you needed after you got home from hospital? (Were you able to get it? / How did you find it?)

Do you feel that you got adequate support after you got home from hospital?

If yes, what aspects of that support were most beneficial / useful in helping you with the process of adjusting to life after a stroke?

If not, what do you think would have helped you with the process of adjusting to life after a stroke?

SERVICES NOW

Are there any other services or follow up you currently have or have had since your stroke that we haven't talked about? How was this arranged?

What have you found to be helpful / beneficial about these services? Is there anything in particular about these services that has helped you to get your life back on track?

EXERCISE / PHYSICAL ACTIVITY

What were your attitudes and feelings about exercise before you had a stroke? Did you do any regular exercise?

What kind of exercise do you do now? Describe – last 2 weeks?

What were the main reasons you had for doing (above mentioned) exercise?

If don't exercise, is it something you would like the opportunity to do?

What are some of the challenges you face in being able to exercise?

SOCIAL / LEISURE / WORK PARTICIPATION

Before the interview you filled out a piece of paper that asked you about how you spend some of your time...

What types of leisure or social activities do you currently engage in?

After your stroke, how did you get involved with these?

What are some of the challenges you face in being able to participate in those leisure /social activities you wish to?

PARTICIPATION AND SERVICES

Have any of the (above) services you received helped you to – participate in exercise / leisure/social activities? How?

FINAL THOUGHT

If I was given the job of putting together a service to try and meet the needs of people after they have had a stroke - what suggestions or advice would you give to me from your experiences? What would be essential to this service in your opinion?