

STROKE SURVIVORS' EXPERIENCES OF AND NEED FOR PRIMARY CARE AND COMMUNITY HEALTH SERVICES—A SYSTEMATIC REVIEW OF THE QUALITATIVE LITERATURE

Dominika M Pindus¹, Ricky Mullis¹, Lisa Lim¹, Ian Wellwood¹, Viona Rundell¹, Noor Azah Abd Aziz², Fiona M Walter¹, Jonathan Mant¹

¹Department of Public Health and Primary Care, University of Cambridge; ²Department of Family Medicine, UKM Medical Centre, the National University of Malaysia

INTRODUCTION

Long-term community healthcare services for stroke survivors remain underdeveloped while patients report many unmet needs. Systematic synthesis of stroke survivors' needs and experiences of healthcare can aid intervention and service development.

AIM

To systematically review qualitative literature on stroke survivors' long-term needs and experiences of primary care and community healthcare services.

METHODS

Search: electronic databases MEDLINE, EMBASE, PsycINFO and CINAHL (until May 2015).

Inclusions: (1) peer reviewed qualitative studies in English; (2) *Population:* community dwelling stroke survivors and/or carers (≥ 18 years); (3) *Interest:* needs and experiences of healthcare services after discharge from the hospital; (4) *Context:* delivered in primary care / community care. **Exclusions:** (1) quantitative studies; (2) mixed patient populations; (3) other than community setting (e.g. inpatients, nursing homes); (4) conference abstracts. **Quality assessment:** CASP Qualitative Research Checklist; Dixon-Woods criteria (status of paper in relation to research objectives: Key, Satisfactory, Irrelevant or Fatally Flawed).

Meta-synthesis was based on meta-ethnographic approach *second-order constructs* (authors' interpretations of participants' accounts). Two reviewers identified common themes across all papers. *Third order constructs* (reviewers' interpretations of second order constructs) were developed collaboratively within a group of qualitative researchers and clinicians.

RESULTS

After screening 1240 titles, 435 abstracts and 86 full texts, 38 papers were included in the synthesis. Studies mainly originated from: the UK (17), North America (9) and Australia (7). 24 studies included survivors ≥ 1 year after stroke. We identified 3 Key Papers. The papers achieved an average quality assessment score (methodology) of 8.49 (SD=1.30) out of 10 on the CASP checklist.

Synthesis

Four main categories of second order constructs were identified (Figure 1):

1. Continuity of care
2. Access to services
2. Information
3. Quality of communication

Third order constructs (Figure 2)

1. Passive / Active Services:

Passivity of services was expressed as:

- The need for pro-active follow-up after discharge
 - Healthcare professionals not actively providing information about stroke, secondary prevention and access to services
2. The passivity of services leads to **Personal Experience of Abandonment**, especially for groups where services are limited (e.g. younger stroke survivors).
 3. **Change and fluidity of needs:** Support provided needs to be time-aligned with the trajectory of recovery, which is different for each individual.

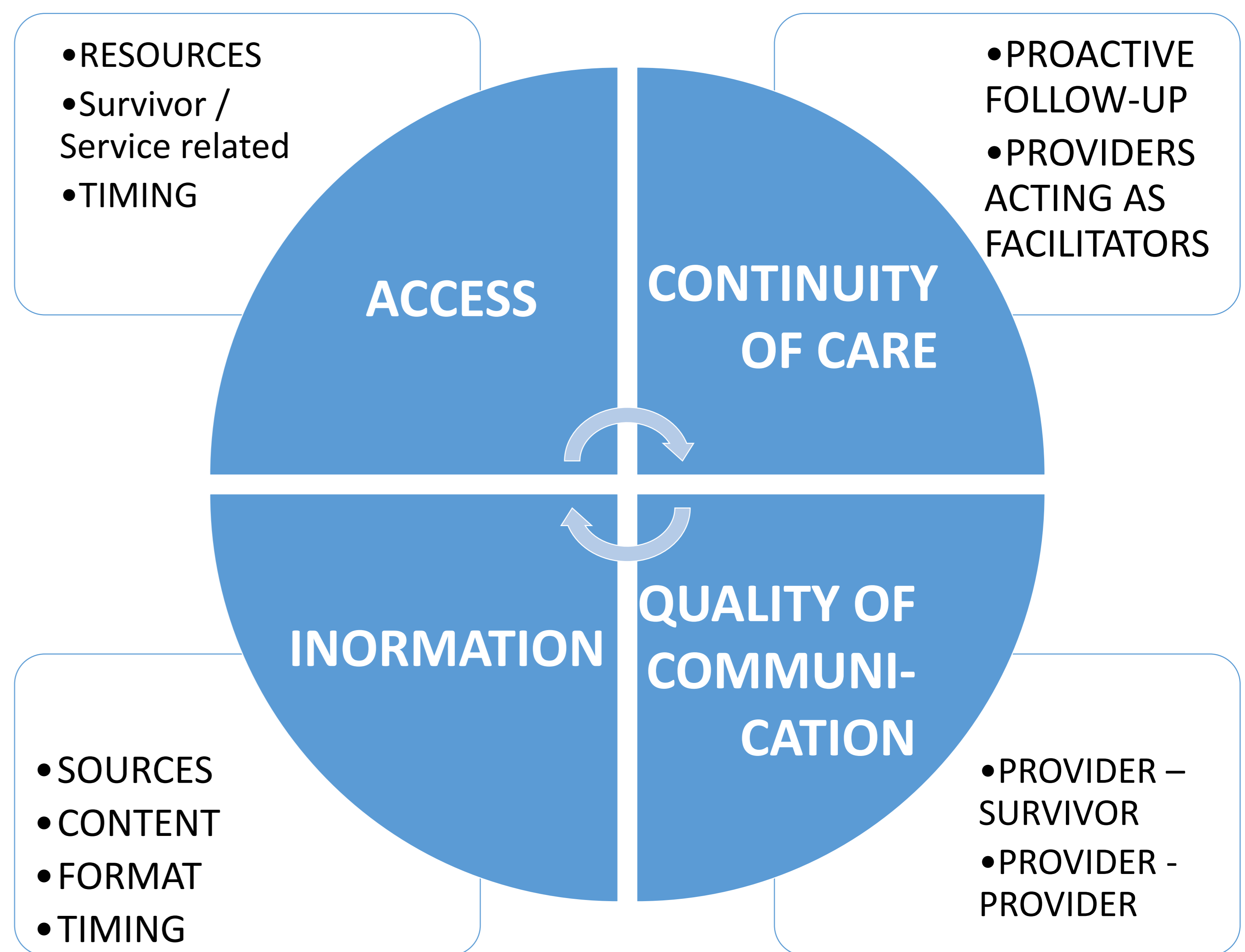


Figure 1. Second order constructs: Stroke survivors' needs and experiences of primary and community care services after discharge from the hospital:

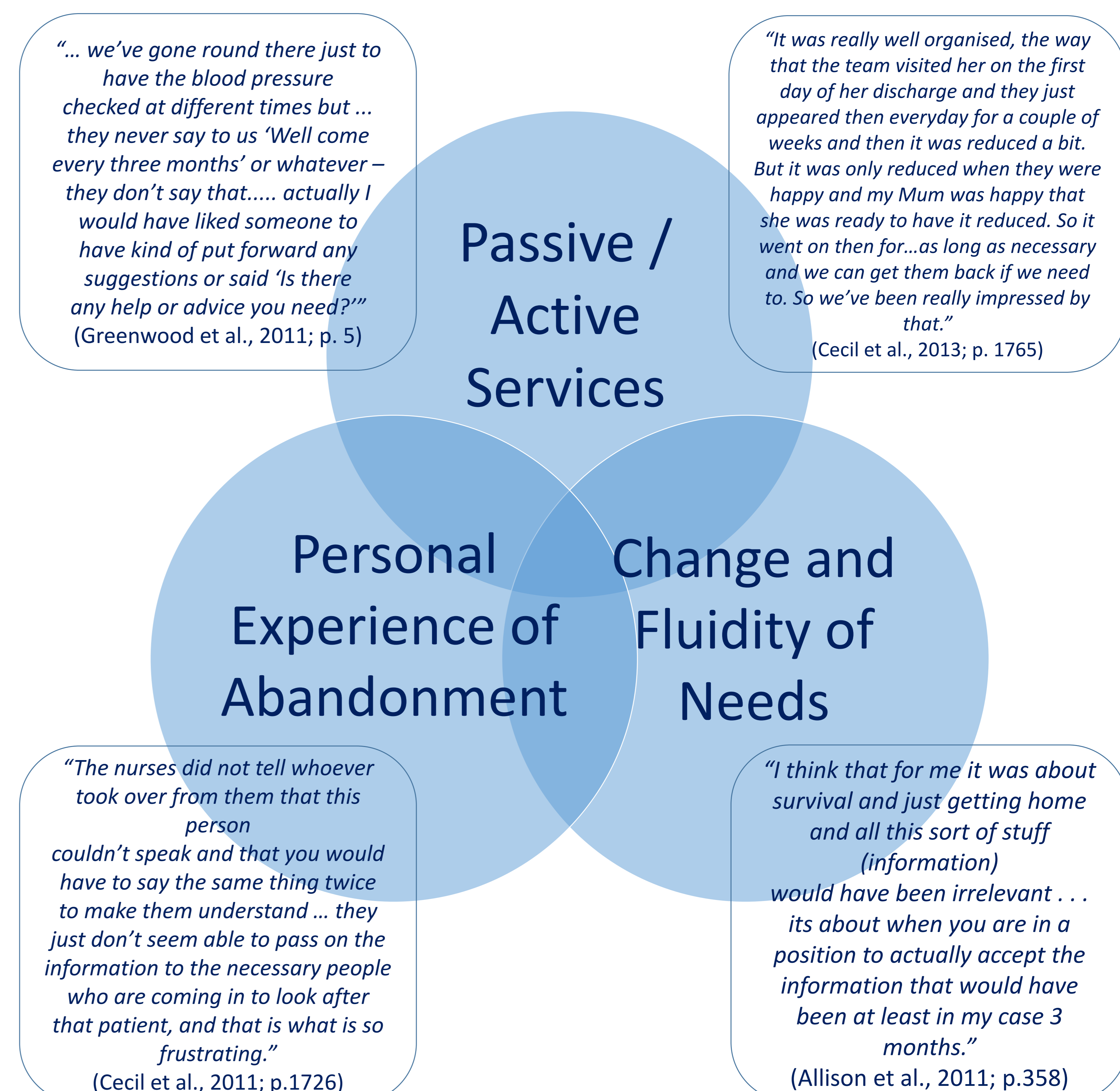


Figure 2. Third order constructs: Convergence of service characteristics, personal experience and trajectory of changing needs

DISCUSSION

Interventions focused on timely and proactive contact of primary care and community health services with stroke survivors have the potential to address survivors' feelings of abandonment after hospital discharge.