

# THE EXPERIENCES OF AND NEED FOR PRIMARY CARE AND COMMUNITY HEALTH SERVICES IN INFORMAL CAREGIVERS OF STROKE SURVIVORS—A SYSTEMATIC QUALITATIVE REVIEW

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## INTRODUCTION

Informal caregivers of stroke survivors report unmet needs relating to stroke survivors and also needs specific to their caregiving role. Caregiver specific needs include stress, anxiety, the need for support, information, training and being considered a partner in their caregiving capacity. Some of these needs could be addressed within primary care thus potentially improving caregivers' quality of life. However, as yet no systematic review of literature has focused specifically on stroke caregiver needs and on their experiences of primary and community care services.

## AIM

To systematically review qualitative literature on the needs of caregivers of stroke survivors living in the community, and their 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:** informal caregivers of community dwelling stroke survivors ( $\geq 18$  years); (3) **Interest:** needs and experiences of healthcare services after stroke survivor's discharge from the hospital; (4) **Context:** delivered in primary care / community care.

**Exclusions:** (1) quantitative studies; (2) studies focused on caregivers of mixed patient populations; (3) other than community setting (e.g. inpatients, nursing homes); (4) conference abstracts.

**Quality assessment:** CASP Qualitative Research Checklist and 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 using *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.

## Synthesis

Two sets of second order constructs were identified:

(1) those related to healthcare needs of stroke survivors (Figure 1); (2) caregiver specific needs (Figure 2). Caregiver specific needs related to **training**, and the **ongoing support** in areas such as emotional and social support and establishing a routine. The need for **back-up services** and **respite care** were also emphasised.

## Third order constructs (Figure 3)

- Passive / Active Services:** the lack of active follow-up, and ongoing support for both stroke survivor and caregiver led to feelings of dissatisfaction and abandonment.
- Personal experience of abandonment:** the need for ongoing long-term but often lacking support contributed to caregivers' burden, anxiety and worries of what may happen if they became ill. Availability of back-up services, ongoing support from HCPs and voluntary agencies could address some of these feelings.
- Change and fluidity of needs:** The need for ongoing support in the post-acute adaptation phase highlighted the changing needs of caregivers in relation to the natural trajectory of stroke recovery.

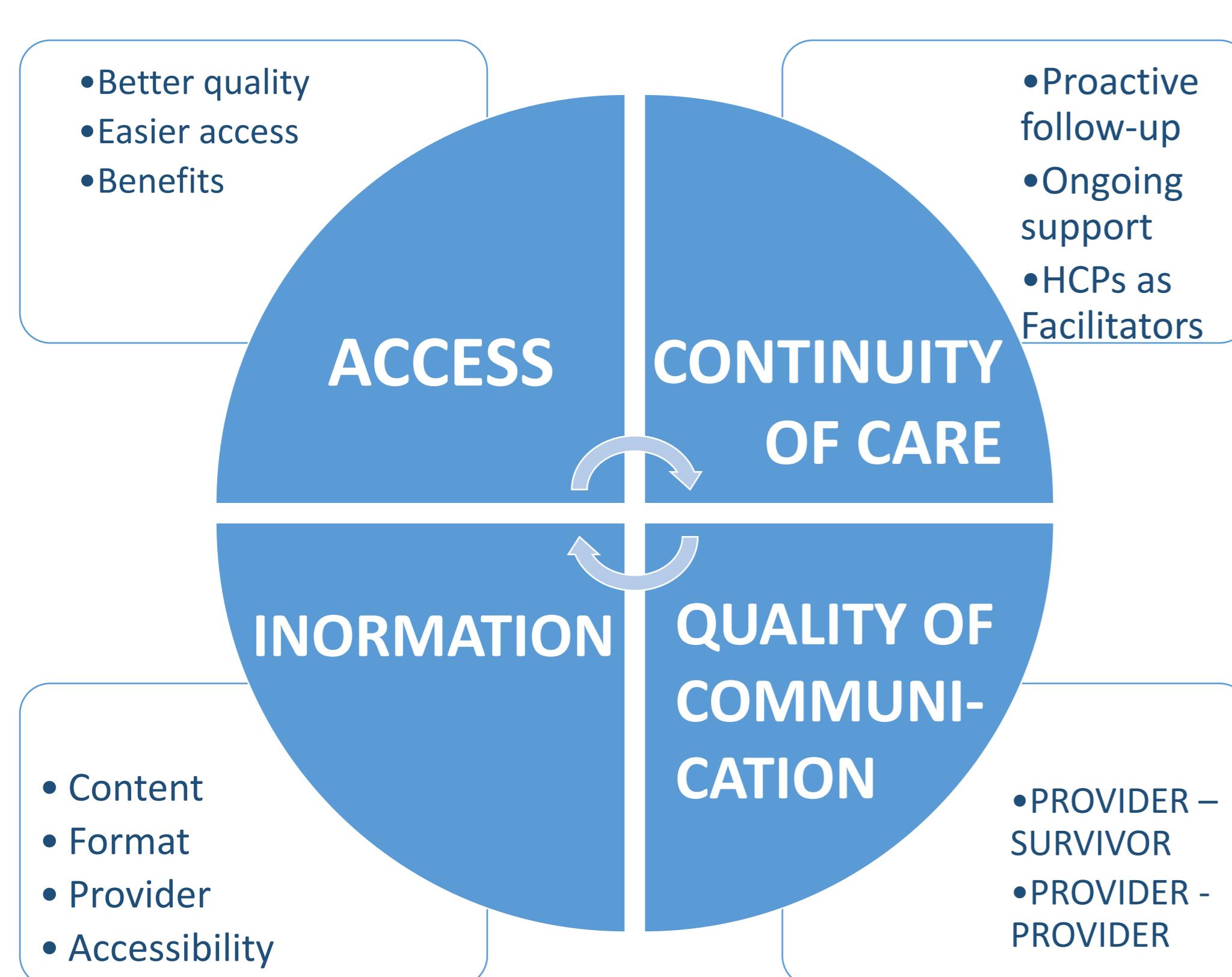


Figure 1. Second order constructs: Caregivers' perceptions of the needs for healthcare services for stroke survivors after hospital discharge.

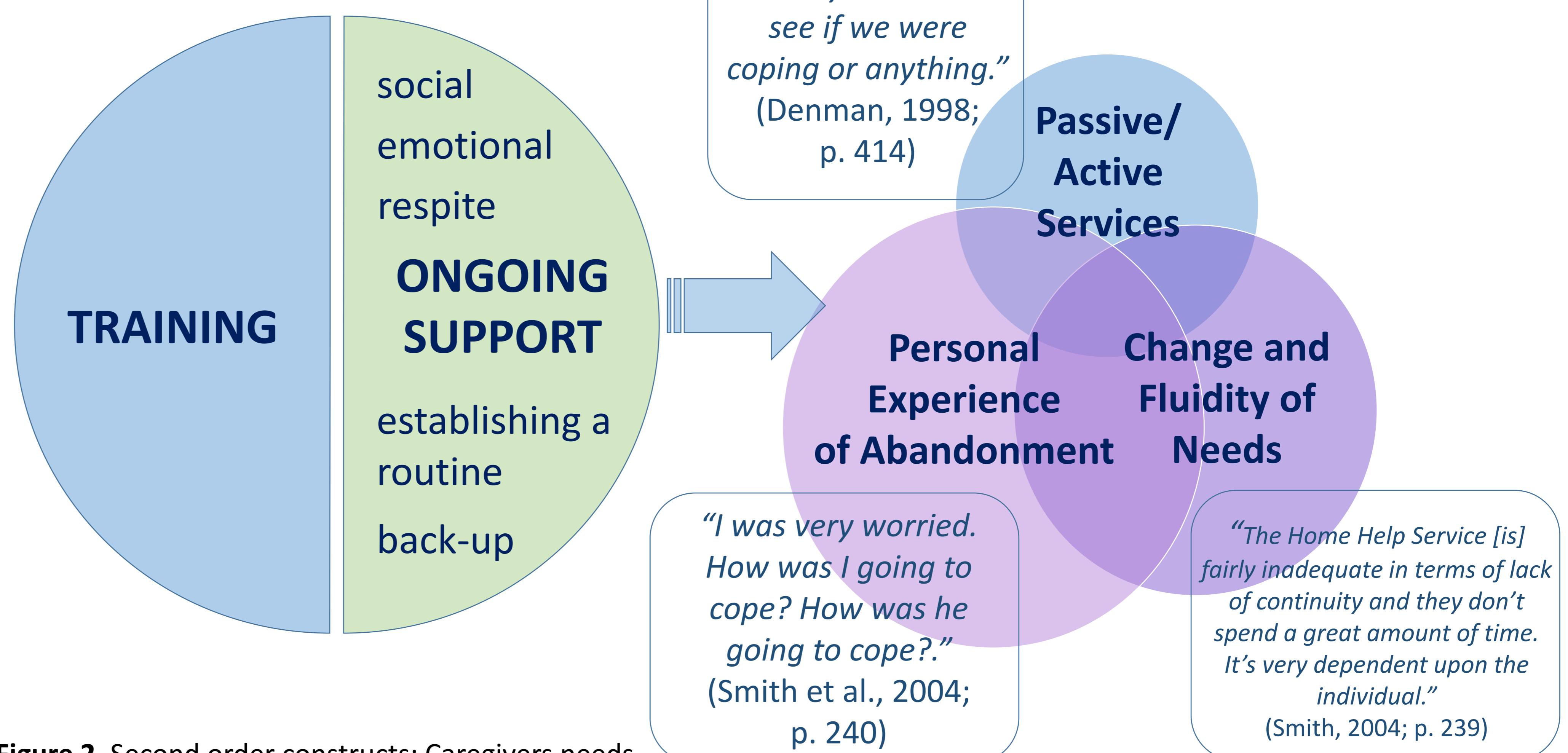


Figure 2. Second order constructs: Caregivers needs for training and support from healthcare services.

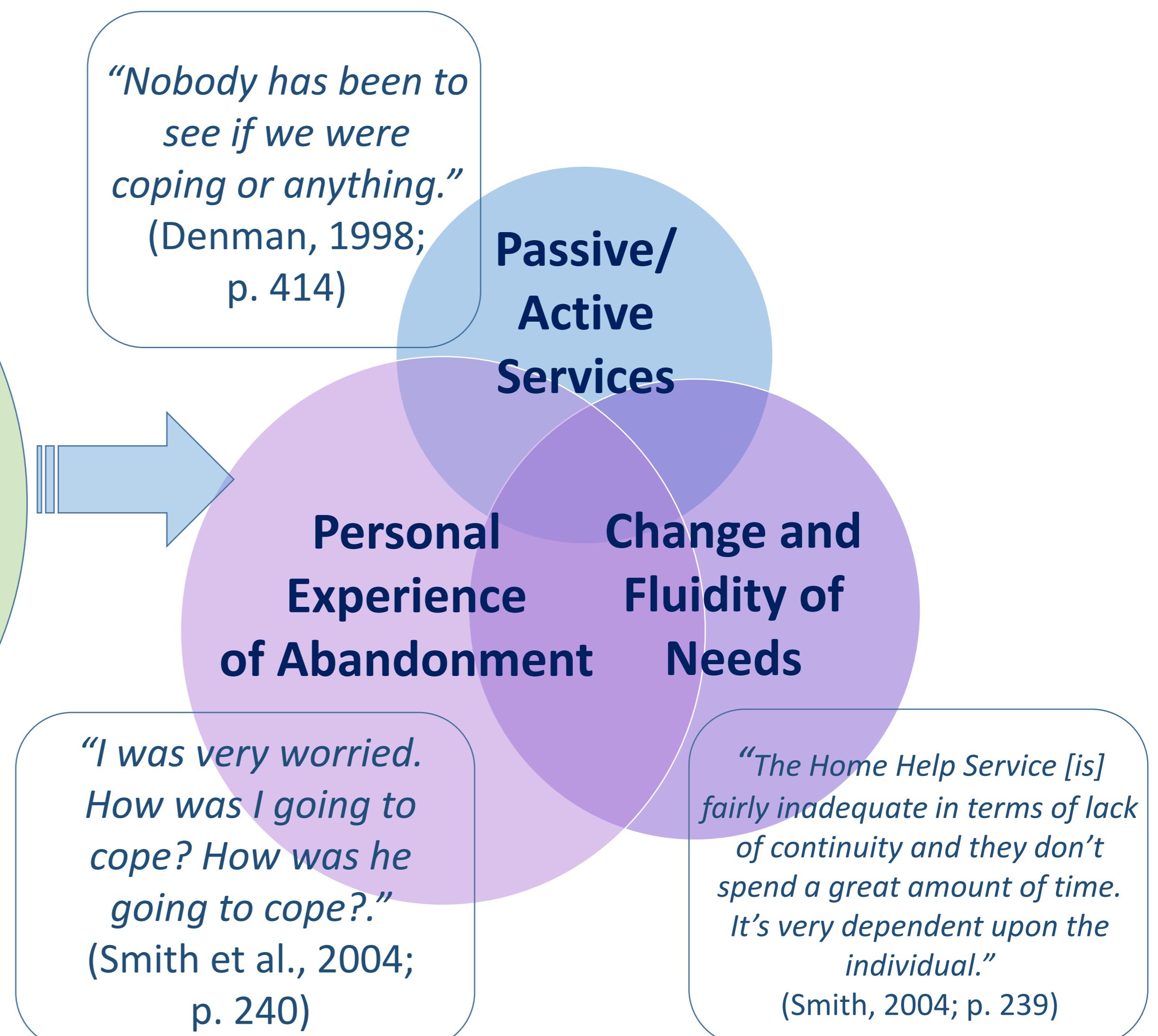


Figure 3. Third order constructs: The needs for healthcare after hospital discharge in the eyes of caregivers of stroke survivors.

## RESULTS

After screening 1240 titles, 435 abstracts and 86 full texts, 33 papers (including 537 caregivers) were included in the synthesis; 14 papers focused specifically on caregivers. Studies originated from: the UK (18), North America (10), Australia (4) and Sweden (1). Caregivers of stroke survivors who were at least 1 year after stroke were represented in 62% of the studies. The papers achieved an average quality assessment score (methodology) of 8.60 (SD=1.82) out of 10 on the CASP checklist and 6 were identified as Key Papers.

## DISCUSSION

Caregivers of stroke survivors have two distinct set of needs: those related to stroke survivor's health and follow-up, and those specific to their own situation as a caregiver. Interventions focused on training, proactive and ongoing support with the availability of emergency back-up services, and someone to talk to within primary care and community services could help address caregivers' feelings of abandonment and anxiety.