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Judith Dianne Pugh

Kathleen McCoy

Anne M. Williams

Catherine A. Pienaar

Brenda Bentley

See next page for additional authors

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Authors

Judith Dianne Pugh, Kathleen McCoy, Anne M. Williams, Catherine A. Pienaar, Brenda Bentley, and Leanne Monterosso

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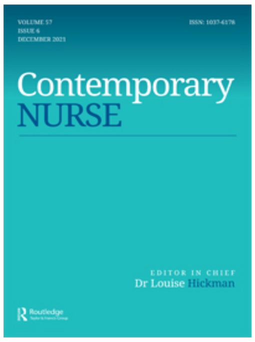

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Title: Neurological patient and informal caregiver quality of life, and caregiver burden: A cross-sectional study of postdischarge community neurological nursing recipients

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Authors:
1.Judith Dianne **PUGH**, PhD, MEd, RN
Adjunct Senior Lecturer
School of Nursing and Midwifery
Edith Cowan University, Joondalup, Western Australia

Neurological Change and Development Nurse, Neurological Council of Western Australia
Nedlands, Western Australia

Email: j.pugh@ecu.edu.au
ORCID ID 0000-0002-1835-1330

2. Kathleen **MCCOY**, MSc(Neuro), BSc(Hons) RN
Executive Director, Neurological Council of Western Australia
Nedlands, Western Australia

Professional Affiliate and Honorary Senior Professional Fellow,
WA Neuroscience Research Institute, Nedlands, Western Australia

Adjunct Associate Professor, Discipline of Nursing
Murdoch University, Murdoch, Western Australia

Email: ed@ncwa.com.au
Tel: +61 418 916 811

Corresponding author
3. Anne M. **WILLIAMS**, PhD, MSc, BSc (Hons), RN **(Corresponding Author)**
Professor of Health Research, Discipline of Nursing
Murdoch University, Murdoch, Western Australia

Research Consultant, Centre for Nursing Research
Sir Charles Gairdner Osborne Park Health Care Group, Nedlands, Western Australia

Research Consultant, Nursing & Midwifery Research & Practice Network
Fiona Stanley Fremantle Hospital Group
Murdoch, Western Australia

Research Consultant, Solaris Cancer Care
Collaborative Research Team
Cottesloe, Western Australia

Email: anne.williams@murdoch.edu.au
Tel: +61 488 203 888
ORCID ID 0000-0003-1564-8574

4. Catherine A. **PIENAAR**, MSc(Med), BSc(Nurs)
Project Officer, Child and Adolescent Health Service
Perth Children’s Hospital
Nedlands, Western Australia

Email: Cathy.Pienaar@health.wa.gov.au
ORCID ID s 0000-0003-3679-8715

5. Brenda **BENTLEY**, PhD, MA, MPA
Senior Lecturer, Discipline of Counselling
Murdoch University, Murdoch, Western Australia

Email: dr.brenda.bentley@gmail.com

6. Leanne **MONTEROSSO,** PhD, BN(Hons), GCEertTerTeach, RN, RM, NNT FACN
Professor and Chair of Nursing, School of Nursing and Midwifery
The University of Notre Dame Australia, Fremantle, Western Australia

St John of God Murdoch Hospital, Murdoch, Western Australia

Email: Leanne.monterosso@nd.edu.au
Tel: +61 8 9433 0103

Author contributions:

Criteria	**Author Initials**
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	JDP, KM, AMW, CP, BB, LM
Involved in drafting the manuscript or revising it critically for important intellectual content;	JDP, KM, AMW, CP, BB, LM
Given final approval of the version to be published. Each author should have participated sufficiently in the work to	JDP, KM, AMW, CP, BB, LM

take public responsibility for appropriate portions of the content;	
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	JDP, KM, AMW, CP, BB, LM

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Conflict of Interest:

No conflict of interest has been declared by the authors.

Abstract:

Background: Neurological conditions produce considerable disease burden.

Aims To describe quality of life in patients with neurological conditions and informal caregivers receiving postdischarge generic community neurological nursing services, and caregiver burden.

Method: A descriptive cross-sectional design was used with researchers administering the WHOQOL-BREF Australian Version questionnaire and Zarit Burden Interview.

Results: Most patients and caregivers rated quality of life as 'Good'. The patients' physical, psychological and environment domain scores, and caregivers' physical domain scores, were below norms. Half of the caregivers experienced burden and 42% had risk for depression.

Conclusion: A heterogeneous group of patients with neurological conditions had considerable care and support needs for fundamental functioning postdischarge. Quality of life and caregiver burden measures highlight the impact of their circumstances on their health and wellbeing. Research is warranted to determine a comprehensive set of generic needs to guide integrated community nursing services for building patient and caregiver self-management capacity.

Keywords: Neuroscience nursing, Cross-sectional Studies, Quality off Life, Caregivers, Patients

Impact statement

Older adults with long-term neurological conditions are generating increasing healthcare expenditure at national and local levels. It is important that community-based services support them to remain living at home and engaged in their community and reduce avoidable readmissions. Community-based nursing services should incorporate subjective quality of life measurement in regular functional assessments of these patients after hospitalisation. It is also imperative to assess informal caregivers' quality of life and carer-related burden. Routinely capturing patient and informal caregiver perspectives of these aspects of their lives will help planning postdischarge service delivery to enhance self-management capacity.

Introduction

Neurological conditions are diseases of the central and peripheral nervous system (World Health Organization [WHO], 2016) that may disrupt a person’s usual activities or wellbeing. These conditions may be sudden onset, intermittent and unpredictable, progressive, or stable (Neurological Alliance, 2012). Disabilities resulting from some neurological conditions can be ongoing and likely to change the nature and quality of a person’s life, impacting on relationships with family and friends. Quality of life (QoL) is a complicated concept which can be interpreted in many ways (Filipska, K. et al., 2020). It is important for health professionals to assess the QoL for persons with neurological conditions, to highlight actual and problems, and ensure that appropriate strategies and interventions are used to address and manage these.

Community based post-acute care programmes are being implemented as an alternative to inpatient services, to lessen the burden on acute-care hospitals. There is some evidence that suggests these programmes are cost-effective and reduce readmissions and demands on general practitioners (Hall et al., 2012). It is unclear whether such services can improve QoL (Lisby et al., 2019), although this is difficult to determine as numerous models of community post-acute care models currently exist.   The opening of a metropolitan tertiary public hospital in Western Australia (WA) in 2015 provided the opportunity to explore the QoL and service provision needs of neurological patients discharged into a generic community neurological nursing service. The burden on informal caregivers was also explored.

Background

In Australia, neurological conditions cause considerable disease burden, consuming 10% of total health system expenditure, with prevalence and burden increasing with age (Begg et al., 2007). Dementia and stroke, in particular, are expected to profoundly impact healthcare services. Dementia is a leading cause of non-fatal burden in older adults of all genders (Begg et al., 2007) while stroke is a leading cause of fatal burden (Australian Institute of Health & Welfare (AIHW), 2016b). Healthcare expenditure on neurological conditions in Australia is projected to almost triple by 2033, representing the second highest increase after diabetes and outstripping other chronic health conditions (Vos et al., 2007). Moreover, neurological conditions lead other conditions for absolute increase in projected expenditure (Vos et al., 2007).

In 2015-16, Australia-wide, diseases of the nervous system were ranked 13 of 21 among hospital separations by principal diagnosis, and represented 3% of hospital separations (AIHW, 2017). During that same period, diseases of the nervous system represented 1% of ED presentations in Australia and 1% in WA (AIHW, 2016c). Although a small proportion of all ED presentations, the potential impact is high as presentations with a primary neurological diagnosis are mainly for stroke, acquired brain injury, epilepsy, migraine, and transient ischaemic attack (DOH, 2015b). Importantly, 7% of stroke patients in Australia are readmitted within 28 days of discharge largely due to their pre-stroke functional status and/or complications, particularly, falls, urinary tract infections, pneumonia, and recurring stroke (Kilkenny et al., 2013).

As a large proportion of acute care hospital and rehabilitation patients are discharged home (AIHW, 2016a), it is crucial to help them remain living at home and engaged in their community and reduce avoidable readmissions by providing appropriate community support services (DOH, 2015c). Patients and their informal caregivers have been found to encounter many challenges post-discharge (Pugh, Williams, Bentley, Pienaar, McCoy & Monterosso, 2019). Neurological conditions in particular often cause long-term disability and many of those affected may have normal or near-normal life expectancy (WHO, 2006) which impacts on the workforce participation and financial wellbeing of informal caregivers (Bittman et al., 2007, Schofield et al., 2014).

A review of potentially avoidable hospitalisations among people with chronic conditions in Australia found the most effective initiatives were characterised by multidisciplinary team care, prompt identification of patients at risk, care coordination, integrated service delivery, and equitable access to primary health care (Katterl et al., 2012). WA community service organisations provide community-based clinical and/or non-clinical services to more than 19,800 people living with 130 plus neurological conditions and/or informal caregivers (DOH, 2015a, DOH, 2015b). These services are valued, as neurological conditions contribute greatly to the State's disease burden (Hoad et al., 2010). In 2016, a non-government organisation (NGO) commenced a generic community neurological nursing service in metropolitan WA, based on a model of care in regional WA (see McCoy & Chan, 2016). This nursing service provides supported patient discharge from acute care hospital to home for a heterogeneous group of patients with long-term neurological conditions who may be undergoing individual personal realignments while dealing with the challenges of ageing and disability (Alkema, 2016).

Qualitative evidence suggests that neurology-generalist nurses could bridge the gap between hospital and home to enhance self-management and continuity of care for patients with long-term neurological conditions (Pugh, McCoy, Williams, Bentley, & Monterosso, 2019). Such initiatives are expected to improve the individual's QoL and reduce informal caregiver burden. The subjective perspective of the effectiveness of efforts towards integrated care delivery after hospitalisation and self-management support for these patients is an important objective of needs assessments and program evaluations. However, before determining whether there is a differential impact of generic community neurological nursing services on patient and informal caregiver QoL, and caregiver burden, the NGO required baseline measures. The aim of this study was to describe the QOL of adults with neurological conditions postdischarge from an acute care hospital, at the initial assessment by a generic community neurological nurse, and that of their informal caregivers. Informal caregivers were defined as unpaid family or friends who provided ongoing care. Caregiver burden was also measured. The significance of this work was the establishment of baseline measures from which the impact of the generic community neurological nurse service could later be evaluated..

Method

Study design

This descriptive study used a cross-sectional design incorporating questionnaires.

Participants

A convenience sample of adult patients referred to the community neurological nursing service between 1 October 2016 and 27 June 2017 was recruited within two weeks of discharge from a tertiary WA public metropolitan hospital. Convenience sampling was chosen due to the limited timescale set by the project's funder. The patients' adult primary informal caregivers, that is, persons regularly assisting them without payment, such as family or friend, were also invited to participate. Patients were eligible if 18 years or older with principal medical diagnoses in the Australian Refined Diagnosis Related Group Version 7.0 of the Major Diagnostic Category 01 "Diseases and Disorders of the Nervous System". Exclusions were: same-day medical neurological diagnoses, apheresis, acute/chronic para/quadriplegia, skull fractures, other head injuries, surgical procedures, telemetric EEG monitoring, and nervous system disorders with ventilator support. Additional exclusion criteria were: discharged/transferred to acute hospital/residential aged care services/psychiatric hospital/other health care accommodation; discharged against medical advice/from leave/to other institutions; diagnosis/complication requiring extended hospital stay.

Data collection

The researchers trained the NGO's registered nurses (RNs) to administer the WHOQOL-BREF Australian Version (WHOQOL-BREF) questionnaire (Murphy et al., 2000) to assess patient and informal caregiver QOL, and the Zarit Burden Interview (ZBI) (Zarit, 1980) to assess caregiver burden. The WHOQOL-BREF is an abbreviated 26-item questionnaire of the 100 item WHOQOL. It contains one item from each of the 24 facets of the WHOQOL-100 in the four broad domains of physical health, psychological health or wellbeing, social relationships, and environment, plus two items from overall QOL and general health facets (Murphy et al., 2000). The ZBI (Zarit, 1980) is a 22-item questionnaire of caregiver burden when providing care to a loved one. Burden reflects the caregiver's perception of the emotional, physical, social, and financial impacts of caring on their own wellbeing and capacity to provide care (Rehabilitation Institute of Chicago (RIC), 2018).

The RN assessed the patient's level of functioning and service utilisation using the routinely administered Managing Well Neuro' Checklist (DOH, 2014). The Checklist records the patient's ability to perform activities of daily living (ADLs) (i.e., caring for and moving the body), instrumental activities of daily living (IADLs) (e.g., taking medications as prescribed), cognitive function, and social role functioning (e.g., choices about community activities such as employment, vocational, social and recreational activities).

Ethical considerations

Ethics approval was obtained from hospital (St John of God Health Care Ref. No. 980) and reciprocal approval from the university Human Research Ethics Committees (Murdoch

University 2016/164). Patients were referred to the nursing service by a clinician, RN, or allied health professional at multidisciplinary team meetings, or self-referral. To reduce inconvenience to patients postdischarge, the RN recruited participants to the study and administered questionnaires. During the first postdischarge home visit, the RN informed potential participants of the study purpose, methods, confidentiality, that participation was voluntary and non-participation would not affect nursing services, and that they could withdraw their data up to the point of anonymisation and analysis. Participants received a written information sheet and consent form. All participants provided written, informed consent including to share non-identifiable raw data with the WHO for further WHOQOL-BREF testing. Instruments were used with permission.

Data analysis

IBM SPSS Statistics 24 (IBM® Corporation, 2016, New York, NY) was used for quantitative data analysis. Patient and informal caregiver characteristics were described using descriptive statistics. WHOQOL-BREF scoring, calculated at first RN home visit, followed user manual and interpretation guide procedures (Murphy et al., 2000). The four raw domain scores were calculated and transformed to a 0–100 scale. Transformed scores were scaled positively with higher scores denoting higher QOL.

Histograms showed that patient and informal caregiver data were fairly symmetrical except for the patient social relationship domain, which was moderately-highly skewed. One-Sample *t*-Test determined if a statistically significant difference existed between the participants' mean QOL domain scores and Australian adult population norms reported by Hawthorne et al. (2006). An alpha level of .05 was used for statistical tests.

The informal caregivers' ZBI responses were scored on a 5-point Likert-type scale (0: Never; 1: Rarely; 2: Sometimes; 3: Quite Frequently; 4: Nearly Always). A global score was calculated by summing all items with scores ranging 0–88; higher scores indicated greater caregiver burden (Rankin et al., 1994). Caregiver burden, scores of 0–21 indicated little/no burden, 21–40 mild–moderate burden, 41–60 moderate–severe burden, and 61–88 severe burden (Iowa Geriatric Education Centre, 2016). The proportion of caregivers in each of these categories was calculated. Caregivers with a ZBI score ≥ 24 were considered at risk for depression warranting further assessment (Schreiner et al., 2006). Five domains and two dimensions were calculated from the clusters of items specified in scoring instructions (Zarit & Mapi Research Trust, 2014). The five domains were: (i) burden in the relationship, (ii) emotional wellbeing, (iii) social and family life, (iv) finances, and (v) loss of control over one's life. The two dimensions were personal strain and role strain. Informal caregiver cluster item ratings were summed to produce the score for the respective domain and dimension. Higher scores indicated greater caregiver stress.

Validity and reliability/rigour

Tests of the WHOQOL-BREF psychometric properties show it as valid and reliable (Murphy et al., 2000). The WHOQOL-BREF is recommended by professional associations as reasonable to use in patients with subacute cerebrovascular accident (CVA) or spinal cord injury (SCI), Parkinson's disease or traumatic brain injury (TBI) in outpatient rehabilitation or home health settings, and highly recommended for those with chronic CVA or chronic SCI (Motor Complete/Incomplete) (Raad et al., 2014). The ZBI has frequently been used in studies measuring burden amongst caregivers of older adults with Alzheimer’s dementia (Bédard et al., 2000). The ZBI addresses caregiver personal strain and role strain and has good internal consistency reliability in caregivers of patients with dementia, stroke, and TBI (American Psychological Association, 2016, RIC, 2018).

Results

Participant characteristics

There were 74 participants in this study, 47 (64%) were patients receiving the community neurological nursing services, and 27 (36%) were informal caregivers. More than half of the patient participants in this study (57%) had their informal caregivers participating.

Table 1 summarises patient and informal caregiver characteristics. The median patient age was 74 years (range 29-94); 57% (n = 27) were male, and 58% (n=27) were married/de facto. The highest level of education for most patients was secondary schooling (40%, n=19) with 72% (n=34) having below university or college level education. Most patients (79%, n=37) reported an annual household income < AUD$50,000 with the most common income being AUD$25,000–AUD$34,999 (34%, n=16).

Five diagnoses accounted for a large proportion (77%, n=36) of patient primary diagnoses in their recent hospitalisation: (i) stroke (53%, n=25), (ii) fracture (9%, n=4), (iii) encephalitis (6%, n=3), (iv) falls (4%, n=2), and (v) pain (4%, n=2). The remaining 11 (23%) patients each had a unique primary diagnosis. Considering secondary diagnoses on admission, or which subsequently developed affecting admission care, 66% (n=31) of patients had a single secondary diagnosis, 51% (n=24) had two secondary diagnoses, and 28% (n=13) had three secondary diagnoses. Patients with a primary diagnosis of stroke had the largest proportion of secondary diagnoses (53%, n=25), followed by those with fracture (9%, n=4). Three conditions accounted for 35% (n=17) of secondary diagnoses: (i) hypertension (16%, n=8), (ii) type 2 diabetes (10%, n=5), and (iii) ischaemic heart disease (9%, n=4).

Patients reported 0–12 problems during initial assessment. Four of the 12 potential problems covered by the Managing Well Checklist accounted for 51% of patient problems. These pertained to issues with daily living (e.g., dressing, bathing, food preparation, chores), moving around, sleep and endurance, and bladder/bowel control. Patients also indicated concerns about mood, nutrition, and thinking/remembering. Overall, 28 patients (60%) needed equipment, 23 (49%) needed increased assistance, and the RN referred 23 (49%) to an allied health professional and 5 (11%) to a medical specialist.

The informal caregivers' median age was 66.5 years (range 31-84); most were female (74%, n=20), and most were married/de facto (70%, n=19). In terms of their relationship to the patient, most were partners (70%, n=19) and had been caregivers for five years or less (77%, n=74). Most informal caregivers (93%, n=25) reported nil ill health. The highest level of education for most was secondary schooling (67%, n=18). More than three-quarters of informal caregivers (77%, n=21) reported annual household income as < AUD$50,000, with the most common income categories being AUD$15,000–AUD$24,999 and AUD$25,000–AUD$34,999 (each reported by 19%, n=5 of caregivers).

Patient and informal caregiver quality of life

Patients' and informal caregivers' perceptions of their QOL and health and the differences between their mean transformed domain scores and Australian population norms were calculated. The largest proportion of patients rated their overall QOL as 'Good' (43%, n=20) and an additional 6% (n=3) as 'Very good'. The remaining patients rated overall QOL as 'Poor' or 'Very poor' (28%, n=13), or as 'Neither poor nor good' (23%, n=11). Patient overall QOL was fairly symmetrical (skew -0.370) (Bulmer, 1979). Most patients (30%, n=14) were 'Satisfied' with their health overall, 28% (n=13) were 'Neither satisfied nor dissatisfied', 28% (n=13) were 'Fairly dissatisfied', 13% (n=6) were 'Very dissatisfied', and one was 'Very satisfied' (2%, n=1). Patient overall health satisfaction data was fairly symmetrical (skew -0.147).

Most informal caregivers (59%, n=15) rated their overall QOL as 'Good' and 11% (n=3) as 'Very good'. The remaining caregivers rated their overall QOL as 'Neither poor nor good' (19%, n=5), or as Poor' (4%, n=1). Caregivers' overall QOL data was moderately skewed (-0.618) (Bulmer, 1979). Most informal caregivers (52%, n=14) were 'Satisfied' with their health overall, 33% (n=9) were 'Neither satisfied nor dissatisfied', 7% (n=2) were 'Very satisfied', and 7% (n=2) were 'Fairly dissatisfied'. Informal caregiver overall health satisfaction data was fairly symmetrical (skew -0.341).

Table 2 shows the mean transformed scores of the WHOQOL-BREF for the Australian population reported by Hawthorne et al. (2006) compared with those of participating patients and informal caregivers. One-Sample *t*-Test indicated that the patients' mean physical domain score (*M* = 49.62, *SD* = 18.77) was lower than the general population score of 73.5, a statistically significant mean difference of 23.88, 95% CI [-29.39, -18.37], *t*(46) = -8.72, *p* < .001. The mean patient psychological score (*M* = 57.71, *SD* = 19.33) was lower than the general population score of 70.6, a statistically significant mean difference of 12.89, 95% CI [-18.56, -7.21], *t*(46) = -4.57, *p* < .001. The mean patient environment score (*M* = 67.22, *SD* = 14.66) was lower than the general population score of 75.1, a statistically significant mean difference of 7.88, 95% CI [-12.18, -3.58], *t*(46) = -3.69, *p* = .001. The mean patient social relationships domain score (*M* = 67.39, *SD* = 18.58) was lower than the population norm of 71.5, a non-significant mean difference of 4.11, 95% CI [-9.63, 1.41], *t*(45) = -1.50, *p* = .141.

One-Sample *t*-Test indicated that the informal caregivers' mean physical domain score (*M* = 64.29, *SD* = 17.96) was lower than the population norm of 73.5, a statistically significant difference of 9.21, 95% CI [-16.47, -1.96], *t*(25) = -2.62, *p* = .015. The caregivers' mean psychological domain score (*M* = 66.51, *SD* = 15.83) was lower than the population norm of 70.6, a non-significant mean difference of 4.09, 95% CI [-10.49, 2.30], *t*(25) = -1.32, *p* = .199. The caregivers' mean social relationships domain score (*M* = 63.78, *SD* = 20.68) was lower than the population norm of 71.5, a non-significant mean difference of 7.72, 95%

CI [-16.07, 0.63], *t*(25) = -1.90, *p* = .069. The caregivers' mean environment domain score (*M* = 70.07, *SD* = 17.14) was lower than the population norm of 75.1, a non-significant mean difference of 5.03, 95% CI [-11.95, 1.90], *t*(25) = -1.50, *p* = .147.

Informal caregiver burden

Twenty-six of the 27 informal caregivers completed the ZBI. Table 3 shows domain and dimension scores, and level of burden. The informal caregivers' mean burden score was 22.88 (*SD* = 16.81). Considering level of burden, most informal caregivers (50%) were classified as experiencing 'Little or no burden'. Eleven (42%) caregivers had ZBI scores ≥ 24 indicating risk for depression.

Discussion

The generic community neurological nursing service was in its formative state at the time. The service's aim was to facilitate and support self-management for a diverse population of people with neurological conditions discharged to home. Patients surveyed were predominantly older adults; most post-stroke and most male; while most informal caregivers were female. Almost half of the patients in this study (49%, n=23) rated their overall QOL positively. However, the group's mean physical, psychological, and environment QOL domain scores were lower than Australian population norms (Hawthorne et al., 2006) suggesting that these domains may be priorities for future intervention. QoL is a complex phenomenon which can be influenced by personal characteristics and social circumstances, as well as environmental factors. For example, QoL was found to be higher in older persons in Poland with neurological conditions who were married compared to single persons. Persons living in urban areas were also found to have higher QoL (Rajtar-Bajarczuk et al., 2019). Results from a large sample (n=4628) of persons in the United Kingdom with a wide range of chronic health conditions also found marital status to impact on QoL, as well as educational level and age. Uneducated, single, and older aged persons were found to have lower QoL

scores (Skevington & McCrate, 2012) The majority of patients in our study were married/defacto (58%, n=27), and educated a secondary school level and above (80%, n=38). These personal characteristics may explain our finding of generally positive QoL scores for neurological patients, although the mean transformed scores were found to be lower than the scores reported for general Australian populations (Hawthorne et al., 2006).
In a meta-synthesis of qualitative research, it was postulated that people post-stroke may need to redefine their sense of self and identity and their responses to dependency and support in relationships. Hence, individualised follow-up postdischarge and supportive strategies such as those offered by a community nursing service, may help patients to find new meaning in their lives, regain personal control and increase QoL (Moeller & Carpenter, 2013).

Participants in the current study reported annual household incomes below AUD$50,000, most below AUD$35,000 and below the second quintile for 2016 Australian household incomes (.id Consulting, 2018). Community-based service providers in rural New South Wales believe that poor financial status prevents older patients with chronic ambulatory care conditions from accessing needed services, adversely impacts QOL, and may contribute to frequent and/or avoidable admissions (Longman et al., 2011). Most informal caregivers in this study (~59%) were satisfied with their health. However, the group's mean physical QOL domain score was lower than Australian population norms (Hawthorne et al., 2006), which warrants consideration by the community neurological nursing service provider. The ZBI scores indicated that half of the informal caregivers experienced little or no burden. The remaining caregivers reported mild–moderate or moderate–severe burden and were at risk for depression. This level of caregiver burden was consistent with other populations of caregivers of patients with stroke but was lower than for caregivers of community-dwelling adults with general disability (Schreiner et al., 2006). The older adults with general disability in Schreiner et al.'s study had difficulties with ADL and behavioural disturbances and a large proportion had dementia—the latter was not so in our study. Nonetheless, caregiver burden is thought predictive of depressive symptoms long-term (O'Rourke & Tuokko, 2003).

Individual traits of informal caregivers of post-stroke care recipients, the largest proportion of primary diagnoses in our study, may predispose them to high levels of burden and mental distress long-term irrespective of the care recipient's physical and mental health and functional status (Danker et al., 2016). A cross-sectional study of caregivers of hospitalised chronic stroke patients in South Korea, found that caregiver burden largely determines caregiver QOL (Jeong et al., 2015). The impact of caregiver burden on QOL in that study was exacerbated if the caregiver was a spouse, in poor health, and/or had a low income and/or if the patient was unemployed and/or hospitalised for a prolonged time. By comparison, Pucciarelli et al. (2018) found in the initial year following discharge home that QOL in ‘stroke caregivers’ generally remains stable though anxiety and depression levels may worsen and caregiver burden may fluctuate. They found these characteristics of stroke caregivers predicted lower QOL: older age, male, lower education, living separate from the stroke survivor, caring for younger stroke survivor, and caring for stroke survivor with higher dependency in ADL.

Previous research shows that the physical and psychological burden of intensive caring can have negative impacts on the informal caregiver’s health such as depression, sleep disturbances, stress-related conditions, and musculoskeletal injuries from manual handling the care recipient and/or equipment (Pezzullo et al., 2010). Prevalence of mental health problems among caregivers in the 37 countries of the Organisation for Economic Cooperation and Development is 20% higher than among non-caregivers (Colombo et al., 2011). In Australia, however, the prevalence of mental health problems is 70% higher among caregivers engaged in high intensive caring (> 20 hours/week) than non-caregivers (Colombo et al., 2011). Informal caregivers bear almost three-quarters of financial costs associated with their care-related health conditions and the community the remainder (Pezzullo et al., 2010). These costs can be considerable, for example, in 2010, the sleep impacts of caring and associated disorders (e.g., depression, diabetes, cardiovascular disease) were estimated to exceed AUD$1 billion per annum (Pezzullo et al., 2010). Hence, the community neurological nursing service in this study could play an important role in ensuring prompt assessment, monitoring, and referral of informal caregivers to alleviate their perceived burden and reduce the likelihood of deterioration in their physical health, psychological health, and wellbeing.

Leppin et al. (2014) caution that older and high-risk patients without appropriate support have low capacity for self-care making them vulnerable to costly unplanned readmissions and poor health outcomes. Patients must be able to access care, use care, and enact self-care in order to improve their outcomes. The success of a patient in this regard depends upon the balance between their workload as patients (understanding and planning for care, enrolling help of others, and accessing healthcare services) and their capacity, that is, the resources at their disposal and the quality of those resources categorised similarly to the four QOL domains we measured. Supportive interventions addressing contextual issues and limitations in patients' capacity, that is, the resources available to reduce their workload, are likely to be cost-effective by reducing hospital readmissions (Leppin et al., 2014). Therefore, building the capacity of people with neurological conditions and their informal caregivers should be a service imperative towards improving their QOL. This means providing the postdischarge support to enable them to perform their respective roles, solve problems and set and achieve their goals while adapting to their long-term neurological condition. Appropriately targeted informal caregiver education and training, for example, is a cost-effective strategy for reducing caregiver burden, improving their QOL and psychosocial outcomes, and reducing their reliance on formal health and community services (Pezzullo et al., 2010).

Almost one-fifth of the caregivers surveyed reported annual household incomes in the lowest quintile, that is, the lowest 20% of Australian households. Frequently, informal caregivers forego employment, reduce hours of work, and make other work adjustments in order to fulfil caring responsibilities (Pezzullo et al., 2010). A study of informal caregivers of adults in Australia found an inverse relationship between caring intensity and full-time employment (Bittman et al., 2007). In that study, half of caregivers with intensive caring responsibilities were not employed while those with medium or intensive care responsibilities were marginally attached—they wanted to work but could not. Schofield et al. (2014) similarly found that 50% of informal caregivers of persons with chronic, disabling conditions were unable to participate in the labour force.

In Australia, neurological conditions are amongst the five conditions of care recipients with the greatest impact on labour force participation by informal caregivers of working age such that 60-70% of caregivers in these groups were not employed (Schofield et al., 2014). Affected individuals, informal caregivers and families bear the brunt of financial losses associated with caring particularly for those with intensive caring responsibilities, often women, who likely have lower hours of employment, if employed at all, and lower annual earnings (Bittman et al., 2007). Although labour-force participation among the informal caregivers in our study was not elicited, most were female partners who had been caregivers for five years or less and lived in low-income households. This is important contextual information for community-based healthcare service providers. It follows that navigation of social care services, including financial services/resources, should be part of the community neurological nurses' work with patients with long-term neurological conditions and caregivers. Improving informal caregivers' access to financial resources is important for reducing financial consequences that might otherwise impair their capacity and increase their risk for negative outcomes (Reinhard et al., 2008).

Limitations

The small convenience sample, as well as the large proportion of older aged patients will not be representative of postdischarge patients with neurological conditions and their informal caregivers and as such, the findings of this study cannot be generalised to other cohorts. The low annual household income and the lower levels of patients’ QOL when compared to the general Australian population, may have been associated with the older age of this sample. Further research is warranted with a larger sample to better estimate the QOL domain values in these populations. Nonetheless, the mean QOL domain scores, even those that were not statistically significant, may still be clinically or practically important (du Prel et al., 2009) and from a community neurological nursing service perspective, understanding the influence of various factors on QoL, may enable more effective allocation of resources to those patients and informal caregivers in greatest need. .Furthermore, the establishment of baseline data for this neurological population provides a basis for future longitudinal research into QoL and caregiver burden. Ethnicity was not explored in this current study, and considering the diverse range of ethnicities within Australia, it would be important that this is included in future work.

Conclusion

Notwithstanding the limitations associated with the design of this study, findings highlighted a number of postdischarge needs that could be addressed by a generic community neurological nursing service for patients with neurological conditions and their informal caregivers. QoL among these patients was lower than previous studies conducted with Australian populations in the physical health, psychological health, and physical environment domains, reflecting their care and support needs for fundamental functioning. QoL amongst informal caregivers was similar to Australians generally, apart from the lower physical domain. Half of the caregivers found their role onerous enough to put them at risk of carer-related depression. Low household incomes in the study group, reflecting demographic factors such as age, are likely to impact their health, wellbeing, and living standards. This small-scale study provides the basis for determining the generic needs in a heterogeneous and vulnerable neurological patient population, including informal caregivers, to guide the provision of postdischarge services that enhance their capacity for self-management. Further research is required to explore whether a generic community neurological service model addresses and supports the needs of this population.

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Table 1. Characteristics of patients (*n*=47) and informal caregivers (*n*=27)

Characteristics	Patients *n* (%)	Informal caregivers *n* (%)
Age in years, median	74 (range 29-94)	66.5 (range 31-84)
Gender		
Male	27 (57)	7 (26)
Female	20 (43)	20 (74)
Education level		
Primary school	8 (17)	
Secondary school	19 (40)	18 (67)
Apprenticeship	7 (15)	
University or college	10 (21)	7 (26)
Postgraduate	2 (4)	
Unknown	1 (2)	
Marital status		
Single	3 (6)	2 (7)
Married or de facto	27 (57)	19 (70)
Separated	1 (2)	
Divorced	7 (15)	4 (15)
Widowed	9 (19)	
Declined to answer		2 (7)
Annual household income[†]		
< $5,000	2 (4)	1 (4)
$5,000 to $9,999	1 (2)	
$10,000 to $14,999	3 (6)	3 (11)
$15,000 to $24,999	10 (21)	5 (19)
$25,000 to $34,999	16 (34)	5 (19)
$35,000 to $49,999	5 (11)	6 (22)
$50,000 to $74,999	3 (6)	2 (7)
$75,000 or above	4 (9)	3 (11)
Do not know	1 (2)	1 (4)
Declined to answer	1 (2)	1 (4)
Informal carers' relationship to the patient[‡]		
Partner		19 (70)
Child		3 (11)
Other relative		2 (7)
Other (excluding friend or neighbour)		2 (7)
Declined to answer		1 (4)
Duration of informal caregiving[‡]		
< 1 year		10 (37)
1- 5 years		10 (37)
6 - 10 years		1 (4)
11 - 15 years		1 (4)
16 - 20 years		2 (7)
> 20 years		2 (7)
Declined to answer		1 (4)

[†] Annual household income in Australian dollars.

‡ Questions on caregivers' relationship to patient and duration of caring answered by carers only.

Table 2. WHOQOL-BREF scores of Australian population, Neurocare patients, and informal caregivers.

	Australian population norms (N = 866) Mean (SD)	Patients (*n* = 47) Mean (SD)	*p* value	Informal caregivers (*n* =26) Mean (SD)	*p* value
Domain[†]					
Physical	73.5 (18.1)	49.62 (18.77)	**< .001**	64.29 (17.96)	**.015**
Psychological	70.6 (14.0)	57.71 (19.33)	**< .001**	66.51 (15.83)	.199
Social relationships[‡]	71.5 (18.2)	67.40 (18.58)	.141	63.78 (20.68)	.069
Environment	75.1 (13.0)	67.22 (14.66)	**.001**	70.07 (17.14)	.147
Quality of life rating[§]		3.23 (1.03)		3.84 (0.69)	
Health satisfaction[¶]		2.81 (1.08)		3.59 (0.75)	

† Domain scores transformed to a 0-100 scale.
‡ Data missing for one patient.
§ Two caregivers did not rate their quality of life.
¶ All 27 caregivers rated their degree of satisfaction with their health.

Table 3. Zarit Burden Interview scores of informal caregivers (*n* = 26).[†]

	n (%)	Mean	SD	Range
Global score[†] (Possible range 0–88)		22.88	16.81	1–59
Domain[‡] (Possible range)				
Burden in the relationship (0–24)		7.19	4.76	0–17
Emotional well-being (0–28)		6.50	5.66	0–20
Social and family life (0–16)		4.19	3.81	0–13
Finances (0–4)		1.19	1.33	0–4
Loss of control over one's life (0–16)		3.81	2.95	0–10
Dimension[‡] (Possible range)				
Personal strain (0–48)		11.58	8.33	1–30
Role strain (0–24)		6.46	5.69	0–16
Level of burden[‡] (Possible range)				
Little or no burden (0–20)	13 (50)			
Mild to moderate (21–40)	8 (31)			
Moderate to severe (41–60)	5 (19)			
Severe (61–88)	Nil			
Risk for depression[§]				
Nil apparent risk	15 (58)			
At risk	11 (42)			

† One informal caregiver did not complete the Zarit Burden Interview.
‡ Higher scores indicate greater carer stress.
§ Global scores ≥ 24 considered risk for depression (Schreiner, Morimoto, Arai, & Zarit, 2006)