A case study of Rehabilitation in the Community
after a major health crisis

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Summary

Introduction

Exploration of broad health related impacts and the rehabilitation outcomes for a person living with a disability who survived a health crisis and protracted stay in hospital

A series of informal interviews helped to create a voice for the person to reflect on a very intense and traumatic health scare and to acknowledge recent progress

- Equity Issues
- Preventative Care
- Hospital Care
- Planning for Home Life
- Monitoring and Remodelling

Background

Client living independently in the community.

Enjoys attending concerts and volunteers at music events.

Born with Spina Bifida and Hydrocephalus. Has experienced respiratory and renal health issues. Multiple surgeries from early life to present day.

About eighteen months ago……

A snuffle turned into a cold which got worse….until…..the client was not responsive one morning when staff arrived to assist with hygiene care. Emergency call was made.

A Time of Crisis

Admitted to Intensive Care with Septic Shock and Respiratory Failure.

Ongoing unstable respiratory function and hospital acquired infections forced discharge plans to be abandoned three times over the next 2 months.

Client progressively lost respiratory functioning, muscle strength. No longer transferred independently. Energy levels declined. Confusion increased. O2 dependent via N/Specs. Confidence decreased.

Physiotherapy regime & Rehabilitation not available upon discharge

Equity Issues as an Inpatient

Consistency of Care – Expertise

Specialist Support post ICU

Department Shunting

Provision of Equipment - sling

Issues cont.

Constantly changing workforce – nursing staff exposure 150 +

Personal allocation to more than 36 different staff members (including meal break relief). Skill mix.

Adverse events – skin impacts, MRSA

Specialist Reviews – clinic transfers

Variable work practices, protocols, preferred ways of enacting care.

Different cultural norms (routines / reporting).

Different equipment available for use in different ward environments.

How did the client respond?

“The nurses don’t know how to care for me. Why am I on a ward where they don’t have proper mattresses and lifters?”

“They don’t plug in my chair. They can’t drive it”

“Everyone says they will be back soon or when they finish their break, but then the next one goes on a break and there is no-one to help” “I need to be lifted up the bed and I need help to turn”

“He said he would come and he didn’t and I don’t know anything”

Developing a Quality Pathway

Hospital Disability Liaison Staff

Community Co-ordinator / Agency

Family

Health Support Worker Staff

Allied Health / RN

What did we do?

Community Health Support Worker staff rostered hours in the hospital setting (funding approved via Co-ordinator) with RN back-up. Personal care hrs.

Family members were able to visit frequently to assist in advocacy of care

Prompt feedback to senior nursing and / or medical staff to relay concerns or lodge a complaint.

Community Health Plan and Community Health Diary were available and used to assist in orientation to the person behind the diagnoses.

Client comments

“

I think the girls know me best”

“It was better with my staff. They listen. I don’t have to wait. I don’t have to start again”

“They know how to care for me, my skin.   X……knows all about me. Everyone knows when I am fed up and ....!

The nurses think you need tablets but they don’t think you need to talk about …horrible things and being upset ”

“Can’t stand needles and they always do more than one stab”

Planning for Home

Client status became 'Level 3 Complex Care' - need for equipment, additional HSW staffing, additional HSW training to transition to home.
Deemed suitable for a high-needs placement / 24 hr care support // location kms away)

Clinics provided permanent loan equipment

Purchased own items for home set-up

Staff training commenced – 7 new procedures

Further Equity Issue – Access to Services

What did we do?

Agency and Co-ordinators negotiated a carer package of additional day hours and an on-call overnight HSW staff. Renegotiated hours PRN

Flexible approach to care in client's preferred home environment

Multiple client reviews via RDNS DST – initially daily training, then twice weekly progressing to fortnightly. Specialist reviews – changes.

(BS – 17 wounds / Oximetry) Care enacted, monitored and assessed via RN

Seven revisions of documents and related training instructions

Respiratory Physiotherapist Assessment – 6 initial – home & gym regime

A Long Way to the Top

“ I couldn’t wait to get out. When I was really sick I didn’t care. When I was a bit better…..well….I really hate hospital. I call it ‘The Slammer’ because its like a prison!”

“ I was sicker, but I wanted to get home and get away from there”

“ Too much waiting around and they don’t do things the way I like”

“No, no, no. Cant go anywhere because the tube only reaches the door”

Ongoing Support at Home

Core group of regular HSW staff supporting over an increasingly flexible roster and ongoing training for procedures to support health needs.

HSW staff supported the in-home regimes, rest-on-bed regime, minor skin and wound care needs, reported all changes.

HSW staff supported the client to maintain a full day

RN provided additional 3 hours of visits per week during transitional phase (approx 3 months)

What worked?

Being available - flexible visits, additional visits, discussions with family

Being adaptable – Training HSW with all at-home routines. RN visits.

Being creative – Choice. Maximum client involvement in training.

Being realistic - Alterations to daily life. Limitations on energy. Miles of tubing

What were the BIG issues?

Transitioning from a wellness model to a supportive care model

Impacts of Illness – Adaption

Anxiety – client and HSW staff (limitations / obtaining competency)

Grieving for end of relationships – staff changes

Change in Family availability and support

Training - eager workforce not yet a capable workforce

The client remembers:

“ I remember yawning all the time. I thought the staff would help me with going out. I couldn’t go everywhere the same as before. I could go shopping but only four hours, the tanks would nearly run out. It was better with the ….. If I woke up with a headache I would be worried. I have Hay Fever headaches”

I had to have help because I couldn’t get on the bed by myself. I couldn’t do much.

“Some people made things worse.”

Modelling and Remodelling

There have been no serious Respiratory Health impacts since discharge. Minor issues for GP / RDNS DST RN capture / review

Review of several months ago – ceased daytime O2 via N/Specs.

Next review a few months later - ceased overnight O2 via BiPaP.

Latest review via Respiratory Specialist – no changes to current o/night regime of BiPaP on air only.

Physiotherapy Regime continues 1 x weekly gym session and home physio routine (most days) with HSW staff reminders

Autonomy of choices with care – anxiety spike – longer weaning period

Snapshot after 12 months

The client and the HSW team re-invented life in the community together.
Small core group – currently 6 fully trained staff. Agency Staff rarely.

Agency Support – changes to contact hours

Back-up from RN available – weekly-to-fortnightly visits continue

Staff training is ongoing with Refresher sessions

Reconnecting to Self

Training and related matters became routine events and made less impact on daily life. Client actively participates in training and assists to prepare and check equipment. Initiates contact with Services as necessary, changes own appointments, more confident.

More outgoing with a HSW staff as companion.

Stayed overnight in another setting

Enjoys a variety of outings to shows, concerts and fringe events

A few months later….

Overnight BiPaP on air only.

Adopted 2 cats

Active social life – funding arrangement changed – hours of support adjusted allowing greater flexibility with activities and socialising.

Only one rewrite to the Health Plan document in last few months

Core staff of four to six HSW's

Hospital last month for a planned surgical procedure. ICU x 1 night!

Looking back…last comments

"I feel less anxious at night and I mostly sleep better"

"I need reminders, everything goes in the diary"

"Knew I was better when I eventually went off oxygen"

"Last summer was pretty good. I went out a lot"

"I went to 'The Concert on the Green' and that was when I felt normal. I really enjoyed it and I had energy to stay awake"

Summary

The case study highlights how the client felt and reacted to a crisis of health. During the months in hospital the main concerns were about lack of attention to detail and depersonalised client care. There were barriers to equipment, expertise & continuity of care which the client and their support network were able to challenge. The client adapted to changes slowly over time. Regaining a sense of self was identified by the client when they reconnected to social activities and previously valued & meaningful routines.

Postscript

RN care continues to provide a vital hospital avoidance strategy. The client has recently stayed in hospital for planned surgery with no adverse impacts.

Thankyou