Stellenbosch University

INTEGRATING A TEAM-BASED COMMUNITY-ORIENTED INTERVENTION FOR STROKE

Division of Family Medicine and Primary Care

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Stroke rehabilitation

International best practice guidelines:

- Continuum
- Organised stroke care
- High intensity
- Multi-disciplinary teams

LMIC

- Not feasible
- Community-based rehabilitation model
- Task shifting to mid- and grassroots
- Train family caregivers
- No evidence

Objectives

- **Situation analysis** of outcomes of home- and community-based care (HCBC)
- Determine **experience & needs** of stroke survivors, their caregivers and community health workers (CHWs) in the Cape Winelands district of the Western Cape, SA.
- **Design & develop** and
- **Implement** a contextually appropriate stroke homebased training programme for CHWs.

Setting: Cape Winelands

- Low-resource rural
- Population: 866 000
- Incidence of stroke **higher** than national average
- > 600 admissions/annum
- No formal stroke clinical practice pathways
- Short hospital LOS
- Discharged home

PHC resources

- 332 CHWs
- 10 fulltime and 4 sessional MDPs

Cape Winelands and sub-districts:

1. Stellenbosch
2. Drakenstein
3. Witzenberg
4. Breede Valley
5. Langeberg

Methods

- Design
  - Multistage mixed method design
  - Situation analysis
    - Two convergent stages
    - Quantitative longitudinal survey
    - Qualitative descriptive exploratory study (FGDs)
  - Training programme
    - Designed, developed and implemented
    - Participatory action research
    - Co-operative inquiry process

RESULTS

Situation analysis

Environmental factors

- 11% informal housing
- Architectural barriers
  - Entrance to the house (63%)
  - No and/or inaccessible bathrooms (53%)
  - No and/or inaccessible toilets (51%)
- Poverty (71% of households <R4 000.00/month)
- Transport barriers (63%)

Personal factors

- Low educational level: no/some/completed primary school
  - Stroke survivors 62%
  - Caregivers 48%

Health care services

Acute

- 97% admitted to hospital (median 5 days; IQR 3-14)

Rehab/therapy services

- Unavailable or inaccessible

HCBC

- 30% no visits
- First assessment by HCBC: 65 days (IQR 42.0-93.8)
- Median 3.0 sessions (IQR 2.0-7.5)
- Median duration of visit: 20 minutes (IQR 15.0-30.0)

Assistive products

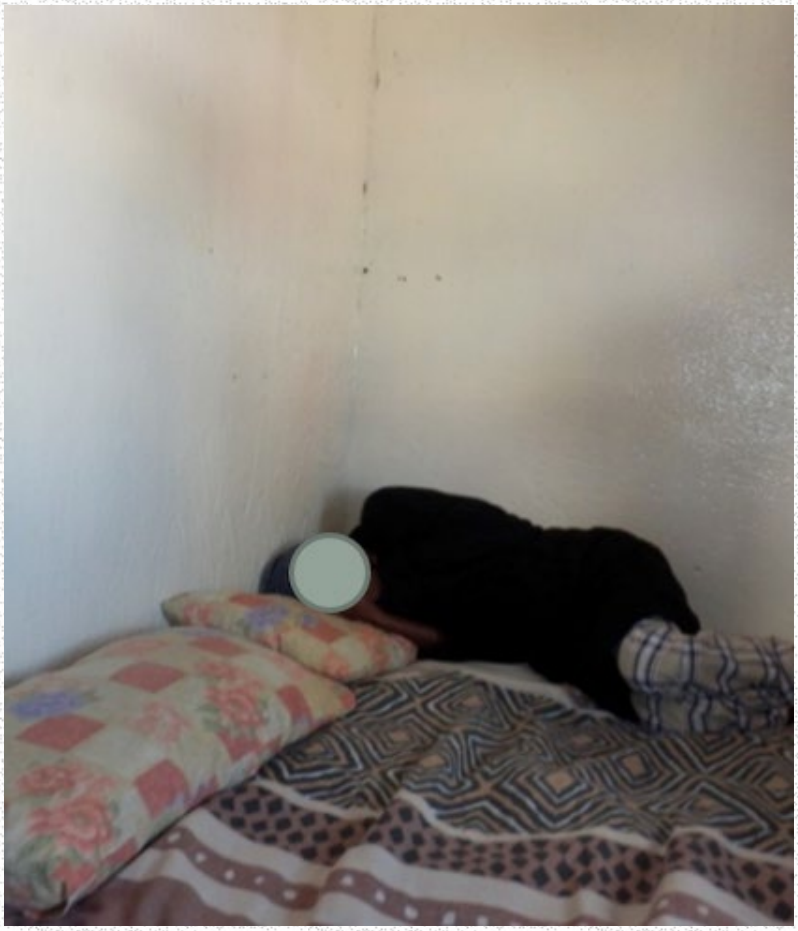
- 91% needed assistive products
- 48% received (DOH supplied half)
- 21% purchased the product themselves

- Highest provision
  - Mobility devices (wheelchair and walking devices)

- Lowest provision
  - Devices of ADL and incontinence

High emotional & caregiver strain burden

- Caregiver strain
  - Remained unchanged
- Caregivers and stroke survivors
  - Profound sense of loss
  - Feelings of pain, sorrow, despair, frustration and anger
- Stroke survivors
  - Depression and suicidal wishes
  - Dependency: low self-worth and guilt

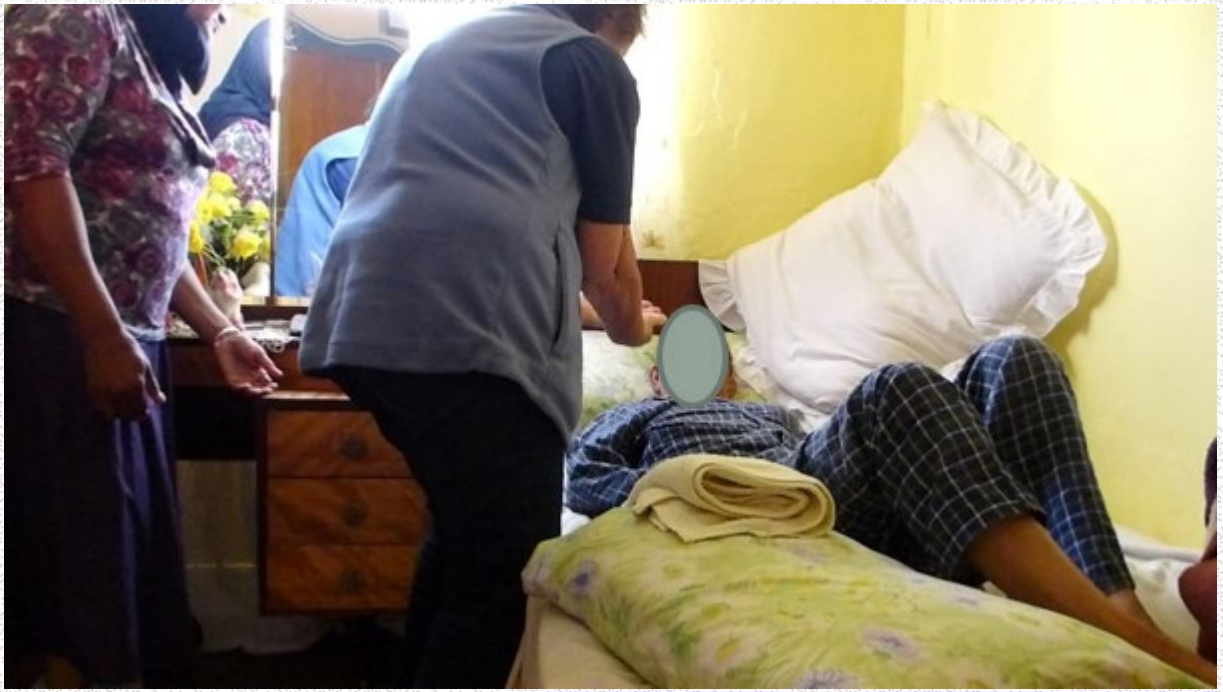


Function (BI)

- Significant improvement (p=0.019)
- Yet dependence high
- >50% dependent for every item
- Incontinence
  - Compounded by:
    - Dependency
    - Architectural barriers
    - Lack of assistive products

Caregiver knowledge and skills

"I did not know…There was no one to ask…I had to figure it out all by myself…"



Satisfaction

- Lack of / poorly defined services
- Perpetuated dependency
- Conflicting expectations
- Overall satisfaction with HCBC was low
  - 47% of caregivers
  - 17% of patients

CHWs: Service capacity

- Insight into problems
- Positive about role
- Continuity of care
- Lacked knowledge

"If I get there, what am I actually supposed to do?" (CHW, FG-6)

"You have to actually! On your own! How can I make things easier? You need to figure out ways on your own – what works for you and what works for the him [stroke survivor]." (CHW, FG-5)

CHWs: Professional support needs

- Not acknowledged
- Not part of the team
- Isolated
- Dysfunctional referral systems
- Lack of a uniform training approach

RESULTS

Design, develop and implement training programme

Programme design/development

MDPs: No training/experience in design/development of:

- Community-based interventions
- Training programmes
  - Identification/analysing learning needs
  - Instructional methodology
  - Time required
  - Assessment
  - Plain language

- Barriers to cloud-based collaborative environments

Training programme and resources

- 21-hour programme (16 modules)

- Includes:
  - Trainer's manual
  - Participant reference manual
  - PowerPoints
  - Videos
  - Stroke survivor and caregiver booklet

Training programme

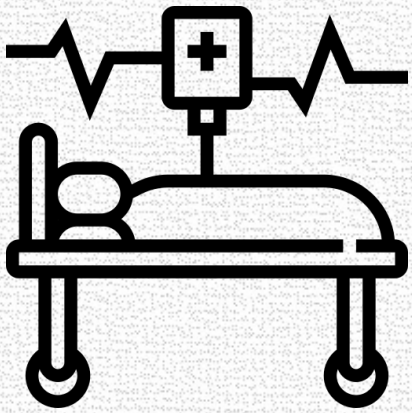
- First
- Participative approach
- Informed by needs of target of population
- PHC philosophy
- Addressed significant community health problem
- Appropriate technology and resources

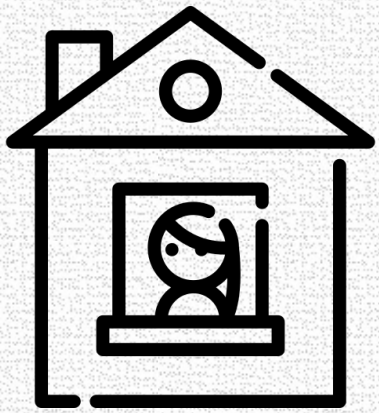
Impact on HCBC

- Defined CHWs and HCBC scope and role
- CHWs empowered & confident
- Patient-centred approach
- Shift in stroke survivor and caregiver attitude

Impact as PHC intervention

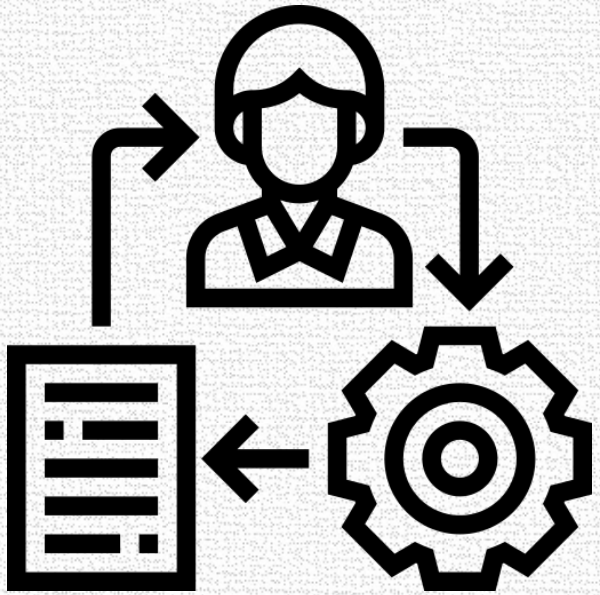
- Engagement: CHWs & MDPs
- Facilitated interdisciplinary learning
- Promoted comprehensive, uniform approach
- Strengthened continuity of care
- Extended rehabilitation service into homes





Service barriers

- MDPs:
  - Current service mandate
  - Perceived loss of core professional role
- Lack of leadership and structure to drive change
- Challenges in coordinating care across multiple sectors and healthcare levels



Conclusions

- Current care
- Fragmented
- Poor outcomes
- Everyone had to figure things out by themselves
- Appropriate responsive home-based services needed
- CHWs pivotal
- Define role and scope of:
  - CHWs and HCBC
  - MDPs

Recommendations

- Adopt model of CHW led rehabilitation training of caregivers
- Change service mandate & address service barriers MDPs
- Training and support for MDPs

Recommendations

- Clinical practice pathways and referral guidelines to:
  - Improve coordination of care
  - Appropriate referral to formal rehab services
  - Facilitate seamless transition from hospital to home
- Increase access to AP, esp incontinence & toileting
- Participative approach:
  - Model for future community-based interventions
- Further evaluation of impact of training programme required

Questions

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Ethics

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