

**An investigation of family carers' needs following stroke survivors' discharge from acute hospital care in Australia**

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## **ABSTRACT**

### **Purpose**

To contribute to the international knowledgebase on informal stroke care-giving, validated tools previously used in Hong Kong and the UK were used with Australian stroke carers to assess their stroke-related knowledge, perceived needs, satisfaction with services received and sense of burden after stroke patients' discharge home from acute hospital care.

### **Methods.**

Record audit and telephone interviews with two cohorts of 32 carers recruited in Sydney and Brisbane 1 and 3 months post hospital discharge, using validated scales and open questions in May-July 2006.

### **Results**

Female carers, those with prior care-giving responsibility, and those interviewed at three compared to one month post discharge reported greatest needs and burden from the care-giving role; needs alone significantly predicted burden. Getting information and being prepared for life after discharge were central concerns. Some felt this was accomplished, but inadequate information giving and communication mismatches were apparent.

### **Conclusions**

Service providers need to develop partnership working with stroke families and provide a network of services and inputs that cut across conventional boundaries between health and social care, public, private and voluntary organisations, with care plans that deliver what they delineate. Carers' issues transcend the boundaries of countries and healthcare systems; collaborative service development is advocated.

## **KEYWORDS**

Stroke      Nursing      Caregivers      Needs assessment      knowledge      satisfaction  
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## INTRODUCTION

More than one third of a million Australians were estimated to be stroke survivors in 2003, with more than 80% reported as disabled, half from the stroke [1]. As a consequence of falling in-patient stays for stroke patients (in the UK, from 34 days in 2001, to 23.7 days in 2008 [2]), stroke survivors may return home following relatively brief periods in hospital, requiring protracted if not life-long care in the community. With only 15% in institutional accommodation, the bulk of this care is delivered by informal, family carers [3].

Family care-giving for stroke survivors can encompass a very broad spectrum of physical, psychological, social and cognitive support activities. Of disabled Australian stroke survivors at home, around half need help with housework, mobility, transport etc, and around a quarter need help with self care and cognitive tasks. This can entail substantial time commitment; more than half of primary carers spend 40 hours or more each week in their caring role. With just over half of Australian stroke survivors (54%) receiving informal as well as formal (paid) care and almost one third (32%) solely supported informally, informal care-giving makes a sizeable contribution to supported community living [3].

The challenges can be considerable. Care-giving may represent a substantial departure from pre-stroke roles and relationships, and stroke carers may face this with little time to prepare or adjust [4]. A great deal rides on their preparedness and ability to cope: their own health and well-being, the quality of life and sustainability of community-living for the stroke survivor. Carers in Queensland, Australia reported spending 4.6 and 3.6 hours per day assisting patients with daily activities at 6 and 12 months post-stroke [5]. In Western Australia, emotional ill-health and disrupted social lives were reported in 79% of carers [6]. Given this, it is unsurprising that depression has been reported in 34% to 52% of carers [7]. Consequently, studies have sought to identify characteristics of carers and survivors that influence carer outcomes.

Reviewing qualitative studies, Greenwood et al [8] found recurring themes of loss of freedom, and need for information and emotional support. Positive experiences derived from greater closeness to the survivor or family, and from pride and fulfilment from the role. Reviewing quantitative studies, Greenwood et al [9] found a predominant focus on negative carer outcomes. Carer characteristics such as self-esteem and coping, perceived burden and physical health influenced carer outcomes. Focusing on studies predicting carer burden, Rigby et al found characteristics influential on reported burden were not consistently examined across studies [10]. Few examined longer-term effects, although one Victorian Australian study (n116) found carer depression at 3 years linked with stroke survivors' mood disorder, but less anxiety and irritability where carers had greater social support [11]. Overall, however, mixed but seldom high quality of studies, diversity of carers, varied timing and assorted outcome measures limit conclusions. Limited information has not precluded development of interventions for family carers. Information interventions have demonstrated improved patient and carer knowledge of stroke with little impact on other outcomes [12]; some benefit has been seen from counselling, problem-solving, support and training delivered by various media and professional groups [13].

A clear message is that it is an unsafe assumption that families can and will deliver necessary care without, at the least, adequate preparation via appropriate interventions to support their care-giving role and minimise associated burdens [13-20]. However, for services to be able to meet needs, likely local service demand must be anticipated. To date, limited research in this area has been undertaken outside of Europe and the US [9].

This project used methods and tools previously used in London and Hong Kong [18-20] to examine carers' perspectives of their care-giving situation and the extent of their perceived burden; to explore their needs, knowledge of stroke and satisfaction with services received after stroke patients' discharge home from acute hospital care. It was premised on assumptions extrapolated from the literature: that greater perceived needs would be accompanied by greater

burden, less satisfaction with services received, and poorer knowledge and understanding of the stroke-related situation [8-10,12,13].

## **METHODS**

The aim of the study was to advance international understanding by replicating in an Australian context investigation of the stroke care-giving situation previously undertaken in Hong Kong and the UK. Objectives were:

- To identify family carers' self-reported: needs, knowledge of stroke and management of its sequelae, satisfaction with service provision, and sense of competence with care-giving and its associated burden.
- To explore associations between carer characteristics and their self-reported needs, knowledge of stroke, satisfaction with service provision and caregiver burden, and identify factors predictive of burden.

### **Research Design**

This descriptive study used survey instruments delivered through telephone interviews and medical record audit with a convenience sample of acute stroke patients from two hospitals in two Australian states.

### **Research settings**

Participants were recruited from two Australian Acute Stroke Units (ASU) located in Sydney (New South Wales) and Brisbane (Queensland). In Sydney, the ASU comprised 8 designated stroke beds within a 30-bed neurology and transitional care ward; in Brisbane it comprised a 12-bed dedicated ASU. In both locations team meetings were held twice weekly; community and rehabilitation services were sparse and experienced high demand.

## **Participants and recruitment**

The study focused on family carers of patients admitted and subsequently discharged to non-institutional living arrangements from acute hospital care following admission with a clinical diagnosis of acute stroke (ICD-10 codes 160-164). Those transferred from acute hospital care to off-site rehabilitation services were excluded as their discharge procedures were likely to differ. Participants were required to have adequate English language skills to complete an interview.

At both sites patients admitted to ASUs were approached by a member of the research team in the week prior to stroke patients' discharge from hospital. Participating patients consented to access to their medical records and to contact with their carer to arrange a telephone interview after discharge. Participation was only possible where both patient and carer gave consent.

A second Sydney group were recruited from hospital records of patients with an identified carer, discharged within the previous 3 months. Records identified 70 patients, of whom 60 had an identified next of kin, 20 of whom were spouse or partner living at the same address. Postal addresses were not available for non-partner next of kin. Information about the project was mailed to both these 20 patients and carers. Where both returned signed consent forms, carers were contacted via telephone to arrange a telephone interview. All carer participants took part via telephone interview at times to suit their convenience during May-July 2006.

## **Data collection: Secondary data**

Healthcare records of consenting patients were accessed and data related to discharge preparation activities extracted. Demographic details and the stroke patients' functional abilities in activities of daily living pre-stroke and at discharge (modified Barthel Index: mBI) were collected [21]).

## **Data collection: Telephone interviews**

Interviews were conducted within 1 and 3 months of hospital discharge. Carers' self-perceived needs, competence in caring, knowledge and satisfaction with services were assessed using scales previously developed for and used with stroke carers.

*The Carer Assessment Scale (CAS; [19]).* This 18-item scale comprised generic, holistic assessment of physical, practical, psychological, and social needs. Statements required Likert-type responses ranging 'No', 'Not Much', 'Some' or 'Great' problem; total scores range 0 - 54 with higher scores indicating greater needs. Internal consistency of CAS items has been demonstrated with alpha coefficient for scores of 0.83 and 0.85 [20] and 0.85 and 0.79 [18] before and after discharge, respectively; 0.85 in this study.

*The Knowledge of Stroke scale (KOS; [18]).* This 27-item scale examined level of stroke knowledge. Three response categories – Correct or Incorrect Knowledge or Don't Know – covered four dimensions: knowledge of stroke disease (6 items), risk factors (7 items), stroke prevention (9 items) and therapy (5 items). One point was allocated for each correct response; 'don't know' and wrong responses were differentiated.

*The Sense of Competence Questionnaire (SCQ; [22,23]).* This 27-item scale assessed perceived burden and competence in caring within three subscales: satisfaction with dependent person as recipient of care, satisfaction with own performance as caregiver, consequences of caring for personal life. Statements required one of four responses from 'Disagree Very Much' to 'Agree Very Much'. Scores ranged 27 - 108, with higher scores indicating more negative perception. Good reliability has been demonstrated with Cronbach's alpha coefficient 0.83, intraclass correlation coefficient 0.93 [23]; Cronbach's alpha coefficient 0.88 in this study.

*The Carer Satisfaction Scale [18,24].* Twelve questions reflected carers' perspectives of care delivery during and after hospitalisation. The scale required 4-point Likert-type responses

from 'Strongly Agree' to 'Strongly Disagree'; higher scores indicate greater satisfaction, ranging 12 - 48. Cronbach's alpha coefficient was 0.88 in this study.

Open questions sought detail of problems and experiences, and any additional issues.

## **Data Analysis**

Data were analysed using SPSS for Windows Version 18 using appropriate parametric / non-parametric analyses. Participants' demographic characteristics (age, sex, state of residence, duration of current care-giving role, presence/ absence of previous care-giving experience) were examined in relation to participants' self-reported needs, knowledge, satisfaction with stroke services and sense of competence/ burden of caring. A 5% level of significance was accepted, with Bonferroni adjustment for sub-group analyses where appropriate. To investigate factors contributing to carers' sense of competence and perceived burden of care-giving, forward stepwise regression analysis was used to explore the impact of factors theoretically identified as likely contributors: (dummy coded) group memberships, previous care-giving experience and sex, self-reported needs and satisfaction with services. A minimum of 30 participants was adequate, with  $\alpha = 0.05$  for inclusion and 0.1 as criteria for removal from the model [25].

Open question responses were transcribed using word processing and content analysis employed to identify and enumerate patterns of response [26] by a single researcher (LP).

## **Ethical considerations**

Written informed consent was obtained from all participants. Approval was obtained from the Human Research Ethics Committees at both sites and the academic institution.

## **RESULTS**

### **Patients and carers**

In total 36 stroke patient – carer dyads were recruited, with full data available for 32 (21 from Sydney, 11 from Brisbane) due to late withdrawals following changes in patients' situation. All Brisbane and 15 (71.4%) of the Sydney patient and carer groups were of White Australian ethnic origin, with 6 (28.6%) in the Sydney ASU-recruited group classified as 'other Asian'. Prior to this stroke, 11 of the 18 female and 3 of the 14 male carers already had care-giving responsibilities. At the time of interview 9 combined care-giving with paid employment, 2 on a full-time basis. Comparing the three recruitment groups, there were no significant differences according to patients' age, sex, length of stay in hospital or mBI scores pre-stroke or at discharge. Neither were there any differences for carers' age or sex (Table 1). Those recruited by post were interviewed significantly later following stroke survivors' discharge from hospital, at mean (SD) 75.2 (21.8) days from discharge to interview compared with 31.4 (5) days for those carers recruited on the ASUs ( $p < 0.001$ ).

*Insert Table 1 about here*

A minority of carers reported having met with patients' therapists in hospital; 3 Sydney and 1 Brisbane carers had met a physiotherapist; 4 carers in both locations had met an Occupational Therapist (OT), with 1 Sydney and 2 Brisbane patients having OT home visits prior to discharge.

### **Carers' knowledge of stroke**

Carers were asked whether each of the CAS items (Table 2) had been discussed in advance of hospital discharge. Items most frequently cited were advice about expected course of recovery (n11), and medications (n9). Lack of knowledge and difficulty accessing it were commonly reported (Table 2).

*Insert table 2 about here*

Of the KOS questions, few attracted many incorrect responses but lack of knowledge was borne out by the number of 'don't know' responses: with 5 participants declining to answer this component, 161 of a total of 729 (22.1%) responses indicated absence of knowledge. With maximum possible score of 27 from the KOS scale and median (25,75 quartile) scores of 21.0 (17,23), there was no relationship between state of residence, length of hospital stay, patient or carer age, sex, prior or duration of current care-giving experience and knowledge scores. Related samples Friedman's two-way Analysis of Variance demonstrated significant difference in the distribution of subscale scores ( $p < 0.001$ ), which remained significant for all pairwise tests (all  $p < 0.011$ ). Broadly unrelated response patterns were also indicated by low correlation coefficients (Table 3).

*Insert table 3 about here*

### **Carers' self-reported needs**

One single carer reported no needs using the CAS. Problems mentioned by the greatest numbers of carers included their restricted social lives, tiredness, distress at the stroke survivors' state, the stroke survivors' mood fluctuation and difficulties getting information to prevent a further stroke (Table 2). Median (25, 75 quartile) CAS scores were 5 (2.0, 11.75), with no relationship between state of residence, length of hospital stay, age of stroke survivor or carer. However, significant differences were found between median (25, 75 quartile) scores of 10.5 (2.0, 16.0) for female carers and 3.0 (2.0, 5.0) for males ( $z = 8.780$ ,  $p < 0.003$ ). Those with pre-existing care-giving responsibilities reported significantly greater needs at 12 (4,18) for those with compared to 3 (2,8) for those without prior experience ( $z = 5.776$ ,  $p < 0.016$ ). At median (25, 75 quartile) 3 (2,5), lower need scores were reported by those interviewed closer to hospital discharge than those interviewed later, with median scores 11 (9,20) ( $z = 15.148$ ,  $p < 0.001$ ).

Carers were asked to identify their three areas of greatest difficulty (Table 4). One cluster centred around inter-personal difficulties with the stroke survivor: communication

problems, their fluctuating moods and behaviour. Others related to lack of information about the stroke itself and related topics; effects of the caring role for carers' life-styles, and psychological stresses encountered.

*Insert table 4 about here*

### **Carers' satisfaction with healthcare services**

With median (25, 75 quartile) scores of 37 (31.50, 41.0), there was no significant difference according to state of residence or recency of hospital discharge and satisfaction scores. No relationship was seen between age of stroke survivor or carer, or sex of carer and satisfaction with healthcare services. However, a weak positive association was seen between patient length of stay and carer reported satisfaction with services ( $r_s=0.409$ ,  $p<0.002$ ). Scores were not significantly different for those with and without prior care-giving experience, at 33 (28, 37) versus 39 (33, 42.75), respectively. Collapsing response categories to agreement and disagreement indicated highest overall levels of dissatisfaction arising from (non) receipt of information.

### **Carers' sense of competence and perception of burden**

The SCQ comprises 3 sub-scales, for which scores were calculated independently and summed for a total score [22]. Median (25, 75 quartile) total scores were 42.5 (27.5, 57.5) with no association between scores and patient or carer ages, or patient length of hospital stay. There was a significant difference between scores reported by female and male carers, at 47.5 (38, 54.25) and 38 (28, 44), respectively ( $z=-2.661$ ,  $p<0.007$ ). Responses were significantly more negative from those with prior care-giving responsibilities (48 (43, 58.25) versus 35.5 (29.5, 43);  $z=-3.612$ ,  $p<0.001$ ) and those interviewed later rather than earlier post stroke (48 (43, 59) versus 38 (32, 44.5);  $z=-2.879$ ,  $p=0.004$ ). Findings from Sydney carers were significantly more negative than those from Brisbane, at median (25, 75 quartile) scores of 44

(39, 51.50) compared to 37 (32, 41) ( $z=-2.164$ ,  $p<0.031$ ), possibly reflecting the contribution of those with longer duration of care-giving. Common areas of difficulty derived from feeling unable to leave their family member alone (n10, 31%), that they didn't have enough time for themselves (n9, 28%), that their social lives suffered as a result of care-giving (n12, 37.5%).

Examining subscale scores, the first 7-item subscale focused on satisfaction with the stroke survivor as a care-recipient; with maximum 28, median (25, 75 quartile) scores were 8 (5,11). The second 12-item sub-scale focused on satisfaction with their own performance as a carer; with maximum 48, scores were 17 (10, 24). The third 8-item sub-scale examined the consequences of involvement in care for the personal life of the caregiver; with maximum 32, group scores were 16 (9.5, 22.5). With item numbers per subscale and the increased risk of Type 1 error with multiple analyses taken into account ( $p<0.0166$ ), scores of the third subscale were significantly more negative than other subscales (both  $p<0.001$ ); consequences of involvement in care for the personal lives of caregivers were the major sources of negative effects of care-giving for these carers.

There was no association between patient or carer ages and subscale scores. Examining sub-scale scores according to timing of interview demonstrated significantly more negative findings for all three subscales from those interviewed at around three rather than one month post hospital discharge (Figure 1;  $z=-2.675$ ,  $p<0.009$ ;  $z=-2.507$ ,  $p<0.012$ ;  $z=-2.431$ ,  $p<0.014$ , for subscales 1-3, respectively). Examining sub-scale scores according to sex of carer demonstrated more negative reports from female carers, which did not reach the Bonferroni-adjusted level of significance ( $p<0.027$ ,  $p<0.041$ ,  $p<0.041$ , respectively). Examining sub-scale scores according to carers' state of residence revealed significant difference for the third subscale, with more negative findings from Sydney ( $z=-2.391$ ,  $p<0.016$ ). Examining sub-scale scores according to whether or not the carer had prior care-giving responsibilities demonstrated significantly more negative responses from those with this experience to subscale three only ( $z=-3.352$ ,  $p<0.001$ ).

## **Associations between needs, knowledge, satisfaction with services and caregiver burden**

Carers with higher reported need scores reported lower satisfaction with services ( $r_s = -0.567$ ,  $p < 0.001$ ); lower service satisfaction scores and higher self-reported needs were related to greater burden scores ( $r_s = -0.394$ ,  $p < 0.025$ ;  $r_s = 0.826$ ,  $p < 0.001$ , respectively). No relationship was seen between carers' scores for sense of competence and burden in care-giving and their knowledge of stroke. Hence stroke carers with greater needs tended to be less satisfied with services but despite non-receipt of information being reported as a major service dissatisfaction and one of the commonest areas of reported need, knowledge was not related to perceived burden.

Forward stepwise multiple regression was employed to examine relationships between carers' perceived burden and state domicile, interview timing, previous care-giving experience and sex (dummy coded); self-reported needs and satisfaction with services. This demonstrated only self-perceived need scores (CAS) contributed significantly, accounting for around 68% of variance (beta 1.194, SE 0.146, adjusted R<sup>2</sup> 0.681).

## **Carers talking**

Open questions sought detail of problems and experiences, and asked about additional issues not raised by the scales. Carers' narratives provided detail and personal meaning related to areas raised by the tools but no new topics were identified.

## *Stroke as a family affair*

Throughout, carers talked of the effect of the stroke not just for themselves but their children, wider family circle and social networks. Children's lives were intimately affected, from their co-option as relief carers, to needing to be 'sensitive' to newly-cohabitant grandparents'

frailty, and loss of contact with family members due to a 'difficult' stroke survivor. This posed additional strain for carers, many of whom had multiple caring responsibilities.

#### *Changed personality, roles and relationships*

Many carers perceived they were now living with a different person. Occasionally there were bonuses, with, for example, adoption of a more laid-back approach; more often personality change was not for the better. Carers found themselves with new roles and altered personal relationships. Occasionally spending time together, going through the experience together brought people closer but reports were more often of deterioration in relationships. Prior to discharge, carers reported lack of knowledge or preparation for these changes, having 'no idea about personality and mood changes' (S15). One was told to anticipate personality and judgement effects, but in terms of, 'things he can't do, such as climbing ladders' (S14).

#### *Uncertainty and anxiety*

Uncertainty was a dominant theme of these reports. Many carers complained they didn't know what had caused the stroke, what they could do to prevent another, what sort and degree of recovery might be possible. The hindsight view of eleven of 32 carers was not just that they didn't have the information they needed, but that it had not been given. Many lived with a constant state of anxiety, unable to let the stroke survivor out of their sight, or, if unavoidable, using elaborate precautionary systems.

#### *Conflicted attitudes*

Despite the cost of care-giving, many saw this as natural, the proper exercise of their responsibilities, fulfilment of a reciprocal cycle of care-giving, and expression not just of duty but love, for the person who was and the person now. As a consequence, some carers lived with a love-hate relationship with the situation as distinct from the person. Whilst there was gratitude

that the stroke had been survived, for therapy and recovery, there were also complaints about what had not or should not have occurred during the hospitalisation.

## **DISCUSSION**

The importance of the contribution of family carers to recovery, maintenance of function and provision of long-term care and support is increasingly recognised: in the UK since the Carers (Recognition & Services) Act and in Australia through policy directives such as the Carers Action Plan [28,29]. A good understanding of the perspectives and experiences of those who care for stroke survivors is important to ensure services meet users' needs and respond to policy. To date little detailed or in-depth study has been conducted in Australia.

### **Identifying carers' self-reported needs**

Stroke family carers' reported needs have been classified in six areas: for information about the nature, causes and consequences of stroke, and available services; difficulties around the mood state and behavioural responses of both patients and carers; carers being obliged to take on new roles and responsibilities, often with little preparation; carers experiencing reduced social and leisure time, increased isolation; the financial repercussions of a caring role; difficulties finding the balance of needs between the stroke survivor and carer [30]. Study findings support this, with priority problems and needs for these Australian carers reported as inter-personal difficulties with the stroke survivor, lack of information, the effects of the caring role for carers' lives, and resultant stresses.

Using the CAS tool similar priorities have been reported by carers in other locations; for example, health problems caused by caring, tiredness and restricted social life; financial difficulties, conflict caused by responsibilities and distress at stroke survivors' altered condition [18-20]. That the same priorities are identified by carers in four cities and three continents underlines the universal and ubiquitous nature of these needs, and supports the above

classification [30]. In response, service providers need to consider how to address the principles that carers' physical, emotional and career needs are identified, acknowledged and responded to [28,29], to protect carers' quality of life and the sustainability of the care-giving situation.

### **Differences in patterns of reported needs**

Comparing these median and mean scores of 5 and 7.5 to those reported by stroke carers in other locations, the first Hong Kong study ranked but did not sum scores, and the second cohort from that locale reported mean scores of 19.7 at two weeks after discharge [19,20]. This is noticeably higher than the other cohorts, with median score of 8 from the London cohort at 4-6 weeks after discharge [18]. Time may have been a consideration in relation to perceived needs, with the higher scores obtained earlier in Hong Kong and later in Australia (around 3 months) post discharge, compared to groups interviewed at around 1 month. Initial anxieties and uncertainties may have been high but to some extent subsided by 4-6 weeks, but by 3 months longer term implications of the caring role may have begun to be recognised. Cultural differences may also have contributed in the Hong Kong Chinese study.

Patients scored and prioritised lack of information highly; the single most frequently mentioned discharge preparation was receiving advice about expected course of recovery, yet only reported by 11 (34%). This was born out by 22% of knowledge scale responses indicating absence of knowledge and the predominant theme of uncertainty in their discourse. Despite this, knowledge did not significantly influence burden.

### **Sense of burden and competence**

A substantial body of work has examined carers' sense of burden. Rigby et al [10] found 24 studies examining correlates of burden; 25-54% of carers reported feeling burdened but with no consistent predictive pattern. This was probably unsurprising given the heterogeneity of timing, assessments and carer cohorts, but highlights the importance of good communication

between professionals and carers, and seeking the perspectives and needs of carers as well as stroke survivors.

At 42.5, median burden scores of these carers were not dissimilar to other cohorts: the original Dutch carer groups scored median 42 at 6 months (n166), median 38 at mean 17 months (n47), and mean score 47 at 3 years (n115) post-stroke [22,23]. More recent cohorts scored somewhat higher; another Dutch group with median 57 at 6 months (n151) [31]; the London cohort, with median 50 at 4-6 weeks (n33) [18]. Scores indicate the variability of cohorts across place and time, but within a relatively narrow range: medians 38 to 57 of a possible 27 – 108. Lacking normative population values for comparison, it is difficult to gauge the magnitude of distress these figures represent. However, with group maximal medians a little over half ceiling values, it is not unreasonable to surmise that these carers' experiences were not solely that of burden. This was born out by item median scores indicating strong agreement with statements that carers felt pleased about and useful in their interactions with their family member, and obtained a sense of their capability in the role. Conversely, and unsurprisingly given the priority problems and details they discussed, scores also revealed responsibility weighed heavily and many felt the physical and psychological effects within their own lives.

Stroke family care-giving is increasingly recognised as an integral part of stroke management, requiring that professionals assess and plan for this component of stroke patients' journey. To date, such assessment has been bedevilled by a multitude of different tools, challenging collation or cross-study comparison [10]. The assessment tools used in this study have been used previously with stroke family carers in Hong Kong and London [18-20]. With Australian states independently responsible for acute healthcare services, this suite of tools has now been used in three countries with four healthcare systems. This is a small but unique resource. Further, CAS findings significantly predicted carer burden scores, underpinning the value of conducting and using such assessment data to plan support for the care-giving role.

The scale and nature of this study must be born in mind. However, carers have been identified as a 'hard to access' group; even for quantitative studies, small numbers are not uncommon; for example, 14 and 40 carers in Hong Kong [19,20], 13 carers in Victoria, Australia [27]. The CAS scale was developed for use with stroke carers by nurses, without direct input from stroke carers. Nonetheless, its inclusiveness of stroke carers' perspectives was supported by piloting [19] and concurrent use of additional open questions has not uncovered new topics [18]. Scales employed in this study have all been used in prior stroke studies, but with limited investigation of their psychometric properties. This will be an important area for future study.

### **Messages for health services**

Study participants were interviewed by a researcher independent of the hospitals during time periods when effects of acute service delivery were still key; the importance of assessment of carers' support needs was demonstrated. Female carers and those interviewed longer after discharge reported greatest burden and needs; those with prior care-giving responsibilities reported greater needs and more negative consequences from the care-giving role. The merit of targeting support particularly for female caregivers, those with prior care-giving responsibilities and with greater perceived needs should be examined. Association between increasing needs with decreasing service satisfaction indicated that, in these carers' perceptions at least, services were least satisfactory where they were most needed.

Given that carers reported problems getting information about health and services, stroke and secondary prevention it was surprising that no link was seen between knowledge and burden scores; perhaps lack of information was not specifically perceived as burdensome or perhaps items did not capture the information carers desired. Getting information and being prepared for life after discharge were central concerns for these carers. Some felt this was accomplished, but inadequate information giving and communication mismatches were apparent. Carers' expectations were not always wholly reasonable but there were complaints of

lack of consultation about discharge arrangements even where their co-operation was essential. Non-receipt of information was the biggest source of dissatisfaction with services, yet knowledge was unrelated to either satisfaction with services or perceived needs. This may have been due to small sample size, but it may be that whilst lack of information was a major complaint, knowledge deficits were not the main drivers of general service dissatisfaction and did not impact daily needs. This is an important consideration, given that to date information-giving has been the main focus of interventions to support stroke carers. Smith et al [12] reported 17 interventions focused on education or information-giving, whilst Brereton et al [13] were only able to find eight studies focused on other interventions. This indicates an area for future research and service development.

For the present, current services could focus better on preparing families and carers for post-discharge care-giving, and set up appropriate supports to sustain this. Indices of need and burden were worse at three than one month, which is cause for concern at how carers are supported to sustain their role. Few carers had contact with therapists; many reported being unprepared for the scope and scale of life changes that they as well as the stroke survivor encountered. Whilst therapists experience the same difficulties as researchers accessing family carers, Kalra et al [17] demonstrated that carers can be engaged in preparation for life post discharge.

## **CONCLUSION**

Informal carers provide the bulk of stroke care-giving, and for many the personal toll is heavy. If this is to be sustainable, efforts must be made to ameliorate the burdens and enhance the positive aspects of care-giving. To do otherwise risks unnecessary hardships and public expenditure when informal arrangements fail. However, effective support of informal carers challenges all levels of health and social care policy and practice.

At service provision level, providers are challenged to encompass real partnership working with stroke families; to define and operate 'teams' to include not just health professionals but informal and lay supporters as well. At a commissioning and policy level, health and social care professionals are challenged to make services and budgets function with horizontal integration rather than within silos. Supporting carers requires a network of services and inputs that cut across conventional boundaries between health and social care, public, private and voluntary organisations. Importantly, carers need help to navigate these systems; to have care plans that deliver what they delineate, regular review and a point of contact for trouble-shooting and reassessment when situations change. This study has flagged that common issues for carers transcend the boundaries of countries and healthcare systems; what is required now is international response.

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## **DECLARATION OF INTEREST**

The authors report no conflict of interest.

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		<b>Sydney (recruited in ASU) (n10)</b>	<b>Sydney (recruited by post) (n11)</b>	<b>Brisbane (recruited in ASU) (n11)</b>	<b>Sig</b>
<b>Patients</b>	Mean (SD) age (yrs)	66.4 (16.0)	62.8 (12.7)	60.1 (19.2)	NS
	Median (IQR) *LOS (days)	9.5 (8.75 12.5)	8(6,12)	12 (11,15)	NS
	Median (IQR) **mBI pre-stroke	20 (19.5,20)	20 (20,20)	20 (20,20)	NS
	at discharge	18 (16.75,20)	17 (16,20)	20 (17,20)	NS
<b>Carers</b>	Mean (SD) age (yrs)	57 (7.3)	63.8 (15.9)	56.7 (15.0)	NS
<b>Patient is</b>	Female/ male	7/3	3/8	5/6	NS
<b>Carer is</b>	Female/ male	5/5	8/3	5/6	NS
<b>Carer is:</b>	spouse partner	6	11	7	
	daughter/ son/ in law	4	0	3	
	parent	0	0	1	
<b>Time</b>	Mean (SD) discharge to interview (days)	31.9 (6.4)	75.2 (21.8)	30.9 (3.6)	f=38.36, df2, p<0.001

**Table 1: Details of patients and carers**

\*LOS length of (hospital) stay

\*\* modified Barthel Index

<b>Carer Assessment Scale item:</b>	<b>n</b>
Restricted social life	18
Getting stroke prevention information	16
Distress at sick state	15
Own tiredness	13
Survivors' mood fluctuation	12
Assisting with ADLs	12
Getting information about services	12
Unco-operative behaviour	11
Lack of respite services	11
Finances	7
Inner role conflict	7
Communication	4
Getting equipment	4
Lack of family help	3
Lack of friends' support	3
Own health	3
Elimination problems	1
Embarrassed by personal care	0

**Table 2: Number of carers who identified each CAS item as a problem**

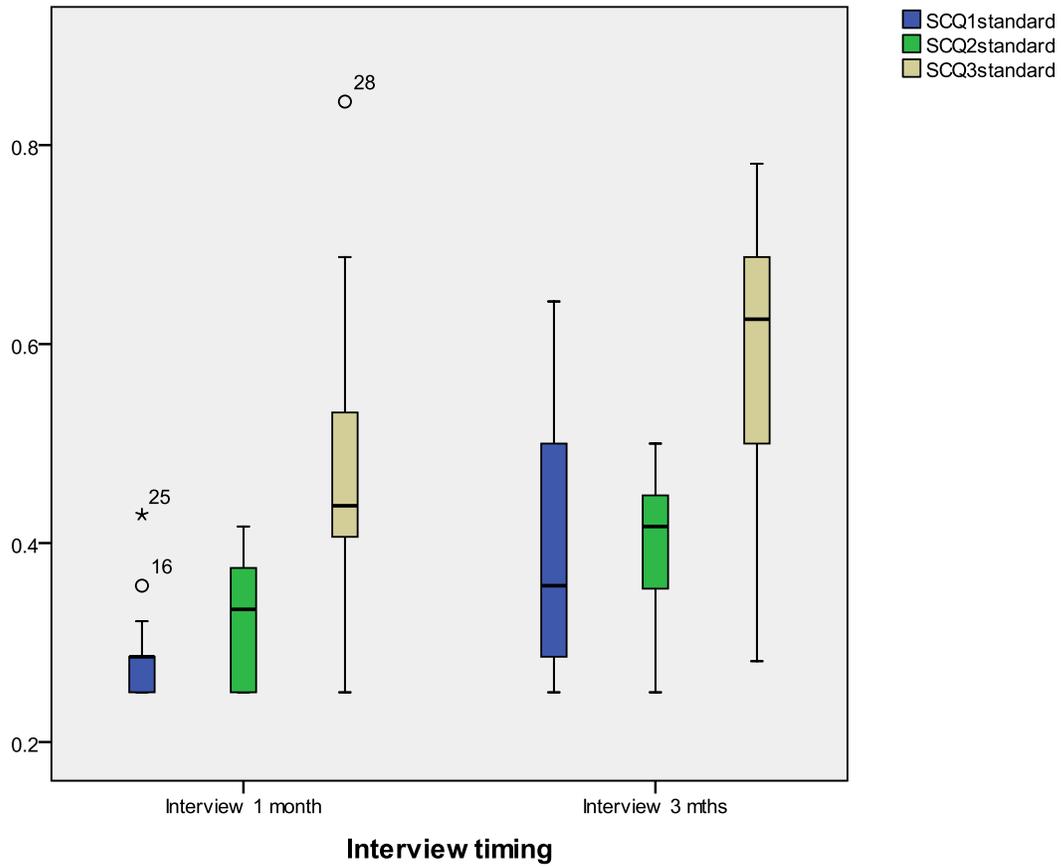
Subscales	Scores median (IQR)	Spearman's correlation co-efficient; significance			
		Disease	Risk factors	Prevention	Therapy
Stroke disease (max 6) median (IQR)	4.5 (4,5)	1	0.379 p=0.051	0.159 p=0.438	0.17 p=0.397
Stroke risk factors (max 7) median (IQR)	4 (3,6)	0.379 p=0.051	1	0.463 p=0.017	0.365 p=0.062
Stroke prevention (max 9) median (IQR)	7 (5.75,8)	0.159 p=0-438	0.463 p=0.017	1	0.543 p=0.004
Stroke therapy (max 5) median (IQR)	3 (1,4)	0.17 p=0.397	0.365 p=0.062	0.543 p=0.004	1

**Table 3: Knowledge of Stroke sub-scale scores and Spearman correlation coefficients.**

IQR: interquartile range

<b>Priority problems:</b>	<b>Total</b>
No priority cited	15
Info about stroke prevention	7
Distress at witnessing sick condition	7
Communication	6
Unco-operative behaviour	6
No longer the same person	6
Tiredness	6
Constant worry	6
Fluctuating mood	5
Social life restriction	5
Info about health & services	3
Lack of information about condition	3
Accessing respite care	3
Unable to leave survivor alone	3
Helping with ADLs	2
Getting equipment	2
Lack of help from family	2
Time commitment entailed	2
Financial problems	2
Inner conflict	1
Depression	1
Uncertainty about future	1
Survivor's poor memory	1

**Table 4: Top three priority problems reported by carers.**



**Figure 1: Carers' Sense of Competence Questionnaire sub-scale scores standardised to take account of item numbers, according to timing of assessment.**