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Utilising co-design to improve outpatient neurological care in a rural setting

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Cover Page Footnote

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Utilising co-design to improve outpatient neurological care in a rural setting

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Abstract

It has been identified that the physiotherapy needs of patients with central neurological conditions are specific and that this cohort are generally under-serviced in rural and remote areas in Australia. A quality improvement project was undertaken to improve patient experience in outpatient physiotherapy services in Tasmania, facilitating increased self-efficacy and quality of life, in patients with central chronic neurological conditions. An experience-based co-design approach was utilised, involving past and current patients as well as physiotherapy staff in the project design, data collection, analysis and evaluation phases. The results suggest that timely access to care and goal achievement are common areas of need across both patient and staff cohorts. Patients also identified that shared-decision making is important for improving patient experience and staff were generally unclear on what services were available. The findings from this study demonstrate the importance of including patients and staff in the health service improvement process.

Keywords

Patient experience, physiotherapy, co-design, rural health, neurological care, engagement

Introduction

Healthcare in Australia faces the challenge of delivering equitable health services to its many rural areas across all disciplines. Despite numerous studies showing that people who live in rural and remote areas have poorer health outcomes and higher health needs than those in metropolitan areas^{1,2,3} access to health services is still a major barrier for timely and appropriate outpatient care. In particular, the ability of the physiotherapy workforce to meet growing demand in Australia is uncertain.⁴ More than 80% of physiotherapists work in major cities in Australia⁵ which leaves the rural and remote areas under resourced. A number of important factors relating to rural physiotherapy service provision in Australia have been defined including macro level policy, funding, service priorities/capacity and capabilities of the outpatient physiotherapy teams.⁶ Physiotherapists play a key role in the acute care and rehabilitation of their patients and the promotion of health in their communities.⁷ The design and delivery of physiotherapy services, particularly in rural and remote areas, can be an influencing factor in the utilisation of these services from a patient and staff perspective, as shown in a recent study looking at the utilisation of services outside business hours.⁸ Patient involvement in health service planning, design and implementation is increasingly recognised in Australia as a way to ensure that health service provision is relevant to patient and family

needs. Utilising patient involvement to better understand experience in relation to health service delivery and outcome can assist in developing appropriate services for all users. Specifically, improved insight into the physiotherapy needs of rural communities is required to further understand the challenges faced by health care practitioners and patients in accessing and utilising these services.

The aim of this study is to collect stakeholder experiential information to inform redesign of a rural outpatient physiotherapy service. This redesign will allow the physiotherapy department to better meet the needs of the patient and staff users in the future. The use of stakeholder experience will ensure all aspects of care are considered in the redesign process. We aim to focus on understanding the physiotherapy experience of patients undergoing a change in health status with a central chronic neurological condition (CCNC) as well as the experience of staff who refer these patients to an outpatient setting, using an experience-based co-design approach. This patient population has different needs to an orthopaedic or musculoskeletal patient group that outpatient physiotherapy is traditionally set up for. Due to this, there is a risk this cohort is being therapeutically underserved as a result of a referral and triaging process that focuses on identifying a separate set of conditions and priorities. Health services, generally, best resource acute

rehabilitation for neurological conditions, access reduces and becomes less structured as the timeframe extends post diagnosis.⁹ Experience-based co-design (EBCD), a quality improvement, participatory method, is beneficial for health service improvement as it entails staff, patients and their families or carers reflecting on their experiences of a particular service to identify improvement priorities.¹⁰ It involves shared decision making and a thorough analysis of the current systems as well as explaining expected benefits of new, improved systems.¹¹ EBCD ensures that patients and health care staff are involved in the future design of physiotherapy services. This method means more than just being responsive to patients and listening to their needs; patients are directly contributing to the design of their care.¹²

The primary conditions in this cohort encompass a range of medical conditions including Stroke, Parkinson’s disease (PD), Multiple sclerosis (MS) and acquired brain injury (ABI). It was important to represent stroke patients in particular, with stroke being a leading cause of disability and morbidity in the Western world.¹³ Previous studies have shown the importance of supporting patients in the chronic stage post-stroke to reduce the risk of negative associations including depression, anxiety and poor quality of life.¹⁴ Central nervous system repair continues to occur with motor learning practice at any time post-stroke and therefore professional guidance remains an important tool for ongoing problem solving, planning and tailoring realistic goals. Physiotherapy management is broadly supported for all conditions affecting movement and movement quality including PD,^{15,16} MS¹⁷ and ABI.¹⁸ A recent qualitative study evaluating ABI patient experience post discharge¹⁹ suggests that access to outpatient therapy

in the chronic phase was difficult to navigate and there was difficulty identifying and locating suitable services. Therefore, ensuring that the health system is working with these patients during health status change is paramount to their ongoing quality of life and future care. A further patient satisfaction study of patients with ABI suggests that the main areas that contribute to high levels of satisfaction in physiotherapy rehabilitation are the amount of therapy provided, quality of treatment, therapy environment and follow up arrangement.¹⁸ Within the physiotherapy profession there is increasing recognition that research into patient views of services provided should be undertaken in addition to studies that examine the efficacy and benefits of physiotherapy.²⁰

Methods

Participants

Nine patients of the Tasmanian Health Service (Devonport) physiotherapy outpatient clinic, who have a CCNC, participated in this study in one of three ways, as per the co-design method (Table 1). Firstly, one patient was a co-investigator involved in the design of the study including the semi-structured interview questions and providing patient-focussed feedback to the research group throughout the study. Secondly, four patients were part of a group that trialled the interview questions to ensure suitability. Thirdly, four patients formed the study group itself and participated in semi-structured interviews and follow-up focus group sessions. The mean age of the patient participants was 60 years with 44% being female. Five healthcare staff⁹ (Table 2), who had worked with this specific cohort of patients in a range of settings (general practice, inpatient and emergency department),

Table 1: Patient Participant Characteristics

Patient Participants	Age	Gender	Condition
Patient 1	49	M	ABI
Patient 2	34	M	ABI
Patient 3	54	F	MS
Patient 4	78	M	Parkinson’s
Patient 5	62	M	Stroke
Patient 6	65	F	Stroke
Patient 7	70	M	Stroke
Patient 8	49	F	Stroke
Patient 9	78	F	Stroke

Table 2: Staff Participant Characteristics

Staff Participants	Work Setting	Experience (years)
Staff 1	Physiotherapist	>10
Staff 2	Physiotherapist	>10
Staff 3	DEM	>10
Staff 4	Medical ward	0-5
Staff 5	GP	>10

participated in semi-structured interviews and follow-up focus groups sessions)

Procedures

An experience-based co-design (EBCD) approach was utilised for this study (Figure 1). This approach is designed to bring patients and their families and healthcare professionals together to improve healthcare experiences, systems and processes. Co-design typically requires between 6-12 participants for qualitative data collection.²¹ Purposive sampling of patient participants was performed by their treating physiotherapist, who invited them to be a part of the study. An information sheet and consent form were provided prior to their involvement and family members and/or carers were also invited to be involved. Semi-structured interviews were undertaken at Devonport Community Health Centre and patients’ homes by a physiotherapist who was not the treating clinician for that patient. The patient was asked about their experiences with the physiotherapy outpatient service in relation to access, support and goals of care challenges. Staff were also purposively selected, approached by the clinical team and invited to be a part of the study. Staff members who were interested contacted the research team and were provided with an information sheet and consent form. Semi-structured interviews took place at Mersey Community Hospital where staff were asked about their experiences with accessing services, potential improvements, and the future of physiotherapy for this cohort of patients. Ethical approval was obtained from the Tasmanian Health and Medical Human Research Ethics Committee (H0017727).

Analysis

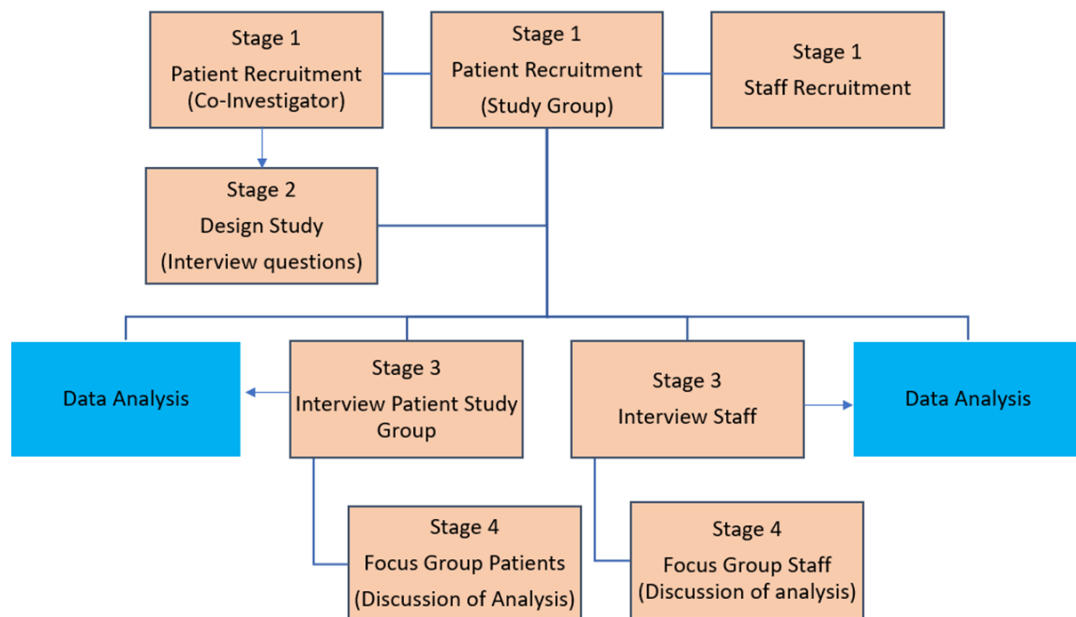
Data collected from the semi-structured interviews (patients and staff) underwent separate thematic analyses utilising the two-part approach described by Attride-Stirling.²² The first part of the thematic analysis involved developing thematic networks and consisted of three main steps:

1. Breaking down the text – developing the thematic network
2. Exploring the text – describing the thematic network
3. Integration – interpreting the patterns within the thematic network

Three members of the research team developed the thematic networks by independently coding the transcribed data and identifying basic themes. The coding was done by identifying pieces of text pertaining to similar ideas. The researchers met on several occasions when basic themes were compared and scrutinised, these basic themes were compiled into ‘organising themes’ which streamlined them into similar issues.

The second part of the thematic analysis involved identifying and combining organising themes into global, overarching themes. Global themes are designed to superordinate all data into key, transcending paradigms. Three members of the research team examined the thematic networks and worked together to develop these final, global themes. Following check, re-check, review and

Figure 1. Outline of Experience-Based Co-Design Approach



further analysis, consensus on the final product was reached.

These themes were then discussed in focus groups (one for patients and one for staff) to ensure the analysis reflected the needs and expectations of the participants. Any discrepancies were discussed during the focus groups and, if necessary, further analysis was performed.

Results

Patient Cohort

Three global themes extracted from the interview data for the patient participants in this study include timely support, goal achievement and inclusive decision making. The main areas of discussion in these interviews centred around service provision, effective treatment, expectations and how to improve the patient experience.

Theme 1: Patients value timely support to help them manage their situation

Patients indicated that longer wait times can be a factor that influences their physiotherapy outcomes and that they value short waiting times. In order to improve their physiotherapy experience, more timely access to public service was discussed. This included the need to utilise costly, private services to avoid waiting long periods in the public system. Patients offered a number of perceived reasons for this wait including a lack of resourcing (appropriate staff numbers) and lack of process.

“But all the waiting time...this last fall I had in October; only two weeks ago did I get an appointment (6 months)”

“Unfortunately, it’s a staffing thing, you have to wait such a long time”

“You have to wait such a long time for your appointment by which time you’ve gone backwards. Nobody’s fault, but in the meantime, you are just banging in there”

Theme 2: Patients value physiotherapy input to achieve goals

All patients placed high value (in terms of quality of life) on achieving their individual physiotherapy goals using methods such as exercise, problem solving and moral support. Patients felt that pain, logistical issues, and work life create barriers to attending therapy. They wanted more focus on the individual nature of each patients’ issues and expectations.

“Physio was fantastic, helped me a lot”

“(therapist) was good – she explained if you fall and there is no one there to crawl to a chair...you need to know what to do if you fall and you can’t get up”

“I felt good afterwards. I felt like I was making progress slowly but surely”

“She got me to take pictures (on smartphone), that was a good idea, I thought”

“Encouragement and doing the exercises I was given”

“Giving exercises, and coming next time and checking I was doing it”

“It’s just that there isn’t enough (physiotherapy) and I don’t go enough”

“(physio is) really beneficial to me, I notice it when I don’t do it”

“Physio is just so good for me”

Theme 3: Patients want to be included in the decision making regarding their care

Patients indicated that it was important for them to be involved in the decisions regarding their care, treatment, and goal setting. Patients willingly provided opinion on things that worked, and did not work, for them. They felt that a tailored approach, rather than a blanket approach was more appropriate for CCNC.

“I was asked to go to the balance clinic – which I didn’t benefit from as I could not stand up”

“Well, I have struggled with my balance. That would be the main thing (future physiotherapy) can provide”

“We were doing hydrotherapy sessions for a while and they were good”

“I had hydrotherapy, which was good, but the getting there and getting in and out...it was awkward”

“(hydrotherapy) It’s not something I’ve taken up mainly because of time restraints, because of my work, and it’s just the pool so it’s wet hair and all that”

“Exercise classes, remedial massage and generally physiotherapy, I would definitely do that (through the public system) if it was available”

*“When I was down in **town, I went through extreme physio – I was doing a lot more there (in rehab)”*

These results were presented back to interview participants in a focus group, where they confirmed results were correctly interpreted from their perspective. There were no discrepancies noted between the analysis and the participant expectations. One reflection of the patient focus group was that initial concerns about participants confidence participating in a shared forum were misplaced.

Participants appeared empowered, valued and enthusiastic about discussion of their experience with peers. This method of data collection presented a potential missed opportunity for the research team as no formal data collection occurred during follow up sessions. The shared sense of purpose appeared to allow patients to ‘open up’ more than the research team felt they did in their individual interviews. This meant along with confirming the global themes, new ideas and concepts were raised, but not followed up on.

Staff Cohort

Global themes extracted from the interview data for the healthcare staff interviews included clinician genuineness, timely care, clarity of availability of services and patients not being seen. These themes highlighted the main issues as perceived by staff when accessing the current physiotherapy outpatient services for patients with CCNC.

Theme 1: Referring Clinicians want to do the best job they can for their patients

The data showed that the clinical staff who are providing referrals to this service want to deliver patient-focussed outcomes but often the process is not clearly defined. Staff genuinely want to ensure that their patients receive appropriate and timely care and want to be as involved as they can in delivering this service.

“Reducing hospital attendance time is really important”

“The best ways to refer is always important (to be communicated); it’s a matter of getting information into one spot so that it is always ready”

“Pretty much every inpatient admission will be followed up with an outpatient referral”

“If it is a deteriorating condition, rather than a static one, even more so (needing long-term physiotherapy input)”

“I would say we need more involvement (in physiotherapy care) and more access overall”

Theme 2: Referring clinicians care about patients receiving timely care

All staff commented about the perceived wait times for patients with CCNC accessing services. These comments reflect a general consensus that their perception of the acuity of the referral was not consistent with the triaging process and subsequent wait time for physiotherapy services.

“Public list can take a while”

“We know there is a big waitlist (in public physiotherapy outpatients)”

“You’re wanting, ideally patients to be followed up within a couple of weeks”

“I only have issues when there are issues with access”

Theme 3: Physiotherapy services available to this cohort aren’t clear

The general picture from staff, pertaining to the local outpatient physiotherapy setting, was that improved pathways and clear criteria for referral of patients with CCNC are areas for development.

“Given its neurological (is outpatients a suitable setting) to practice getting on and off bed / floor”

“Whether the referral is felt to be appropriate – feedback might assist that process”

“We have used community physio because she can do more functional assessment”

“You guys decide if outpatient physio is going to be helpful (once patient is admitted)”

“Most of them need lifelong physiotherapy support”

“Outpatients has been more musculoskeletal orientated”

Theme 4: Not all patients serviced through the health system are being captured by the physiotherapy department

The data suggested there were consistent missed opportunities for the public system to capture and service this cohort during an acute change in health status. Comments about the public versus private system and the timing for access to care were emphasised across all global themes.

“A lot of them I send privately”

“We are probably too focused (on a medical issue) to reliably refer everyone if their presenting condition isn’t their chronic neurological condition”

“You guys do a lot of self-referrals”

“You guys decide if outpatient physio is going to be helpful (once patient is admitted)”

In the follow-up focus group, staff members received this data well and there were no discrepancies between the analysis and their expectations – confirming that the global themes reflected their sentiments. The staff focus group as a data collection tool was quite different to the patient group; although themes were again confirmed, discussion didn’t broaden or develop. Instead the group chose to

reflect and consolidate the findings of the interviews, without new ideas stemming from the discussion.

Discussion

The aim of this study was to collect stakeholder experiential information to inform the future re-design of outpatient physiotherapy services. Specifically, physiotherapy patients with CCNC undergoing a change in health status. We achieved this through working with patients and staff to identify current unknown gaps in the service with a view to addressing them based on the experiential information collected. The main findings showed that global themes appear to overlap between patients and staff, with inter-relationships stemming from uncertainty about what services are currently offered. Lack of understanding as to the scope of public outpatient physiotherapy was highlighted from a number of perspectives. Patients felt 'intense rehabilitation' or passive therapies such as remedial massage should be offered, whereas staff questioned the suitability of the outpatient environment to meet their patient's needs. The data also suggested that patients and staff hold similar views around physiotherapy outpatient access and timeliness of care. There were also differences between patient and staff data, centring around the homogenous nature of the staff experience, relative to the heterogenous and individualised nature of the patient experience.

Previous survey data⁶ showed that public physiotherapy services in rural Australia decrease with increasing populations due to the prioritisation of the needs of hospital inpatients. As in our study this can result in long wait periods for access to outpatient physiotherapy services and thus, a decline in patient experience. Participants, although generally satisfied with their treatment, expressed their concerns about low staffing levels in relation to long wait times for initial contact and consultation. The implications for patients having to wait for extended periods are not only related to reduced quality of life, but also a missed opportunity to implement therapeutic risk management strategies as described in the staff experience data as well as published literature. For example, Dobkin⁹ suggests that poor access to resources supporting goal-oriented practice is one reason why stroke patients are sedentary 81% of the day up to 12 months post-stroke, increasing their risk of mortality. Similarly, access to timely care for patients with PD is important to minimise secondary complications¹⁵ and delays in physiotherapy interventions for patients with spasticity related to MS may further negatively impact their quality of life.²³

With workforce shortages in health well documented in rural and remote areas, it is no surprise that patients believe this to be a major issue. Some patients in our study chose to see a private physiotherapist at times to address

their own personal needs and requirements. There were also staff who referred patients to private practice due to perceived long waiting periods and lack of clarity on what services the public system could offer. Contrary to previous findings¹⁹ our results indicate that all patients were able to easily identify referral pathways to access public services during a change in health status. However, long wait times counteracted the positive experience of care received.

Our patient data shows the value of quality of life improvement, with staff themes supporting this as a mutual goal of therapy. It is well known that the majority of stroke patients report a decline in quality of life post-stroke. This study supports the importance of physiotherapy in regaining quality of life in all patients with CCNC. Using physiotherapy to set goals, develop movement strategies and maintain function is an integral part of managing health status change.²⁴ This is consistent with reports from our patient cohort who indicated that goal achievement is a highly valued part of physiotherapy. Similarly, evidence suggests that exercise has a positive influence on the quality of life of elderly people with neurodegenerative disorders and exercise has been consistently shown to improve motor and non-motor features of PD.²⁵ The patients in our study indicated that there was a strong emphasis on exercise-based interventions and this relationship between quality of life and exercise may be a reason why some patients felt physiotherapy was so rewarding. Meeting the expectations of patients has previously been shown to be a critical component in patient satisfaction²⁶ and involving patients in the planning and development of health care services has been shown to improve the health and quality of life of patients.²⁷

A consistent message throughout the staff interviews, was that clinicians are trying to do the best job they can for their patients by providing patient-centred care through physiotherapy as much as possible. Implicit in this is that staff value physiotherapy care for their patients. They would like timely, comprehensive care and feedback to ensure they are communicating clearly. These expectations and desire for improved feedback mechanisms provides an avenue to improve handover strategies and better define services. The cohort of patients utilised in this study have a unique set of physiotherapy needs. Central chronic neurological conditions often change over time,²⁸ during this change in health status, timely professional guidance unique to the individual's situation was sought by all patients interviewed. There is value in ensuring that physiotherapy services meet the needs and expectations of patients with CCNC. The same can be said for staff who are referring, triaging and treating these patients, as indicated in our results. Although patients with ABI are a minority in this population, it is important to note that access, transparency and availability of services have been

shown to be important factors relating to quality of life post discharge for these patients.²¹

We found there was no ‘one size fits all’ for managing this cohort, particularly in relation to goal achievement and quality of life. Patient expectations, motivation, support systems and health literacy all differ dramatically. The variation in preference stems from a combination of individual characteristics and clinical presentation and is influenced by the processes available for staff to refer, triage and treat. For example, post-stroke or brain injury, physiotherapy needs will depend on the severity of the stroke or injury and its consequences as well as the cause of health status change.^{13,29} Similarly, the needs and frequency of input for patients with Parkinson’s disease and multiple sclerosis will depend on the progression of the disease and the individual lifestyle goals of the patient¹⁵. Patients place high value on shared decision making, and the importance of this theme has been demonstrated in previous studies.²⁵

Physiotherapy support of patients who are in an acute phase of health change or transitioning to another mode of care, such as a funded scheme to provide long term support, is particularly important for rural and regional areas. Whilst adequate service provision has been shown to be an enabler for these patients, it is also vital that there is an understanding by all stakeholders of the processes available for patients to access care.

Limitations

One major limitation of this study is the small final cohort for each sub-group of physiotherapy patients utilised for data collection. The patient participants were selected on their suitability for verbal interview, potentially missing further insight from patients with verbal communication issues. Data capture was not performed during the focus group as this was not in the study design, retrospectively it appears this was a potential source of lost information. There was a small number of staff participants involved in this study with co-design typically requiring 6-12 participants. Our cohort included 4 staff members from three health settings and 5 patients with three different CCNC. Results therefore may not be generalisable to other rural health service areas.

Future studies should target these limitations, with larger samples aimed at reaching data saturation. Similarly, aiming to capture the experience of patients with verbal communication issues would build on our study and provide more generalisable results. Finally, defining the neurological condition more specifically, and targeting subsets would increase the richness of experiential information gathered. This could inform more condition specific management strategies or validate a patient focused approach to the management of CCNC.

Conclusion

Improving our own understanding and defining the goals of our service in relation to this cohort is the first step in health service improvement through co-design. This process enabled informed service development strategies for triaging this cohort. It has also helped engage and inform referring clinicians in the patient centred care of CCNC undergoing health status change. Based on the findings from this study the Tasmanian Health Service - North West Region Physiotherapy Department has commenced an action plan to change triaging processes, use more accurate baseline assessment techniques, structure care with a focus on patient lead goal setting and ensure referral processes are more clearly communicated with the broader health care team. Future co-design initiatives in the department will involve a greater emphasis on consumer focus groups, as this format delivered outcomes surpassing expectations for the group studied.

A recommendation for the use of co-design to develop understanding of the expectations and priorities of staff members and patients alike can be given.

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