Factors associated with quality of life and caregiver strain amongst frail older adults referred to a community rehabilitation service: Implications for service delivery

Abstract

**Purpose:** To identify factors contributing to reduced quality of life and increased caregiver strain in an older population referred to a community rehabilitation team and to recommend service delivery models.

**Methods:** Analytical cross-sectional study arising from baseline assessments from 107 subjects drawn from a randomised controlled trial of community rehabilitation service delivery models.

**Setting:** A community rehabilitation team based in Brisbane, Queensland, Australia.

**Measures:** Primary outcome variables include quality of life (EQ-5D & VAS) and Carer Strain Index. Predictor variables include participation in functional activities, history of falls, number of medications, number of co-morbidities, depression, environmental hazards, physical function and nutrition. Association between variables assessed using linear regression.

**Results:** Major factors contributing to reduced quality of life were having reduced participation in daily activities, depression, and having poor vision. Having poor nutrition and no longer driving also contributed to poor quality of life. The major factor contributing to increased caregiver strain was reduced participation in daily activities by the older person.

**Conclusions:** Community Rehabilitation Services working with older populations must adopt models of care that screen for and address a wide range of factors that contribute to poor quality of life and caregiver strain.
INTRODUCTION

Community Rehabilitation Services treating frail older adults are inconsistent in the range and delivery of services offered. Whilst some teams offer only specialist services such as spinal cord injury or stroke rehabilitation; other services are required to treat older adults with a wide range of issues associated with ageing such as frailty, falls, osteoporotic fractures and other neurological conditions. Community Rehabilitation Services have developed in an ‘ad hoc’ way often without understanding the needs of the community, identifying an appropriate skill mix for the team or surveying available evidence on best practice models of care. Many services lack outcome measures and do not use standardised assessments [1].

Given this; it is very difficult to define a best practice model of care for community rehabilitation. There is a scarcity of research determining the best models of care likely to be due in part to the broad scope of community rehabilitation services [2].

Improving health-related quality of life (HRQoL) is considered to be a key focus and goal for health services treating older people [3]. Whilst this goal is an accepted priority for rehabilitation services, there are many factors outside the patient’s primary diagnosed condition that can impact on their HRQoL. A Canadian study in a population of older people receiving home care services found that lower quality of life scores were related to depression, co-morbidities and older age (>85) [4]. Another study in a similar cohort found significantly lower HRQoL results in those with mild to moderate cognitive impairment and lower activities of daily living (ADL) performance [5]. Depression and lack of social supports were found to be related to low quality of life in a study of women receiving home health care [6].

These previous studies have focussed on specific populations of older people receiving home care services. In clinical practice, community rehabilitation services are often required to treat
patients with a wide range of conditions and co-morbidities who may not have previous experience with community health services. There is a need to investigate factors associated with HRQoL amongst this patient population to inform and refine service delivery models for community rehabilitation services.

Client factors (intrinsic and extrinsic), family support and environmental factors impacting on the individual must also be considered for any service provision to this community dwelling population. There is a trend by hospitals to reduce length of stay by either facilitating early discharge from hospital (e.g. hospital-in-the-home programs) or moving clients into the community setting to undertake the rehabilitation component (day hospital or domiciliary based allied health interventions) [7]. The impact of such programs affects not only the clients but more so the caregiver. If informal care arrangements break down, older people become reliant on formal care which also affects health care budgets. It has been estimated that the cost of replacing all the informal care by formal care providers in Australia would be 30.5 billion dollars per year (2005 figures) [8]. Caregiver Strain has not been well researched in the past. Where it has been researched it has been correlated with care recipient’s activities of daily living (ADL) ability [9, 10], inadequate social support [11], and ability of the care recipient to self medicate [12]. A US study of the health impact on caregivers of frail older adults found the caregiver emotional strain was the strongest common predictor of both poor perceived health and functional limitations[13]. These studies compared only a few predictor variables with caregiver strain. There may be many other factors which contribute to caregiver strain that have not been previously examined.

This study aims to identify factors associated with poor HRQoL and caregiver strain outcomes amongst older community dwelling adults undertaking a community rehabilitation program and propose service models which may ameliorate these factors in this population.
METHODS

Study design

An analytical cross-sectional study arising from baseline assessments for a randomised controlled trial comparing community rehabilitation service delivery models was conducted. Full methodology of the trial has been previously reported [14].

Participants

All consenting participants (n=107) referred to a community rehabilitation service based in Brisbane, Australia were eligible for the trial if they were referred to the service for falls or functional decline, were aged 60 years and over and were able to complete a timed up and go test [15]. Participants were excluded if they resided in high level care, were non ambulant or were assessed by an Occupational Therapist or Physiotherapist at the initial assessment as being unable to participate in a rehabilitation program due to physical or cognitive function (screening performed using the abbreviated mental test score (AMTS)) [16]. Participants were referred from the emergency departments of three local hospitals after presentation for a fall or from general practitioners on the basis of having a recent fall or for poor balance and/or functional decline.

Measures

Outcome variables collected included HRQoL, measured using the European Quality of Life five dimensions (EQ-5D) and visual analogue scale (VAS), and the Carer Strain Index (CSI). The EQ-5D and VAS are widely used and recognised instruments for recording generic HRQoL and have been validated for a variety of clinical conditions [17, 18]. For the purpose
of this study United Kingdom weights were used to calculate utility weights for the EQ-5D [19]. The CSI is a short and easily administered screening instrument with 13 items related to strain and has acceptable reliability and validity in an older population [20].

Explanatory variables included demographic, general health, physical function, cognitive function, body mass index (BMI), occupational functioning and environmental risks.

Demographic and health assessments contained within the Ongoing Needs Inventory [21] (ONI) were used to collect demographic data and basic health data (by self-report). Variables included age, gender, living arrangement (alone or with others) and the number and type of co-morbidities and medications. Participants were asked if they were still driving (Y/N), how many falls they had within the last 6 months and whether they suffered urinary incontinence (Y/N). Sensory impairment (vision and hearing) was self-rated on a four point scale (excellent, good, fair or poor). The participants’ weight and height were measured in order to calculate BMI and nutritional status was screened using the malnutrition screening tool [22] modified for the community setting [21]. Mental health was assessed using the K10 depression scale [23] and cognition was assessed using the Abbreviated Mental Test Score (AMTS) [16].

A battery of physical assessments was used to assess underlying physical functioning. Mobility was assessed using the timed up and go [15]. Balance was assessed using the Romberg balance assessment [24], testing balance for up to 30 seconds with feet together and eyes shut. Use of a walking aid for indoor mobility was also recorded. The 9-hole peg test [25] was used to measure upper limb function on both the left and right upper limbs. This tool can be used in the assessment of combined factors of upper limb function (coordination, speed, strength and range of motion). The Frenchay Activities Index (FAI), a self-report functional participation scale, was used to assesses participation in a combination of activities
of daily living, leisure (social and participative) and work [26].

**Procedure**

Data were collected by treating staff of a Community Rehabilitation Service based in Brisbane, Australia. Staff were trained in the use of the assessment tools by the chief study investigator. All participants were assessed jointly at home by an Occupational Therapist and Physiotherapist. For participants who had caregivers present at initial assessment (co-resident or residing elsewhere), the caregiver was asked to complete the CSI.

**Analysis**

Baseline and demographic data were presented in terms of mean (standard deviation) or frequency (percentage). Association between explanatory and outcome variables was examined individually using univariate linear regression analyses. Data were analysed using STATA version 9.2 Texas (StataCorp).
RESULTS

Data from 107 participants with completed initial assessments were used for the purposes of this study. Of these participants, 45 had caregivers who completed the CSI.

Demographic and baseline participant characteristics are presented in table 1. Participants ranged from 61 to 91 years old, were mainly female and mostly lived with others in their own homes. Participants generally did not drive, had poor health related quality of life on both EQ-5D and VAS and showed reduced participation in work, activities of daily living and leisure activities as measured by the FAI. A high proportion of the participants (40%) had a body mass index of under 24 which has been linked to increased morbidity and mortality in older populations, [27] and is also a marker of frailty [28]. Just over half the participants required a walking aid for indoor use. For the caregivers, 10 respondents (22%) scored 8 or over on the CSI indicating high levels of strain [20].

**Insert table 1 about here**

Table 2 presents the results of univariate analyses of associations between independent variables and the quality of life and caregiver strain outcomes examined. For the EQ-5D significant positive associations were found with increased levels of participation in normal activities and being able to drive. Factors which negatively impacted on quality of life were depression, impaired hearing and vision and poor nutritional intake.

**Insert table 2 about here**

Associations between independent variables and the EQ-VAS outcome were similar to those for the EQ-5D. Again a significant positive association was found between the level of participation in normal activities and perceived HRQoL. Negatively impacting factors were found to be depression, having poor reading vision and poor nutrition.
For the CSI, a significantly lower level of caregiver strain was associated with the recipient of the care showing increased levels of activity and participation in activities captured within the Frenchay Activities Index. Caregivers of clients who were overweight (as compared to normal weight) also displayed lower caregiver strain. Depression, reading vision and intact balance of the client were close to significance.

DISCUSSION

Overall the results of the regression analyses indicate that factors such as participation in daily activities, depression, sensory factors (vision), and nutrition play a much greater role in determining HRQoL than tests of physical capabilities which were found not to have significant associations with these outcomes.

The FAI measures participation in activities of daily living and broader community participation. Rehabilitation services have been criticised previously for predominately providing impairment based goals and therapy for clients, rather than focussing on client centred goals which are often related to improving participation [29]. Given that increased participation in normal activities was significant both for the patient in terms of improved quality of life and the caregiver in terms of reduced strain; rehabilitation services need to provide opportunities to improve participation. Rehabilitation services may benefit from using a universal framework such as the International Classification of Functioning, Disability and Health (ICF) [1]. Using the ICF domains of activity and participation to guide goal setting and treatment and to clarify team roles may assist rehabilitation teams in achieving this outcome. The ICF can also provide a useful way of classifying outcome measures for community rehabilitation [30].

The ICF recognises that a person’s disability operates within the context of their social and physical environment. Addressing not only the participant’s ability to manage their activities
of daily living but also those environmental factors which may limit the person’s ability to engage in their community is an important role for community rehabilitation clinicians. This may involve collaboratively planning and accessing the most disability friendly route of public transport or lobbying the council to install concrete pathways that may enable an older adult with walking aids to be able to access the local shops and partake in physical activity.

Depression is a major factor contributing to poor quality of life. Often improving physical activity and social participation can reduce depression [3]. The results of this study reinforce the importance of using a screening tool for depression in older populations and ensuring appropriate referral is made to specialist mental health services for severe and/or ongoing depression.

The other significant factors found relate to diet, and sensory factors. The impact of nutritional status on quality of life is shown to be significant in this study, however being underweight or overweight was not. In previous research, older adults with lower BMI have been shown to be at greater risk for morbidity and mortality [31]. In assessing the needs of older participants, community rehabilitation services need to screen for nutritional status, measure BMI and have access to specialist dietetics advice particularly for those who are underweight. The influence of the sensory factors of vision sufficient for reading and hearing demonstrates the need to screen for these factors and to refer to appropriate health professionals for assistance.

Studies of predictors of HRQoL in stroke to a large part are consistent with the findings of this paper with major factors being identified as functional status [32-34], depression [33, 34], and social supports [32, 34]. Increasing age and low socioeconomic factors were also shown to contribute to lower HRQoL [35].

Previous studies examining predictors of caregiver strain have had different results to this
Most indicate that having social supports and regular contact with health professionals were important in reducing the burden on care givers [36]. This study did not measure these factors which relate to outside support, rather only factors intrinsic to the participant. The results of this study indicate that improving the client’s participation in daily activities will reduce the burden on their care giver. However, previous research indicates that care givers may also require additional outside support if under substantial strain to prevent care arrangements from breaking down.

This study was limited to one geographical area on the south side of Brisbane and as such results may not be transferable to other locations even within Australia. This data was collected from sections of the community who are already linked into the health care system and only data from participants who consented to be part of the larger study were included. This represents only about one quarter of the participants referred to this service. Additionally the criteria excluded immobile patients and those who were unable to participate fully in a rehabilitation program. These participants may experience different factors that impact on their HRQoL and their care givers may be subject to different stresses than the cohort in this study. A range of data collectors was used so inter-rater reliability may impact on the validity of these measurements. However, all data collectors undertook pre-data collection training to minimise variation in collection. Numbers for this study were moderate, particularly for the CSI reducing the power of the regression analysis to find significant results. This may have resulting in a type II statistical error with some factors which may contribute to HRQoL or carer strain not being identified. Also a small amount of missing data was present with not all data sets being complete.

Only two factors were associated with carer strain in this study and this may be due to the limitations of the study in having only 45 participant caregivers. A larger cohort of caregivers
may be needed to positively identify other factors associated with carer strain so that community rehabilitation programs can better support caregivers to fulfil their roles.

IMPLICATIONS

Traditional rehabilitation focus has been primarily on basic self care skills and functional mobility, which is only a very small component of any person’s HRQoL. A wide range of factors contribute to declining HRQoL and caregiver strain in the older population. Services that target this age group need to screen for a range of issues including nutrition, weight, vision, hearing, depression, balance and mobility and participation in activities of daily living, community and leisure activities. Services need to have access to a wide range of skills to manage these factors; for example; occupational therapy to improve participation, dieticians and nutritionists to target weight and nutrition issues, speech pathology and audiology to manage communication and hearing difficulties and physiotherapy to address mobility and balance issues. The ICF can be a useful framework to use when providing services for older community dwelling adults in order to assess and treat those factors which most impact on HRQoL.

This study is distinctive in examining an extensive number of factors that could be associated with HRQoL and carer strain. The study provides guidance to community rehabilitation teams in developing models of care to assess and treat frail older persons in the community and provides support to using the ICF framework in community rehabilitation.
Acknowledgements
The authors would like to acknowledge the staff of the Community Rehabilitation Service in Metro South Hospital Health District for all the assistance and dedication in the data collection for this paper. Additionally we would like to acknowledge the leadership and guidance from Susan Brandis, Gail Gordon and Carmel Perrett in their role as District Directors of Allied Health.

Declaration of Interest Statement
This research was funded through Queensland Health research grants namely the Community Rehabilitation Workforce Project and the Allied Health research grants.
REFERENCES


Table 1: Characteristics of the sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Measurement</th>
<th>Mean (sd)</th>
<th>Normative Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>years</td>
<td>78.93 (7.67)</td>
<td></td>
</tr>
<tr>
<td>Falls in last 6 months (n)</td>
<td>number</td>
<td>2.24 (1.84)</td>
<td></td>
</tr>
<tr>
<td>Average number of co-morbidities</td>
<td>number</td>
<td>4.0 (2.7)</td>
<td></td>
</tr>
<tr>
<td>Average number of medications</td>
<td>number</td>
<td>6.5 (4.15)</td>
<td></td>
</tr>
<tr>
<td>EQ-5D</td>
<td>scale 0-1</td>
<td>0.56 (0.31)</td>
<td>0.7*</td>
</tr>
<tr>
<td>EQ-VAS</td>
<td>scale 0-100</td>
<td>61.76 (15.62)</td>
<td>68*</td>
</tr>
<tr>
<td>FAI</td>
<td>scale 0-45</td>
<td>19.43 (8.81)</td>
<td>40.86**</td>
</tr>
<tr>
<td>AMTS</td>
<td>scale 0-10</td>
<td>8.68 (1.19)</td>
<td>8-10 †</td>
</tr>
<tr>
<td>Timed Up &amp; Go</td>
<td>seconds</td>
<td>20.57 (14.23)</td>
<td>&lt;10 ‡</td>
</tr>
<tr>
<td>Caregiver Strain Questionnaire</td>
<td>scale 0-13</td>
<td>4.4 (3.53)</td>
<td></td>
</tr>
</tbody>
</table>

Frequency (%)

- Gender (Female): 71 (66%)
- Living alone: 48 (45%)
- Caregiver available: 45 (42%)
- Driving: 23 (21%)
- Balance Problem (Incomplete Romberg): 45 (42%)
- Underweight: 40 (39%)
- Overweight: 32 (31%)
- Walking aid used: 57 (53%)

* Savoia et al (2006) [37] value for over 75 years age group
** Schuling et al (1993) [38]
† Hodkinson (1972) [16]
‡ Bohannon (2006) [39]

EQ-5D = European quality of life five dimensions, EQ-VAS = European quality of life visual analogue scale, FAI = Frenchay Activities index, AMTS = abbreviated mental test score, BMI = body mass index
Table 2 Factors influencing quality of life and carer strain

<table>
<thead>
<tr>
<th>Variable</th>
<th>EQ-5D (out of 1.0)</th>
<th>p</th>
<th>EQ-VAS (0-100)</th>
<th>Beta co-efficient (95% CI)</th>
<th>CSI (0-13)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-0.001 (-0.01,0.01)</td>
<td>0.76</td>
<td>0.194 (-0.21,0.60)</td>
<td>0.35 (-0.044, -0.19,0.10)</td>
<td>0.55</td>
</tr>
<tr>
<td>Gender</td>
<td>0.039 (-0.09,0.17)</td>
<td>0.55</td>
<td>0.541 (-5.94, 7.02)</td>
<td>0.87 (0.285, -1.86,2.43)</td>
<td>0.79</td>
</tr>
<tr>
<td>Co-morbidities</td>
<td>-0.014 (-0.04,0.01)</td>
<td>0.22</td>
<td>-0.364 (-1.51,0.77)</td>
<td>0.53 (0.021, -0.33,0.37)</td>
<td>0.91</td>
</tr>
<tr>
<td>Lives alone</td>
<td>-0.019 (-0.07,0.03)</td>
<td>0.45</td>
<td>-0.47 (-6.67, 5.73)</td>
<td>0.88 (2.432, -0.90,5.8)</td>
<td>0.15</td>
</tr>
<tr>
<td>Driving</td>
<td>0.21 (0.07,0.34)</td>
<td>0.003</td>
<td>4.473 (-2.82,11.76)</td>
<td>0.23 (-1.85, -4.48,0.79)</td>
<td>0.16</td>
</tr>
<tr>
<td>FAI</td>
<td>0.016 (0.01,0.02)</td>
<td>&gt;0.000</td>
<td>0.528 (0.20,0.86)</td>
<td>0.002 (-0.138, -0.25,0.02)</td>
<td>0.019</td>
</tr>
<tr>
<td>Falls in the last six months</td>
<td>0.011 (-0.04,0.02)</td>
<td>0.48</td>
<td>-0.55 (-2.21,1.12)</td>
<td>0.52 (0.378, -0.21,0.96)</td>
<td>0.20</td>
</tr>
<tr>
<td>Incontinent</td>
<td>-0.071 (-0.19,0.05)</td>
<td>0.24</td>
<td>1.643 (-4.52,7.81)</td>
<td>0.60 (1.455, -0.93,3.84)</td>
<td>0.23</td>
</tr>
<tr>
<td>Malnutrition scale</td>
<td>-0.028 (-0.05, -0.01)</td>
<td>0.003</td>
<td>-1.257 (-2.21,-0.30)</td>
<td>0.01 (0.141, -0.19,0.47)</td>
<td>0.39</td>
</tr>
<tr>
<td>Vision - Reading</td>
<td>-0.071 (-0.14,-0.00)</td>
<td>0.049</td>
<td>-5.392 (-9.03, -1.76)</td>
<td>0.004 (1.186, -0.09,2.47)</td>
<td>0.07</td>
</tr>
<tr>
<td>Vision – Long Distance</td>
<td>-0.082 (-0.16,-0.00)</td>
<td>0.041</td>
<td>-1.771 (-5.99,2.44)</td>
<td>0.41 (1.07, -0.24,2.39)</td>
<td>0.12</td>
</tr>
<tr>
<td>Hearing</td>
<td>-0.100 (-0.17,-0.03)</td>
<td>0.005</td>
<td>-2.12 (-5.92,1.68)</td>
<td>0.27 (0.87, -0.55,2.29)</td>
<td>0.23</td>
</tr>
<tr>
<td>Timed Up and Go</td>
<td>-0.002 (-0.01,0.00)</td>
<td>0.30</td>
<td>-0.144 (-0.38,0.09)</td>
<td>0.22 (0.006, -0.06,0.07)</td>
<td>0.84</td>
</tr>
<tr>
<td>AMTS</td>
<td>-0.014 (-0.06,0.04)</td>
<td>0.59</td>
<td>1.038 (-1.58,3.65)</td>
<td>0.43 (0.11, -0.62,0.85)</td>
<td>0.76</td>
</tr>
<tr>
<td>K-10 Depression Scale</td>
<td>-0.015 (-0.02,-0.01)</td>
<td>0.003</td>
<td>-0.897 (-1.40,-0.39)</td>
<td>0.001 (0.152, -0.02,0.32)</td>
<td>0.08</td>
</tr>
<tr>
<td>Balance Intact – Eyes Shut</td>
<td>0.042 (-0.08,0.16)</td>
<td>0.49</td>
<td>0.741 (-5.48,6.96)</td>
<td>0.81 (-1.91, -4.04,0.22)</td>
<td>0.08</td>
</tr>
<tr>
<td>BMI</td>
<td>Underweight (&lt;24)</td>
<td>-0.013 (-0.15,0.17)</td>
<td>0.87</td>
<td>0.13 (8.15, 8.41)</td>
<td>0.98 (-1.95, -4.50,0.60)</td>
</tr>
<tr>
<td></td>
<td>Overweight (&gt;29)</td>
<td>-0.057 (-0.20,0.09)</td>
<td>0.43</td>
<td>-5.81 (-12.69,1.08)</td>
<td>0.10 (-3.20, -5.98,-0.41)</td>
</tr>
<tr>
<td></td>
<td>Walking Aid Used</td>
<td>-0.089 (-0.21,0.03)</td>
<td>0.14</td>
<td>-1.86 (-8.00,4.28)</td>
<td>0.55 (1.330, -0.80,3.46)</td>
</tr>
</tbody>
</table>

EQ-5D=European quality of life five dimensions, EQ-VAS=European quality of life visual analogue scale, CSI=Carer strain index, FAI=Frenchay Activities index, AMTS=abbreviated mental test score, BMI=body mass index