An Exploratory Study on the Experience of Care of Older Persons Transiting from Acute to Post-Acute Care Services

Research Report (For NAI/CSDA): T1-T4 Data

Lee Geok Ling¹
Corinne Ghoh Siew Ngeng¹
Marcus Chiu Yu Lung²⁺
Crystal Chai-Lim³
Goh Soon Noi⁴
Cao Kai¹
Gerald Koh Choon Huat¹
Luo Nan¹
Samuel Neo Kok Hwee⁵

Acknowledgement:

Ms Celest Wong, formerly National University of Singapore, was the chief research assistant for the project.

Ms Mandy Low, formerly Changi General Hospital contributed to the qualitative data analysis for the project.

Dr Wang Pei, Fudan University, contributed to the quantitative data analysis for the project.

¹National University of Singapore

²City University of Hong Kong

³Singapore General Hospital

⁴Changi General Hospital

⁵Tan Tock Seng Hospital

⁺Formerly from National University of Singapore

Contents

Executive Summary Recommendations for Policy Main Text

- 1. Background
 - 1.1. Introduction
 - 1.2. Objective
 - 1.3. Methodology
 - 1.4. Data and Data Analysis
- 2. Key Characteristics of Patients
 - 2.1. Demographic Characteristics
 - 2.2. Health Status
 - 2.3. Socio-economic Status
 - 2.4. Living Arrangement
- 3. Key Characteristics of Caregivers
 - 3.1. Demographic Characteristics
 - 3.2. Health Status
 - 3.3. Socio-economic Status
 - 3.4. Caregiving Characteristics
 - 3.5. Living Arrangement
- 4. Care Transition Experience: Transiting from Acute Care to Post-Acute Care
 - 4.1. Perceived Experience of Care Transition
 - 4.2. Referrals to Post-acute Care Services
 - 4.3. The Care Pathways
 - 4.4. Readmission into Hospital A & E Department
- 5. The Impact of Post-acute Care among the Patients
 - 5.1. Impact on the Health-related Quality of Life
 - 5.2. Impact on the Social Health
 - 5.3. Impact on the Mental Health
- 6. The Impact of Post-acute Caregiving among the Caregivers
 - 6.1. Impact on the Health-related Quality of Life
 - 6.2. Impact on the Social Health
 - 6.3. Impact on the Mental Health
- 7. Discussion, Limitations and Conclusion

References

Executive Summary

This project was commissioned by the Next Age Institute (NAI) and Centre for Social Development Asia (CSDA), National University of Singapore. It was an exploratory study on the experience of care of elderly persons transiting from acute care to post-acute care services. It is a pilot study that adopted a systematic and longitudinal approach to examine the experiences of people aged 60 years and over, in care transition and care pathways. Eight patients and 32 caregivers were interviewed at four time points (1st, 3rd, 6th and 12th months) over a period of 12 months post-discharge from acute care hospitals.

Transitional care programme was introduced in 2011 in acute care hospitals as a new healthcare model that aims to transform healthcare services to be less reliant on hospitals and to shift patient care to the community. The programme further evolves and in 2017, the Hospital-to-Home (H2H) programme, which pools manpower resources and consolidates the existing transitional care programme to help patients with multiple medical conditions reduce their risk of hospital re-admission by offering them services such as home medical, nursing, and psychosocial support. A patient receiving H2H programme is typically seen at home post-discharge, by a team of multi-disciplinary healthcare providers for up to six months, before he is handed over to a community care provider for subsequent care. Patients in acute care hospitals can also be referred directly to existing post-acute care services such as community hospitals, home medical and nursing, rehabilitation centre, and interim care services provided by voluntary welfare service organizations or VWOs.

Overall study aim: The overall aim of the study was to examine how the current health service delivery – that is, the formal and informal care support for older persons transiting from acute to post-acute care services – has helped to integrate and provide care across settings so that the older persons' health is maintained, restored or rehabilitated and that they can age in place successfully.

Study objectives: The objectives of the study were to:

- produce a profile of older patients and caregivers;
- document and chart the pathways of care journeyed by older persons from acute to post-acute care;
- identify factors that influenced older persons' experiences during care transition, and
- determine factors that influenced experiences of family caregivers in their journey of caring for older persons.

This study sample consisted of more male (75.0%) than female (25.0%) patients, with two-thirds of them aged 71 years and over. The patients comprised Chinese and Malay, half each. While all the Malay patients were Muslims, the Chinese patients varied in their religious beliefs. Majority of the patients were married (62.5%), received at least secondary level of education (75%), and had the total monthly household income of \$2000 or less (62.5%). All the patients had been employed previously but the majority of them had stopped working due to health issues or older age. All the patients had at least one chronic disease, and more than half of the patients were at least severely dependent and required assistance for the (instrumental) activities of daily living. All, except one, of the patients had a primary or secondary caregiver, and half of them lived together with their caregiver. Almost all stayed in HDB flats (87.5%), and as a single-generation family (62.5%). Majority of the flats were owned by the patients, with or without their spouse (75.0%).

The caregivers who participated in in this study comprised Chinese (68.8%), Malay (25.0%), and Indian caregivers (6.3%). There were more female caregivers (71.9%), aged between 51 and 70 years old (46.9%). Half were married (50.0%) and most had at least secondary education (81.2%). Forty percent of the caregivers did not have any existing medical condition. Even among those who had existing medical condition, most of them had only one condition (28.1%). The majority of them were employed part-time or full-time, in a non-professional or non-managerial position (43.7%) and earned less than \$2000 per month (65.6%). Changing job, declining job advancement or stopping work to care for the patients were commonly reported among the caregivers.

The majority of the caregivers were children of patients, and it was their first time to take care of older adults. The elderly patients were taken care of by the caregivers, generally in the absence of foreign domestic worker. One possible factor is the financial capability. Spousal caregivers formed a smaller group but they tended to have committed more years and longer hours weekly in the care of patients than the children caregivers or others.

The transition of care from hospital to post-acute care services was generally found to be a less than desirable experience among patients and caregivers. The possible reason was the lack of communication between healthcare providers and caregivers in areas such as health goals of the patient, care plans for the patient, and the use of medications. Almost all the patients were referred and engaged with at least one post-acute care service, and most of them continued their care in the community two days post-discharge. The most commonly reported post-acute care services included inpatient community hospital, nursing home and home medical/nursing care. However, changes in the types or number of services received by the patients were commonly reported among the caregivers for the next 12 months post-discharge. 26.5% of the patients were admitted into the hospital within the first three months after discharge from the hospital, although majority of the patients were not re-admitted into the hospital or visited the A & E department over the 12 months period.

The patients suffered from poor health-related quality of life and social well-being during the period of study. However, they remained strong in their mental well-being; they remained hopeful and were not clinically depressed. The only exception was at T2 (three months after discharge from hospital), when patients seemed to enjoy stronger family relations and not display depressive symptoms. It is possible that family members might have played an active caregiving role during the first three months, which might have contributed positively to the patients' quality of life and mental well-being.

Similarly, the post-acute caregiving experiences had an impact on the caregivers' health-related quality of life, social health and mental health. The caregivers' quality of life of was found not "full health", although the findings indicated an upward trend over time. The caregivers seemed to have suffered from social well-being too, although they were supported by at least two family members during the period of study. More than half of the caregivers reported stressed over caregiving burden and monitoring of the patients' symptoms and disease progress could be one constant caregiving burden.

The small sample size of the study has limited the types and number of statistical tests that could be performed, as well as generalizability of the findings. Future studies may want to recruit a bigger sample size to examine:

- (1) the relationship between the level of care and length of transitional care required and the caregiver stress,
- (2) the relationship between patient's health condition and support available and caregiver stress.
- (3) prior planning, psychological preparation and higher level of social support as a predictor of the coping behaviours of the patients and caregivers
- (4) the costing and financing of the acute and post-acute care services, its cost-effectiveness and its impact on choice of post-acute care service
- (5) the spatio-temporal patterns of care transitions using geographic information systems.

Despite the small sample size, this pilot study had succeeded in its first step to examine a sample consisting of patients and families with varied complex needs systematically and longitudinally. It has resulted in insights into the challenges faced by such families in the transition of care from acute to post-acute care. Maintaining quality of life of the patients and caregivers is one key outcome of the post-acute care services and transitional care programme and the findings seem to suggest that we have more to learn and manage.

Recommendations for Policy

Study aim: to examine how current health service delivery in Singapore has helped to integrate and provide care across settings, from acute to post-acute care, so that the older persons' health can be maintained, restored or rehabilitated and that they can age-in-place successfully

Study objectives:

- produce a profile of the older patients and caregivers;
- document and chart the pathways of care journeyed by older persons from acute to post-acute care;
- identify factors that influenced older persons' experiences during care transition, and
- determine factors that influenced experiences of family caregivers in their journey of caring for older persons.

Recommendation 1: Enhance care transition from hospital to community with better communication on health goals and care plans.

This project found that a number of process improvements were required regarding transition from acute-care setting to community-based setting. Neither caregivers nor patients were well-informed of health care goals or care plans, many which had been made by healthcare providers on patients'/caregivers' behalf, without their input. Many only received information verbally, as well as already packed medications (without explanation on the use or side effects of medicine), and future appointment dates. In addition, caregivers had to manage with multiple medical appointments in the same hospital post-discharge, as well as their readiness to provide care at home, especially when a foreign domestic helper was not employed or when community support was lacking. The low prevalence of hospital readmission or visits to Accident and Emergency (A & E) Department tells only one part of the story, and it is therefore insufficient to conclude that elderly patients were able to rehabilitate and age-in-place successfully. Not visiting the A& E department or hospital does not necessarily indicate success in the transitional care and post-acute care programmes. There is a need to more closely examine and improve the process of care transition and quality of life (QoL) post-acute care.

Recommendation 2: Enhance the psychosocial dimensions of care for older persons in post-acute care.

According to WHO (2018), QoL is a multi-dimensional concept which includes "physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment" (Retrieved from

http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/). This project showed that although patients might have a caregiver, or even be residing with the caregiver, they were not necessarily enjoying good mental and social well-being. In fact, many patients seemed to be socially isolated, with some exhibiting depressive symptoms. Their health-related QoL score indicated that they were never at full health, and their QoL was rated as 'as good as death, if not worse'.

Recommendation 3: Consider caregivers' well-being and building family relationships when planning for post-acute care.

Patient QoL is closely associated with caregiver QoL. Although the project findings indicated that caregivers generally enjoyed a positive relationship with patients, as well as with other

family members, they also showed signs of being socially isolated. More than half of the caregivers reported significant strains and stresses in caregiving, which might be related to the amount of time commitment required in performing specific caregiving tasks. Additional stresses faced in their employment contributed further to their mental stress. The results suggest that availability of instrumental and emotional support, caregiver respite, and preparing caregivers for the caregiving role could help mediate the negative impact of caregiving on caregivers' mental well-being.

1. Background

1.1. Introduction

The exploratory study on the experience of care of elderly persons transiting from acute care to post-acute care services was commissioned by the Next Age Institute (NAI) and Centre for Social Development Asia (CSDA), National University of Singapore, from 2015 to April 2018. To the best knowledge of the research team, it was the first pilot study from Singapore to examine in a systematic, longitudinal manner the experiences of the elderly aged 60 years and over in the care transition and the care pathways.

Recent changes in the health service sector saw an increased emphasis on use of community-based and Intermediate and Long-term Care (ILTC) services following discharge. Transitional care programmes represent one part of a larger shift in health service delivery to improve quality of care and health outcomes, and potentially to reduce costs. In Singapore context, the post-acute care locations would include, but not limited to community hospital, transitional care facility, nursing home, hospice, home-based care service, day-care (rehabilitative) centre, and the patient's home. The pathway of care transiting into post-acute care may be complex, and often a challenging period for older persons, families and even health-care professionals. It is important to examine this phenomenon in a more systematic manner.

Singapore is a fast-ageing country, with 13.0 percent of the population aged 65 and above, up from 9.0 percent in 2010 (Department of Statistics Singapore, 2017). The life expectancy at age 65 years for the males and females were 19.1 and 22.5 years respectively in 2017 (Department of Statistics Singapore, 2017). This implies that an older person may live up to at least 83 years old. It is estimated that by 2020, more than 10,000 people with cancer and chronic diseases would need palliative care, up from 8,000 in 2009 (Lien Centre for Palliative Care, 2011). The statistics of the fast ageing population reflect the importance of looking into an efficient and effective post-acute care service for older persons and their families as a preventive measure of ageing population. Coupled with below-replacement fertility rate in the recent decades, decrease in marriage rates, increase in first marriage at a later age, increase in social mobility and migration, increase in the proportion of nuclear families and increase in the number of women returning to the workforce, fewer children will be readily available for their older relatives.

Transitional care service was introduced in 2011 as a new healthcare model that aims to transform healthcare services to be less reliant on hospitals and to shift patient care to the community (Ng, 2011; Mohandas, 2014a). Transitional care service was also reported "not only allows patients to recover at home, but also frees up beds for more acutely-ill patients" (Mohandras, 2014b). In a typical case when a patient receives transitional care service, he will be visited and managed by a team of multi-disciplinary healthcare providers (doctor, nurse, medical social worker, occupational therapist, physiotherapist, and sometimes pharmacist) in his home after discharge from hospital for up to six months maximally. Simultaneously, family caregivers are also trained in, for example, wound dressing and management of patient's emotional needs, so that they can provide better care for their loved one. In addition, community care providers often step in after the elderly patients are handed over to them to provide subsequent care (Mokhtar, 2016).

In 2017, the Hospital-to-Home (H2H) programme was launched which aims to help patients with multiple medical conditions reduce their risk of re-admission by offering them services such home medical, nursing and psychosocial support (Choo, 2018). The H2H programme adopts a more systematic and structured approach to identify patients with such needs, using objective indicators such as number of hospital admissions, medical history and age to enrol the patients into the programme instead of relying on referrals (Choo, 2018).

1.2. Aim and Objectives

The overall aim of the study was to examine how the current health service delivery – that is, the formal and informal care support for older persons transiting from acute to post-acute care services – has helped to integrate and provide care across settings so that the older persons' health is maintained, restored or rehabilitated and that they can age in place successfully.

The objective of the study is to examine the experiences of care for the older persons when they transit from acute care to post-acute care services by:

- (a) profiling older patients and family caregivers undergoing different care transitions,
- (b) documenting and charting the existing pathways of care journeyed by the older persons,
- (c) identifying factors that influence older persons' experiences in the care transitions and subsequent adjustment, and
- (d) identifying factors that influence the experience of family caregivers in their journey with the older persons.

The following information was collected from each group of participants:

- (a) Profile of the Patients: Demographics; physical, mental, social and economic health profile; impact of care on quality of life.
- (b) Profile of the Caregivers: Demographics, physical, mental, social and economic health profile; time spent in caregiving; perception of caregiving; perceived impact of caregiving on quality of life.
- (c) Care Pathways: The care services received over time; factors that influence older persons' experiences in the care transitions and subsequent adjustment; factors that influence the experience of family caregivers in their journey with the older persons in the care transitions.

1.3. Methodology

Sample and Recruitment Process

The acute hospital setting was the recruitment site as it was the first contact point, from where the patients were referred to various post-acute care services such as community hospital, nursing home, hospice, day-care centre, home-based care service and patient's home, according to the needs and willingness of the patients and/or patients' family caregivers. Specifically, patients who were known to the Medical Social Service Departments (MSSDs) were identified and recruited for the study. The rationale is that patients with complex needs and issues are the target populations when comprehensive care plans would be required. The target number was 60 patients and 60 caregivers with care recipient-caregiver dyad preferred. Where the patients were mentally incapacitated, only their caregiver was recruited for the

study. Unfortunately, only 8 patients and 32 caregivers (out of which there were six patient-caregiver dyads) were recruited and interviewed successfully.

Sixty-four patients and 58 caregivers were approached by representatives of MSSD to obtain the verbal consent to meet the research assistant (RA) onsite or other place of convenience. The RA then provided potential participants with information on and clarification about the study. Of which, 17 caregivers and 40 patients declined to participate. The length of the questionnaire and lack of interest in the study were the two main reasons stated to decline the invitation. Another 16 patients and 7 of the caregivers were found not meeting the inclusion criteria – three were not referred to any post-acute care services, three were out of the recruitment time-frame and one was not a MSSD case. Another two caregivers withdrew their consent before the first interview. Thus, this resulted in 8 patients and 32 caregivers participating at time point 1 (T1).

At T2, four patients died, and two patients and nine caregivers withdrew from the study. Thus there were 5 patients and 24 caregivers.

At T3, one patient died. One other patient and four caregivers withdrew from the study. Thus, there were 4 patients and 20 caregivers.

At T4, two patients died and two caregivers withdrew from the study. Thus, three patients and 18 caregivers remained. All the participants, except for one, were invited to a one-to-one in-depth interview within two months after the last questionnaire survey at T4. In total, two patients and 10 caregivers were interviewed at T5. Figure 1 is a flowchart that depicts the recruitment process and sample.

64Pt & 58CG (57 patient-caregiver **Recruitment Phase** dyad, 1 caregiver only, 7 patient only) (52.3%)Declined: 17 caregivers; 40 patients Drop-out: 2 caregivers Non-eligible: 7 caregivers; 16 patients 8Pt & 32CG interviewed T1 (1 month post-discharge) (6 patient-caregiver dyads; (100%)2 patients; 26 caregivers) Patient withdrew: 2 Caregiver withdrew: 5 Pt died, CG withdrew: 4 5Pt & 24CG interviewed T2 (3 months post-discharge) (4 patient-caregiver dyads; (73.5%)1 patient; 20 caregivers) Patient died: 1 Patient withdrew: 1 Caregiver withdrew: 3 4Pt & 20 CG interviewed T3 (6 months post-discharge) (3 patient-caregiver dyads; (61.8%)1 patient; 17 caregivers) Patient died: 1 CG withdrew: 1 Patient died, caregiver withdrew: 1 3Pt & 18CG interviewed T4 (12 months post-discharge) (3 patient-caregiver dyads; (52.9%)15 caregivers) Declined: 5CG Not approached: 1CG Patient died: 1 2Pt & 12CG interviewed T5 (within 2 weeks after T4) (2 patients from dyad; (35.3%)10 caregivers)

Figure 1 Flowchart showing the recruitment process and sample.

Study Design

This was primarily an exploratory study which was conducted using a prospective, longitudinal approach and mixed methods. The participants were the elderly patients aged 60 and above (also known as patients) referred for post-acute care services/programmes and their informal caregivers (also known as caregivers). They were followed through at regular time intervals for 12 months. Each participant was interviewed at 1 month (T1), 3 months (T2), 6 months (T3) and 12 months' (T4) intervals from the date of discharge. At T5, a subset of participants were selected, using maximal theoretical sampling method, for individual in-depth interview. For T1 to T4, data were collected through the use of established measures and semi-structured interview guides.

This report will report on findings collected from T1 to T4. T5 data will be reported separately as journal publications.

Questionnaires

Two separate sets of questionnaires were constructed specifically for the patients and caregivers. They were designed with reference to validated questionnaires conducted overseas and/or locally. Questions were also adopted from a local study on stroke patients that was conducted by one of the co-investigators of the team (Tyagi, Ong, Ho,....Chou, Cheong, Koh et al., unpublished manuscript).

The following domains were common between the two sets of questionnaires: demographics, health status, health-related quality of life (EQ-5D), social well-being (LSNS-6), and care transition experience (CTM-15). In this study, the HRQoL of the patients was measured using the Singapore version of the EurolQol Group's 5-domain questionnaire (Gao et al., 2009; Luo et al., 2003). The CTM-15 was locally validated (Bakshi et al., 2012).

In addition, the following domains were unique to the patient and caregiver questionnaires each respectively:

a) Patient questionnaire:

- Care experience and mental well-being: Herth Hope Scale(HHS) and Geriatric Depression Scale (GDS)
- Care pathways: Availability of services to care for the patient and waiting time required; any admission to hospital or A&E department.

b) Caregiver questionnaire:

- Caregiving and health: Self-rated impact of caregiving on mental health using Caregiver Strain Index (CSI)
- Caregiving tasks: Time spent caring for patient; time spent caring for others besides the patient; perceived time and difficulty of task provided for patients using Obserst Cargiving Burden Scale (OCBS)
- Caregiving support: Availability of others (family members/domestic helpers) to help care for patient
- Caregiving and labour force participation: Ever taken time off to care for patient and impact on caregiving on employment
- Patient's behavioural problems and caregiver's reaction:

1.4. Data and Data Analysis

The data gathered during the fieldwork were entered into an excel spreadsheet, and then SAS and IBM SPSS statistical 20 programmes for specific analytical tests. For the purpose of this report, key results will be presented. Due to the small sample size, descriptive statistical tests were mainly conducted.

We used Wee et al. (2015) transitional care programmes model as the conceptual framework for our analysis. According to the framework, the performance of the transitional care programmes is measured against (1) reduced or avoidable hospital admissions or visits to emergency department, (2) improved or maintained the quality of life or functions, and (3)

reduced costs. Unfortunately, we were not able to examine the costs due to the difficulties faced in collecting financial data.

2. Key Characteristics of Patients

In this section, the key characteristics of the patients will be presented. Despite the small sample size, the information collected on the socioeconomic and health status of the patients may shed some light on the effects of patient characteristics on caregiver stress and quality of life.

2.1. Demographic Characteristics

Table 1. Social Demographics of Patients

Profile of Patients at T1 (N=8)	N(%)
Gender	
Male	6 (75.0)
Female	2 (25.0)
Race	
Chinese	4 (50.0)
Malay	4 (50.0)
Religion	
Buddhism	2 (25.0)
Islam	4 (50.0)
No religion	1 (12.5)
Roman Catholic	1 (12.5)
Age	
61 – 70 years old	2 (25.0)
71 - 80 years old	4 (50.0)
81 – 90 years old	2 (25.0)
Marital Status	
Married	5 (62.5)
Single	2 (25.0)
Separated	1 (12.5)
Education	
No formal education	1 (12.5)
Primary	1 (12.5)
Secondary	3 (37.5)
Post-Secondary	3 (37.5)

There were more male than female patients (ratio = 3:1), with three-quarters of them aged 71 years and above. Half of the patients were of Chinese ethnic group and the other half Malay ethnic group; no Indian care recipient was recruited. All the Malay patients were Muslims while the Chinese patients varied in their religious beliefs. Majority of the patients were married (62.5%) and had received at least secondary level of education (75%) (Table 1).

2.2. Health Status

Table 2. Health Status of Patients

Profile of Patients at T1 (N=8)	N(%)
Presence of Chronic Disease (mean=4)	
1 Chronic disease	1 (12.5)
2 Chronic disease	1 (12.5)
3 Chronic disease	2 (25.0)
4 Chronic disease	2 (25.0)
5 or more chronic disease	2 (25.0)
MBI Self-care assessment (Shah Version)	
(Mean=49.8)	
00-20 (total dependence)	2 (25.0)
21 – 60 (severe dependence)	4 (50.0)
61 – 90 (moderate dependence)	2 (25.0)
Lawton IADL Scale ($F = 0$ to 8; $M = 0$ to 5)	
(Mean = 2.1)	
1 (low function, dependent)	2 (25.0)
2	3 (37.5)
3	3 (37.5)

All the patients had at least one chronic disease, with more than half had at least four types of chronic diseases. In addition, more than half of the patients were at least severely dependent and require assistance for the activities of daily living, as well as instrumental activities for daily living (Table 2)

2.3. Socio-economic Status

Table 3. Social-Economic Characteristics of Patients

Profile of Patients at T1 (N=8)	N(%)		
Total Monthly Household Income			
Less than \$500	2 (25.0)		
\$501 - \$1000	1 (12.5)		
\$1001- \$2000	2 (25.0)		
\$2001 - \$3000	1 (12.5)		
\$3001 - \$4000	0 (0.0)		
\$4001 - \$5000	1 (12.5)		
More than \$5000	1 (12.5)		
Patient ever worked for pay?			
No	0 (0.0)		
Yes	8 (100.0)		
Reasons for stopping work			
Laid off; fired	1 (12.5)		
Own health problems	2 (25.0)		
Reach retirement age	3 (37.5)		

Exploratory Study on Care Transition of Older Persons

Others	2 (25.0)
Types of Occupation	
Professional	2 (25.0)
Clerical work	1 (12.5)
Cleaner and labourer	1 (12.5)
Others	4 (50.0)

All the patients had an employment history and majority of them had stopped working either because of health issues or old age. More than half of the patients had the total monthly household income of \$2000 or less (Table 3).

2.4. Living Arrangement

Table 4. Living Arrangement of Patients

Profile of Patients at T1 (N=8)	N(%)
Presence of Caregiver	
Yes	7 (87.5)
No	1 (12.5)
Type of Caregiver	
Primary caregiver	5 (62.5)
Secondary caregiver	2 (25.0)
Staying Together with Caregiver	
Yes	4 (50.0)
No	4 (50.0)
No. of generation within same household	
1	5 (62.5)
2 3	2 (25.0)
3	1 (12.5)
Current Place of Residence	
HDB Rental 1-room	2 (25.0)
HDB Purchased 2 to 4-room	4 (50.0)
HDB Purchased 5-room	1 (12.5)
Private Housing	1 (12.5)
Ownership of Residence	
Patient with/without spouse	6 (75.0)
Siblings	1 (12.5)
Patient's sister-in-law	1 (12.5)

All, except one, of the patients had a primary or secondary caregiver, and half of them lived together with their caregiver. Almost all stayed in HDB flats, with half lived in 3-room or smaller flats, as a single-generation family. Majority of the flats were owned by the patients with or without spouse (Table 4).

3. Key Characteristics of Caregivers

In this section, the key characteristics of the main caregivers will be described.

3.1. Demographic Characteristics

<u>Table 5. Social Demographics of Caregivers</u>

Profile of Caregivers at T1 (N=32)	N(%)
Race	
Chinese	22 (68.8)
Malay	8 (25.0)
Indian	2 (6.3)
Gender	
Male	9 (28.1)
Female	23 (71.9)
Religion	
Buddhism	6 (18.8)
Christianity	9 (28.1)
Islam	9 (28.1)
Taoism	4 (12.5)
No religion	4 (12.5)
Age	
21 - 30 years old	2 (6.3)
31-40 years old	5 (15.6)
41 - 50 years old	4 (12.5)
51 - 60 years old	6 (18.8)
61 – 70 years old	9 (28.1)
71 – 80 years old	3 (9.4)
81 - 90 years old	3 (9.4)
Marital Status	
Married	16 (50.0)
Single	9 (28.1)
Widowed	2 (6.3)
Separated /Divorced	5 (15.6)
Education	
No formal education	2 (6.3)
Primary	4 (12.5)
Secondary	13 (40.6)
Post-Secondary	13 (40.6)

In our study, there were more Chinese caregivers (68.8%), followed by Malay (25.0%) and Indian caregivers (6.3%). In addition, our study found more caregivers who were female (71.9%), aged between 51 and 70 years old (46.9%), were married (50.0%) and had at least secondary education (81.2%) (Table 5).

3.2. Health Status

Table 6. Health Status of Caregivers

Profile of Caregivers at T1 (N=32)	N(%)
Suffering from existing medical condition	
No	13 (40.6)
Yes	19 (59.4)
Number of medical condition	
0	13 (40.6)
1	9 (28.1)
2	6 (18.8)
3	2 (6.3)
>3	2 (6.3)

Slightly more than two-fifths of the caregivers (40.6%) did not suffer from any existing medical condition. Even among those who had existing medical condition, most of them had only one condition (28.1%) while four other caregivers (12.6%) had three or more medical conditions (Table 6).

3.3. Socio-economic Status

Table 7. Social-Economic Characteristics of Caregivers

Profile of Caregivers at T1 (N=32)	N(%)
Working Status	
Part-time employment (ave=25.2 hrs)	6 (18.8)
Full-time employment (ave 48.6 hrs)	14 (43.8)
Homemaker/Housewife	3 (9.4)
Unemployed	4 (12.5)
Retired	5 (15.6)
Type of Occupation	
Professional	3 (9.4)
Administrative & Managerial	2 (6.3)
Associate Professional & Technical	1 (3.1)
Clerical worker	1 (3.1)
Sales & Service	7 (21.9)
Production & Related	1 (3.1)
Cleaner & Labourer	5 (15.6)
Monthly Income	
Less than \$500	12 (37.5)
\$501 - \$1000	1 (3.1)
\$1001- \$2000	8 (25.0)
\$2001 - \$3000	0(0.0)
\$3001 - \$4000	3 (9.4)
\$4001 - \$5000	2 (6.3)
More than \$5000	3 (9.4)
Refuse to answer	3 (9.4)

To care for patient, you*	
Change job/employer	17 (53.1)
Decline a job advancement	16 (50.0)
Increase working hours	14 (43.8)
Take time off from work	11 (34.4)
Come late to work	14 (43.8)
Change shift	11 (34.4)
Leave work for patient's medical appt	9 (28.1)
Interrupted by calls concerning patient	8 (25.0)
Decrease working hours	14 (43.8)
Perceived work performance affected	11 (34.4)
Miss working days	13 (40.6)
Finally stop working	16 (50.0)

^{*} There could be more than one response per caregiver.

Slightly more than three-fifths of the caregivers (62.6%) were engaged in either parttime or full-time employment, with most of them employed in non-professional or nonmanagerial position (43.7%) and earned less than \$2000 per month (65.6%); 37.5% of them earned less than \$500. Among those who worked, at least half of them indicated that they had to change job, decline a job advancement or stop working to care for the patients (Table 7).

3.4. Caregiving Characteristics

Table 8. Caregiving Characteristics of Caregivers

Profile of Caregivers at T1 (N=32)	N(%)
First Experience of Caregiving for Older Adults	
Yes	21 (65.6)
No	11 (34.4)
Providing Care for Others besides Care Recipient	
Yes	11 (34.4)
No	21 (65.6)
Relationship to Patient	
Spouse	7 (21.9)
Children	16 (50.0)
Others*	9 (28.1)
Presence of foreign domestic worker	
Yes	10 (31.3)
No	22 (68.8)
Intention to get a foreign domestic worker?	
Yes	3 (13.6)
No	19 (86.4)

^{*} Others include grandchildren, sibling and girlfriend

Slightly less than two-thirds of the caregivers (65.6%) reported that it was their first time taking care of older adults. Similarly, 65.6% of them reported that they did not need to care for others, such as their own children, simultaneously.

Patients' children constituted half of the caregivers, another 28.1% were siblings, grandchildren or girlfriends, and the remaining 21.9% were spouses. Majority of the caregivers did not hire foreign domestic worker (FDW) to help care for the patients. Among those who did not have FDW, majority (86.4%) had no intention to get one (Table 8).

Table 9. Percentage of FDW hired by patient-caregiver relationship and housing types

Type of	Hire	Hire of FDW n (%) No Hire of FDW n (%)			Total		
relationship	Rental 1-	2-4	5 rooms	Rental 1-	2-4	5 rooms	N (%)
	2 rooms	rooms	& above	2 rooms	rooms	& above	
Spouse	0 (0.0)	1 (3.1)	2 (6.3)	2 (6.3)	2 (6.3)	0 (0.0)	7(21.9)
Children	0 (0.0)	2 (6.3)	2 (6.3)	4 (12.5)	7(21.9)	1 (3.1)	16 (50.0)
Others	0 (0.0)	2 (6.3)	1 (3.1)	0 (0.0)	4 (12.5)	2 (6.3)	9 (28.1)
Total N(%)	0 (0.0)	5 (15.6)	5 (15.6)	6 (18.8)	13 (40.6)	3 (9.4)	32 (100.0)

Among those who hired a FDW, there was not much difference among them in terms of the types of caregiver-care recipient relationship. Those who had a purchased flat were more likely to hire a FDW. One possible explanation is the financial ability (Table 9).

Table 10. Time (years) spent in caregiving of patients

Types of Relationship	N	Mean (years)	Mean (hours) in a
			week
Spouse	7	9.2	54.4
Children	16	2.8	30.4
Others	9	3.4*	18.8
Overall	32	4.4	32.4

^{*} One missing datum

It is interesting to note that spousal caregivers reported spending 1.8 to 2.9 times more of hours weekly in the care of patients than children or "other" caregivers. It may also be worthwhile to note that the spousal caregivers had also taken care of the patients for longer years than children or "other" caregivers, 2.7 to 3.3 times more years respectively (Table 10).

3.5. Living Arrangement

Table 11. Living Arrangement of Caregivers

Profile of Caregivers at T1 (N=32) N(%)
Staying Together with Patient	
Yes	23 (71.9)
No	9 (28.1)
No. of generation within same	
1	11 (34.4)
2	9 (28.1)
3	12 (37.5)

Exploratory Study on Care Transition of Older Persons

No. of Children by Caregivers	
0	12 (37.5)
1	3 (9.4)
2	8 (25.0)
3	5 (15.6)
4	1 (3.1)
5	2 (6.3)
6	1 (3.1)
Current Place of Residence	
HDB Rental 1- /2-room flat	6 (18.8)
HDB 2-room flat	2 (6.3)
HDB 3-room flat	7 (21.9)
HDB 4-room flat	9 (28.1)
HDB 5-room flat	3 (9.4)
Private Condominium/Apartment	5 (15.6)
Ownership of Residency	
Self with/without spouse	14 (43.8)
Patient and self	7 (21.9)
Patient with/without spouse	4 (12.5)
Siblings	2 (6.3)
Patient's Children	1 (3.1)
Patient's and children's	1 (3.1)
Staff Quarter	1 (3.1)
Caregiver's children	2 (6.3)

Majority of the caregivers stayed together with the patient (71.9%), as a three-generation family (37.5%), with at least one child (62.5%), in a 3- or 4-room flat (50.0%). 65.7% of the flats were owned by the caregiver alone or co-owned with spouse or patient (Table 11).

4. Care Transition Experience: Transiting from Hospital to Post-Acute Care

In this chapter, we examine the key experiences of the patients and caregivers in the process of transiting from acute to post-acute care.

4.1 Perceived Experience of Care Transition

Table 12 The perceived quality of care transition

Participant	CTM-15 Ave Score (range)
Patient	67.43 (45.24 – 77.78)
Caregiver	67.96 (50.00 – 100.00)

Care Transition Measures (CTM-15) is a self-report measure of the quality of transitional care whereby coordination and continuum of care as patients transfer between different locations is an issue of concern (Coleman, Mahoney & Parry, 2005). Following the instructions for scoring CTM-15 (Coleman, undated), the patients and caregivers were found to have rated similarly the perceived quality of care transition at T1. The patients had an average score of 67.43 and the caregivers had an average score of 67.96, although one of the caregivers had given the highest score of 100 (Table 12). One possible explanation for the results, further corroborated from the qualitative data, was the lack of communication, especially in the areas on the use of medication and patient care plans or health goals after discharge:

"...they put her on several new medications, but no one told me about them. I don't know. It's that time the communication was bad...I would've appreciated it if they taught me about the medication because there's a (lot of medicine and) her medicine schedule is quite complicated." (CC01)

"I only brought all the medication back....if possible, before leaving the hospital, they can explain clearly each of the medication and not just give all the medication for us to bring back." (TC34)

"Nobody give me a (written) plan...I was just told that her (the patient's) rehabilitation will be graded as slow." (SC17)

"No, no health care goals from the hospital...very standard procedure already... You go in, come out, like that." (SC27)

As for the coordination of the post-discharge follow-up visits were concerned, the family caregivers were puzzled by the fact that the appointment was scheduled immdediately one day after discharge (CC01), that there would be a change of appointment date because the doctor was on leave when the family caregiver had already applied leave for that day (SC27). The appointment dates were said to *be "very functional"*, "very instructional" (SC36).

Finally, there was a perceived lack of consideration of the family's preference or patient's needs for the post-acute care arrangement. For example, TC19 said that a nursing home would be preferred for her brother who is deaf and lives alone for safety reason but it

was not accepted; CC05 said that the step-down care was the hospital's "own choosing" because of the relationships between the acute care hospital and the community hospital, rather than the preference of the family.

4.2 Referrals to Post-acute Care Services

Of the 34 patients, 32 of them were referred to at least one post-acute care service after discharge from hospital at T1; of which five patients were referred to two services and another two patients was referred to three services. Those services that were already made available prior to the study were excluded. As shown in Table 13, the most frequent referrals made were community hospital (30.2%), nursing home (14.0), and home nursing/medical care, such as management of wounds and post-acute care follow-up services (14.0%).

Table 13 The types of post-acute care services

Type of Post-acute Care Service*	No. of Referral (%)
Community-based Day Care/Rehabilitation Centre	4 (9.3)
Community Hospital (inpatient)	13 (30.2)
Home Hospice Care	3 (7.0)
Home Medical/Nursing Care (outpatient)	6 (14.0)
Home Supportive Care (e.g. meal delivery)	5 (11.6)
Interim Care Services ¹	4 (9.3)
Nursing Home	6 (14.0)
None	2 (4.7)
Total	43 (100)

^{*} Patient may be referred to more than one form of post-acute care service.

It may be worthy to note that when a referral was made, most of the patients were able to receive the service within two days. However, the average number of days taken from making a referral to receiving the service could be as long as 21.8 days (range = 2 - 187; median = 8).

The remaining two who were not referred to any post-acute care service were due to the unavailability of services to match their needs. One was not referred to the nursing home because the patient was mobile, thus did not meet the admission criteria. The other was not referred because the patient had aggressive behaviour, as shown in the excerpt below:

"...day care kind of places, they will not take someone like her [patient suffering from dementia] and ...the short-short-term respite care also, they will not take people like her. My mum called and then they said they don't take aggressive patients, so that their care takers will not be stressed, Then, I'm like, what about us? Actually, we were thinking if we want to go for a quick holiday or something, we will put her in short-term respite care." (CC01, granddaughter)

4.3 The Care Pathways

Table 14 Care Pathways from T1 to T4 for those patients referred for services

	T1 (N=34)* n (%)	T2 (N=24)* n (%)	T3 (N=21)* n (%)	T4 (N=16)* n (%)
No. of patients receiving services	32 (94.1)	16 (66.67)	15 (71.4)	14 (87.5)
Ave no. of post-acute care services referred	1.3	1.6	1.8	1.7
No. of patients experienced change in the type of services received	NA	14 (87.5)	8 (53.3)	8 (57.1)
Changes in service types/providers Termination of	NA	7	1	0
service • Change in service type/provider	NA	2	3	3
• Increase in service type/provider	NA	4	4	3
Decrease in service type/provider	NA	1	0	2

^{*} If It is a caregiver-care recipient pair, only one will be represented; NA = Not applicable

Table 14 provides a breakdown of the post-acute care services received by the patients over a period of 12 months. As shown in Table 14, there were constant changes in the types and number of services received by the patients across the different time points. The possible reasons for the termination of service included death of patient and not meeting the needs of the patients or family, as illustrated by the excerpt below:

"...they [Home Care Service] said they will help to sweep and mop the floor, wipe the window and hang out the clothes. Most importantly, they require us to have our own washing machine and to wash the clothes on our own. I said might as well you don't come. If I can wash the clothes, I can also hang out the clothes to sun, right? Sweeping the floor, you look at the floor, every day we mop, my floor is not very dirty. I say it is not required. \$4.50 per hour." (TC33, spouse)

The possible reasons for change of type of number of services included changing needs of the patient (e.g. from home care to inpatient care due to pressure sores) and dissatisfaction with the service provided. However, some continued the service despite the dissatisfaction, as explained by the caregiver at T1 and T2:

"I hope he goes. I can relax and do my things. Now that they take care of him over there (Day Care Centre), I can't do many things. At least someone can help to provide food, cook for him, I don't have to cook. So I can do my things, there are many things at home I haven't clean up." (TC11, spouse, at T1)

"He [patient] doesn't really like it.... He didn't have enough to eat there....I don't know how he exercises over there." (TC11, spouse, at T2)

4.4 Readmission into Hospital or Emergency Department

Table 15 Frequency of hospital re-admission or visit to A&E department

Hospital readmissions (N=34)	N (%)
Frequency across T1 to T4	
0	19 (55.9)
1	8 (23.5)
2	5 (14.7)
3≥	2 (5.9)

Table 15 shows that over 12 months, 15 patients (44.1%) were re-admitted into hospital or emergency department at least once. In fact, 26.5% and 5.9% of them were admitted into hospital and A & E Department respectively within three months post-discharge (Table 16), mainly for infection, fever, falls, diarrhea, internal bleeding, edema, diabetes and pressure sores.

Table 16 Breakdown of hospital re-admission or visit to A&E department

Details of Visits (N=34)	N (%)
Hospital readmission across T1 to T4	
T1	5 (14.7)
T2	4 (11.8)
T3	2 (5.9)
T4	4 (11.8)
Visits to A & E department across T1 to T4	
T1	0 (0.0)
T2	2 (5.9)
T3	0 (0.0)
T4	3 (8.8)

4.5 Summary

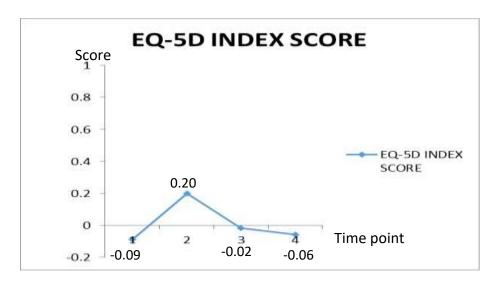
In summary, the patients and caregivers did not report a very satisfying experience in the transition of care from hospital to post-acute care services, with an average score of less than 68 on the CTM-15. Almost all the patients were referred to at least one post-acute care service, with inpatient community hospital service as the most commonly reported post-acute care service referred to. During the period of study, patients reported changes in the types or number of services received. Slightly more than a quarter of them were admitted into the hospital within the first three months after discharge from the hospital suggesting that the elderly patients can be most vulnerable during this period and a review of the support is needed to prevent readmission. However, majority of the patients were not re-admitted into the hospital or visited the A & E department over the 12 months period studied.

5. The Impact of Post-Acute Care among the Patients

In this chapter, we describe the experience of the patients in post-acute care over 12 months, specifically the impact of post-acute care on the health-related quality of life, social and mental health of the patients. The sample size of the elderly patients interviewed was small to start with (N = 8) and ended with three patients at the 12^{th} month post-discharge from acute care (T4).

5.1. Impact on the Health-related Quality of Life

Figure 2 The health-related quality of life of patients

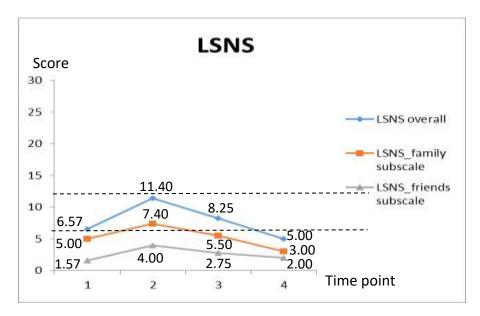


Health-related quality of life (HRQoL) is a multi-dimensional construct that includes physical, psychological, emotional and social domains of functioning, and it focuses on the impact of health status has on quality of life. In this study, the HRQoL of the patients was measured using the Singapore version of the EurolQol Group's 5-domain questionnaire (Gao et al., 2009; Luo et al., 2003). The five descriptors were transformed into a single-utility index that has a value not greater than 1, where '1' represents full health and '0' denotes health as poor as death from the perspective of the general public (Dolan, 1997; Tsuchiya et al., 2002). As shown in Figure 2, the index of the elderly patients was near or below zero. The findings suggested that health of the elderly patients post-acute-care was as poor as death, if not worse than death over time.

5.2. Impact on the Social Health

The abbreviated version of the Lubben Social Network Scale (LSNS-6) was used repeatedly to assess social integration and to screen for social isolation among the patients across the 12 months. Lubben and his team (2006) suggested a cut-off point of 12 for identifying individuals at risk for social isolation. Similarly, those with scores of less than 6 on the Family subscale (items 1-3) were suggested to have marginal family ties and those with scores of less than 6 on the Friends subscale (items 4-6) were said to have marginal friendship ties.

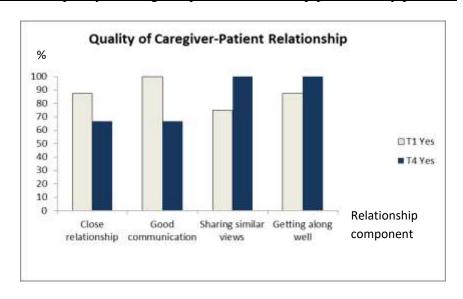
Figure 3. The social networks of patients



As shown in Figure 3, the LSNS-6 overall scores were low across T1 to T4, peaked only at T2. Using the suggested clinical cut-off point, the data seemed to suggest that the elderly patients were at risk of social isolation; the only exception was the healthy family ties found at T2.

An examination of the quality of care relationship between the elderly patients and the caregivers at T1 and T4 indicated that the relationship was generally perceived by the elderly patients as "fairly good or "very good", although there was a reduction in the perceived closeness of the relationship and good communication from T1 to T4 (Figure 4).

Figure 4 The quality of caregiver-patient relationship perceived by patients.



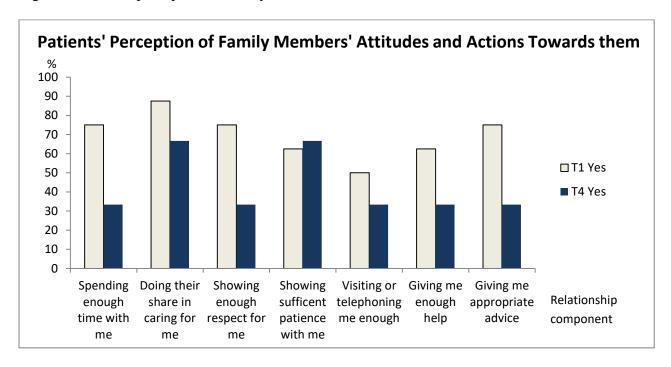
In contrast, the relationship between other family members and the patient deteriorated from T1 to T4, with the exception of the perceived sufficient patience shown by the family relatives towards the patient (Figure 5). One common observation made among the

elderly patients were their concern of being a burden to their children, as shown in the excerpts below:

"They have their own family to take care of, how can they spend time with me? Last time before they got married, we can stay in one house, so it's still possible. They also have their own houses now. They do their own stuff, I do my own stuff. We also live separately." (CP15)

"My both sons have their own families. We don't want to burden them anymore. They have their own responsibilities, to care for their own children. So let us both manage on our own. But they do give us some money every month." (SP20)

Figure 5 Patients' perception of family members' attitudes and actions towards them



Similarly findings were reported among the caregivers, who perceived their children (among the spousal caregivers) or siblings (among adult children caregivers) not doing enough for the care of the patients. This is well illustrated in the exemplar excerpts below:

"All along, they [children] have seldom visited him. Everyone has their own work to do. On weekends, they have to look after their children. Who will visit you? They are busy with their own things." (CC02, spousal caregiver)

"...to be honest, they [siblings] can do much better because they are their parents; they should visit more frequently. But, some even one year only twice, sometimes one year only once.... They come just to visit. Other than that they don't do anything. They just come, talk a while." (TC08, adult children caregiver)

"My sons came down and pay me the money, he said 'Hello!' to the parents and go off. That's all, my sons. They come down and that's all, my 2 sons ... it's a bit

hurting to me, you see, because when they were small, we looked after them. What they wanted, we helped them everything. Now they are married, they care more for the family, children and the wife, you see. I feel sorry about that." (TC13, spousal caregiver)

5.3. Impact on the Mental Health

Hope and depression were measured to assess the mental health well-being of the elderly patients. The Herth Hope Scale (HHS) (Herth, 1992) was used to measure hope and the abbreviated version of Geriatric Depression Scale (Abbrev GDS) (Sheikh & Yesavage, 1986) was used to measure the presence of any depressive symptoms among the elderly patients.

As shown in Figure 6, average score on HHS hovered around 34 points (maximal point = 48). This implies that on average, the elderly patients remained constant in their hope over time. However, it might be worthy to note that the lowest HHS was below half of the maximal point.

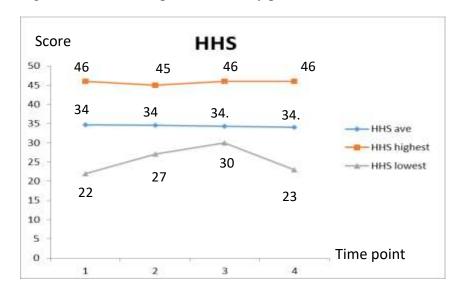


Figure 6 Perceived hope of the elderly patients

Similarly, as shown in Figure 7, with the exception of the average score at T2, the average score on GDS hovered around 9 points (clinical cut-off point = 11). This suggested that the elderly patients were not clinically depressed. However, it might be worthwhile to note that a substantial number of elderly patients scored at least 11 points at each time-point: three out of eight elderly participants at T1, two out of five (40.0%) at T2, two out of four (50.0%) at T3, and two out of three (66.7%) at T4. One possible explanation is that as health deteriorated, it became more and more difficult for the elderly to remain optimistic.

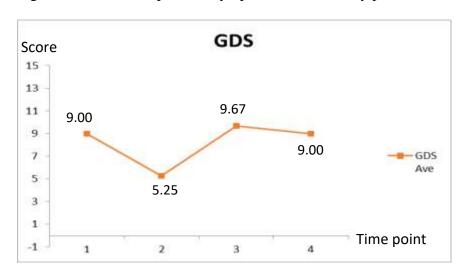


Figure 7 Perceived depressive symptoms of the elderly patients.

5.4 Summary

In summary, the post-acute care service delivery had an impact on the health-related quality of life, social health and mental health of the patients. The patients were found to suffer from poor health-related quality of life and social well-being. However, they remained strong in their mental well-being; they remained hopeful and not clinically depressed.

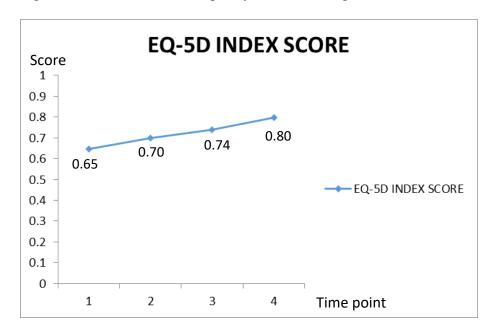
Interestingly, the data at T2 seemed to be in contrast with the data at other time points. At T2, patients were found to have reported a positive score on EQ-5D, a strong family relations and lowest score on GDS. A plausible explanation is that family members might have played an active caregiving role for the first three months, thus contributing positively to the patients' quality of life and mental well-being.

6. The Impact of Post-Acute Caregiving among the Caregivers

In this section, we describe the experience of caregivers during the 12 months, specifically the impact of post-acute caregiving on their health-related quality of life, social and mental health. We began at T1 with a caregiver sample size of 32 and ended with 18 at 12th month (T4).

6.1. Impact on the Health-related Quality of Life

Figure 8. The health-related quality of life of caregivers

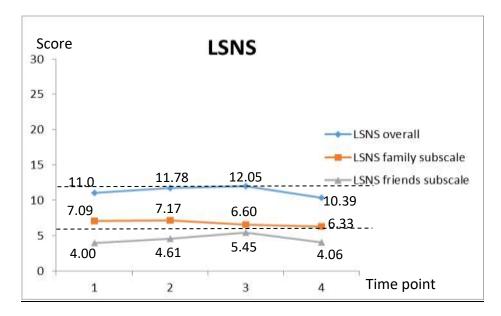


The health-related quality of life (HRQoL) of the caregivers, measured using the Singapore version of the EurolQol Group's 5-domain questionnaire (Gao et al., 2009; Luo et al., 2003), showed that the quality of life of the caregivers was not full health ('1' represents full health and '0' denotes health as poor as death). However, the single-utility index was on a positive slope across the four time points, suggesting an improved quality of life among the caregivers across time. However, it cannot be determined if the improved quality of life was a result of the support of post-acute care services or adjustment made by the caregivers.

6.2. Impact on the Social Health

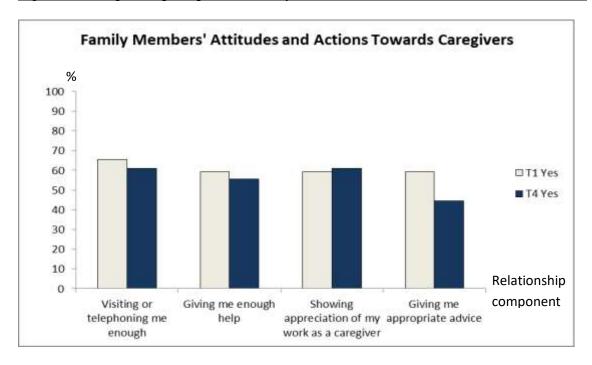
As shown in Figure 9, the LSNS-6 overall score was slightly below the clinical cutoff point of 12 across T1 to T4, with the exception of the LSNS-6 overall score at T3.

Figure 9 The social networks of caregivers



An examination of the LSNS Family subscale (Figure 9) showed that the caregivers were at any time point supported by at least two other family members. This concurred with the perceptions among the caregivers of the types of support they received from family members. As shown in Figure 10, with the exception of receiving appropriate advice at T4, more than half of the caregivers reported receiving emotional and instrumental support from the family members. Compared to the patients, the caregivers seemed to have received more support and concern from the family members than the patients over time (Figure 5, p. 23).

Figure 10 Caregivers' perception of family members' attitudes and actions towards them



In addition, caregivers perceived the quality of care relationship with the elderly patients from T1 to T4 as "fairly" or "very" good, although there was a reduction in the percentage across all the four dimensions at T4 (Figure 11). The findings were quite similar with the perceptions of the patients as shown in Figure 4, although the patients reported they shared more similar views and got along better than the caregivers at T4 (p. 22).

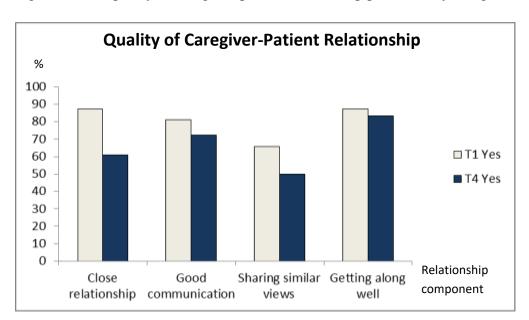


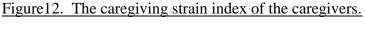
Figure 11 The quality of caregiver-patient relationship perceived by caregivers.

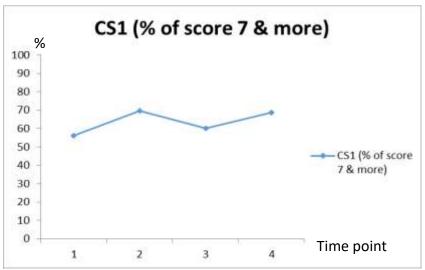
Qualitative data indicate that the nature of disease (such as stroke and dementia) might have affected their communication and thus their relationship. There are others who began the caregiving relationship due to obligation rather than the love as shown in the excerpt below:

"Emotionally, we, how to say, are not really that close. But I have no choice, she has no choice. She and I are always different. We are loggerheads. She never agrees with me and I don't agree with her....I was never close with her. But because she was all alone she doesn't have children, no family, nobody, no [other] brother, sister. I'm alone." (TC07, sister)

6.3. Impact on the Mental Health

The negative impact of caregiving on the caregivers has been well-researched (Son et al., 2007; Gordon et al., 2012; Malhotra et al., 2012). The Caregiver Strain Index (CSI) was used in this study to measure the level of stress experienced by the caregivers across the four time points. The clinical cut-off point score of 7 was suggested for identifying families with potential caregiving concerns where an in-depth assessment to facilitate appropriate intervention is needed (Robinson, 1983). As shown in Figure 12, more than half of the caregivers had a score of 7 or above at any one time point, indicating the presence of caregiving concerns.





An examination of the tasks provided by the caregivers for the elderly patients, using the Oberst Caregiving Burden Scale (Bakas et al., 2004) gave us some insights into the amount of time needed and the level of difficulties faced in caregiving. Table 17a gives a breakdown of the level of difficulty in performing a specific caregiving task (on a scale of 1 to 5, where 1 = not difficult, 2 = slightly difficult, 3 = moderately difficult, 4 = very difficult and 5 = extremely difficult) and Table 17b gives a breakdown of the amount of time required to perform a specific caregiving task (on a scale of 1 to 5, where 1 = none, 2 = a small amount, 3 = a moderate amount, 4 = a large amount and 5 = a great amount).

Table 17a Difficulty of tasks provided by caregivers for elderly patients

Caregiving Tasks	T1	T2	Т3	T4
	Mean (% with	Mean (% with	Mean (% with	Mean (% with
	very or	very or	very or	very or
	extreme difficulty)	extreme difficulty)	extreme difficulty)	extreme difficulty)
1. Medical or nursing treatments	1.9 (14.8)	1.6 (14.3)	1.7 (6.7)	1.5 (15.4)
2. Personal care	2.4 (29.6)	1.9 (9.5)	2.2 (18.8)	2.3 (25.0)
3. Assistance in walking, getting in & out of bed etc	2.3 (25.9)	1.9 (19.1)	2.1 (16.7)	1.9 (25.0)
4. Emotional support	1.8 (15.6)	1.9 (17.4)	2.1 (20.0)	2.2 (25.1)
5. Monitoring patient's symptoms & progress	1.7 (10.0)	1.5 (4.5)	1.6 (10.6)	1.9 (6.3)
6. Providing transportation	2.1 (26.6)	2.3 (26.1)	2.6 (22.3)	2.4 (18.8)
7. Managing finances	1.9 (16.2)	1.9 (13.0)	2.3 (27.8)	2.3 (18.8)

8. Additional household tasks	1.5 (9.7)	1.4 (4.3)	1.9 (6.7)	2.0 (30.8)
9. Additional tasks outside home (errands etc.)	1.4 (3.1)	1.3 (0.0)	1.6 (0.0)	1.6 (0.0)
10. Planning activities	1.4 (6.5)	1.3 (0.0)	1.4 (0.0)	1.3 (0.0)
Managing behaviour problems	1.9 (16.2)	2.2 (26.0)	2.2 (15.0)	2.1 (18.8)
12. Arranging elder care while away	2.3 (30.0)	2.1 (23.8)	1.7 (10.5)	2.2 (26.6)
13. Communication	1.4 (6.2)	1.6 (8.6)	2.1 (15.0)	2.0 (20.0)
14. Managing services and resources	1.8 (9.7)	1.5 (0.0)	1.6 (5.0)	1.6 (6.3)
15. Communicating with healthcare professionals	1.8 (10.0)	2.0 (13.0)	2.0 (15.8)	1.9 (12.6)

As shown in Tables 17a and 17b, the caregivers reported that on average, the caregiving tasks could be performed with "no difficulty" or "slight difficulty", and that required "a small amount" of time. Only a few of the caregiving tasks required "a moderate amount" of time. These caregiving tasks included: providing emotional support or transportation, and doing additional household tasks at T3 and/or T4.

It may be interesting to note that at any one time point, at least 31% of the caregivers indicated that "a large amount" or "a great amount" of time was required to monitor patient's symptoms and progress (refer to Table 17b). Similarly, at least 31% of the caregivers reported that "a large amount" or "a great amount" of time was required at T3 and/or T4 to provide personal care, emotional support or transportation, as well as performed additional household tasks. This may account to the strain and burden experienced by the caregivers.

Table 17b Amount of time required for tasks provided by caregivers for elderly patients

Caregiving Tasks	T1 Mean (% large or great amount of time)	T2 Mean (% large or great amount of time)	T3 Mean (% large or great amount of time)	T4 Mean (% large or great amount of time)
1. Medical or nursing treatments	2.5 (18.5)	1.8 (9.6)	2.1 (17.7)	1.9 (7.7)
2. Personal care	2.3 (22.2)	2.0 (14.3)	2.6 (33.3)	2.7 (33.3)
3. Assistance in walking, getting in & out of bed etc	2.3 (18.5)	1.9 (14.3)	2.3 (23.5)	2.1 (16.6)
4. Emotional support 5. Monitoring patient's	2.8 (32.3)	2.7 (21.7)	3.1 (35.0)	3.1 (37.5)
symptoms & progress	2.9 (34.5)	2.8 (31.8)	2.9 (33.4)	2.9 (31.3)
6. Providing transportation	2.7 (30.0)	2.6 (17.4)	2.9 (38.9)	3.0 (31.3)
7. Managing finances	2.7 (29.1)	2.3 (17.4)	2.7 (31.6)	2.8 (25.0)
8. Additional household tasks	2.4 (22.6)	1.9 (8.6)	3.0 (46.6)	2.2 (23.1)
9. Additional tasks outside home (errands etc.)	2.2 (12.6)	1.8 (0.0)	2.4 (15.8)	2.5 (13.4)
10. Planning activities	1.8 (3.2)	1.4 (0.0)	1.6 (5.3)	1.5 (6.7)
Managing behaviour problems	2.3 (22.6)	2.4 (26.1)	2.5 (20.0)	2.4 (18.8)
12. Arranging elder care while away	2.3 (23.3)	2.2 (23.8)	1.8 (15.8)	2.3 (26.7)
13. Communication	2.2 (18.8)	1.9 (13.0)	2.3 (20.0)	2.4 (33.4)
14. Managing services and resources	2.5 (16.2)	2.1 (4.3)	2.1 (10.0)	2.0 (12.6)
15. Communicating with healthcare professionals	2.6 (19.4)	2.6 (13.0)	2.6 (21.1)	2.3 (18.8)

6.4 Summary

In summary, the post-acute caregiving experiences had an impact on the caregivers' health-related quality of life, social health and mental health. The caregivers' quality of life of was found not "full health", although the findings indicated an upward trend over time. The caregivers seemed to have suffered in social well-being too, although they were supported by at least two family members during the period of study. More than half of the caregivers reported stress related to caregiving burden, especially when majority of them did not have a FDW to help them in the care of the patients. Monitoring of the patients' symptoms and disease progress was a constant caregiving burden over the 12 months of the study.

7. Discussion, Limitations and Conclusion

The main objective of the exploratory study is to examine how the current health service delivery has helped to integrate and provide care across settings, from acute to post-acute care, so that the older persons' health can be maintained, restored or rehabilitated and that they can age in place successfully. We will be discussing the findings with reference to the transitional care programmes model proposed by Wee et al. (2015).

7.1 Hospital Re-admissions and Visits to A & E Department

The findings indicate more than half of the patients (55.9%) did not get re-admitted into hospital or visit A & E Department over the 12 months, although 26.5% of them were admitted into hospital and 5.9% into A & E Department respectively within three months post-discharge. Despite the small sample size, the percentage is not too far different from a study conducted by Singapore General Hospital in 2012 on 800 patients, which found that the re-admission rates were reduced by up to 30% through the transitional care pilot programe (Choo, 2018). The low prevalence of hospital re-admission or visits to Accident and Emergency (A & E) Department tells only one part of the story, and it is therefore insufficient to conclude that elderly patients were able to rehabilitate and age-in-place successfully. Not visiting the A& E department or hospital does not necessarily indicate success in transitional care programmes. There is a need to more closely examine and improve the process of care transition and quality of life (QoL) post-acute care.

7.2 Quality of Life of Patients

According to WHO (2018), QoL is a multi-dimensional concept which includes "physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment" (Retrieved from http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/). The findings showed that although patients might have a caregiver, or even be residing with the caregiver, they were not necessarily enjoying good mental and social well-being. Despite having a good relationship with their caregivers, the patients seemed to be socially isolated, with some exhibiting depressive symptoms. In fact, their health-related QoL score indicated that they were never at full health, and many experienced QoL that the general public would have rated 'as poor as death, if not worse'.

7.3 Quality of Life of Caregivers

Patient QoL is closely associated with the caregiver QoL. Similar to the patients, the caregivers did not see their life as in full health, but they were getting nearer and nearer to full health over time. The caregivers enjoyed a positive relationship with the patients as well as their family members. However, they seemed to show signs of being socially isolated from friends. More than half of the caregivers also reported signs of strain and stress in caregiving, which might be related to the amount of time commitment required in performing specific caregiving tasks. Additional stress faced in their employment contributed further to their mental stress. The findings generally concurred with another local survey on informal caregiving (Chan et al., undated). Different from Chan and team's study, the use of foreign domestic workers to help care for elderly patients was uncommon among the participants in our study. In Chan and team's study, a caregiver's negative reaction to caregiving was

identified as the key predictor of depression. The results suggest that availability of instrumental and emotional support, caregiver respite, and preparing caregivers for the caregiving role could help mediate the negative impact of caregiving on the caregivers' mental well-being. Thus, we could probably infer from Chan and team's study that without making instrumental and emotional support available for the caregivers post-acute care, the negative impact of caregiving on the caregivers' mental well-being may be felt eventually.

7.4 Limitations of the Study

One key limitation of the study is the small sample size, which brought limitations to the types and number of statistical tests that could be performed to examine the possible relationships among the various variables. The small sample size also deters generalizability of the findings. However, the sample consisted of patients and families with varied complex needs, which thus provided us with insights into the challenges faced by such families in the transitional care programmes.

7.5 Recommendations for Future Study

The followings are recommendations for future study.

- 1. The original research proposal had intended to test certain hypotheses but due to the small sample size, the tests could not be performed. Future studies may want to consider the following hypotheses with a bigger sample size:
 - a. Patients with greater level of care is associated with higher caregiver stress and lower satisfaction with service;
 - b. Patient's health condition, dependency level and availability of support predict adjustment, caregivers stress and use of post-acute care services;
 - c. Better coping of patient and caregiver is predicted by prior planning, psychological preparation and higher level of social support.
- 2. The original proposal also intended to examine the costing and financing of the acute and post-acute care services. The hypotheses included
 - a. It is more cost effective in utilising community-based post-acute care services than acute-care services;
 - b. Government financing and subsidy structure influences the choice of post-acute care service.

Unfortunately, we faced tremendous difficulties in collecting financial related information to understand and evaluate the performance of transitional care programmes. Future studies could look into a feasible way to collect such data.

3. The original proposal also intended to identify the spatio-temporal patterns of care transitions. That is, to examine the distribution of service through time and space. Unfortunately, the small data set did not meet the prerequisites to employ GIS to map the care pathways. Future studies may want to consider examining the spatio-temporal patterns of care transitions.

7.6 Conclusion

Despite a small sample size, this exploratory study had made the first step to examine the transitional care programmes in a systematic and longitudinal manner. This report has highlighted some key findings on the profile of the patients and the caregivers, the experiences and pathways of care journeyed by the patients and caregivers, and the impact on their quality of life. Maintaining quality of life of the patients and caregivers is one key

outcome of the transitional care programmes. To support quality of life would mean at least two things: as much freedom from the ravages of disease as possible and the retention of enough functions for active engagement in the world. Based on the findings of this exploratory study, it seems to suggest we have more to learn and manage.

Footnotes

1. Interim caregiving service is service that supports patients and their caregivers who are unable to provide the care support for their seniors when they return home (https://https://www.aic.sg/for-seniors-and-caregivers/all-about-caregiving/caregiver-support)

References

- 1. Bakas, T., Austin, J. K., Jessup, S. L., Williams, L. S., Oberst, M. T. (2004). Time and difficulty of tasks provided by family caregivers of stroke survivors. Journal of Neuroscience Nursing. 36(2):95-106.
- 2. Bakshi, A. B., Wee, S. L., Tay, C., Wong, L. M., Leong, I. Y., Merchant, R. A., Luo, N. (2012). Validation of the care transition measure in multi-ethnic South-East Asia in Singapore. *BMC Health Service Research*. 12:256.
- 3. Chan, A., Ostbye, T., Malhotra, R.,Hu, A.J. (undated). The survey on informal caregiving: Summary report (for MCYS). Singapore: MCYS. Retrieved from https://www.msf.gov.sg/publications/Pages/The-Survey-on-Informal-Caregiving.aspx, dated 21 March 2018.
- 4. Choo, F. (Feb 2, 2018). Hospital-to-Home programme has helped around 8,000 patients. *Straits Times*. Retrieved from https://www.straitstimes.com/singapore/health/public-hospital-transitional-care-programme-has-helped-around-8000-patients, dated 22 November 2018.
- 5. Coleman, E. (undated). Instructions for Scoring the CTM-15. Retrieved from website https://caretransitions.org/tools-and-resources/ctm-15-scoring/, dated 18 May 2018.
- 6. Coleman, E.A., Mahoney, E., & Parry, C. (2005). Assessing the quality of preparation for posthospital care from the patient's perspective: The Care Transitions Measure. *Medical Care*, 43(3):246-255.
- 7. Department of Statistics Singapore. (2017). Population Trends 2017. Singapore: Department of Statistics.
- 8. Department of Statistics Singapore (2017). Death and Life Expectancy. Retrieved from https://www.singstat.gov.sg/find-data/search-by-theme/population/death-and-life-expectancy/related-info, dated 18 May 2018.
- 9. Dolan P. (1997). Modeling valuations for EuroQol health states. Med Care, 35:1095-1108.
- 10. Gao, F., Ng, G-Y, Cheung, Y-B, Thumboo, J., Pang, G., Koo, W-H., Sethi, V-K, Wee, J, Goh, C. (2009). The Singaporean English and Chinese versions of the EQ-5D achieved measurement equivalence in cancer patients. Journal of Clinical Epidemiology, 62:206-213.
- 11. Herth, K. (1992) Abbreviated instrument to measure hope: development and psychometric evaluation. Journal of Advanced Nursing, 17(10), 1251-1259.
- 12. Lawton, M. P & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. The Gerontologist, 9(3), 179-186.
- 13. Lien Centre for Palliative Care (2011). Report on the National Strategy of Palliative Care. Singapore: Ministry of Health.
- 14. Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., Kruse, WR., Beck, JC., and Stuck, AE. (2006). Performance of an abbreviated version of the Lubben Social Network Scale among three European community-Dwelling older adult populations. The Gerontologist. 46(4) 503-513.
- 15. Luo, N., Chew, L.H., Fong, K.Y., Koh, D.R., Ng, S.C., Yoon, K.H., Vasoo, S., Li, S.C., Thumboo, J. (2003). Validity and reliability of the EQ-5D self-report questionnaire in Chinese-speaking patients with rheumatic diseases in Singapore. Annals Academy of Medicine Singapore, 32:685-690.
- 16. Mohandas, V. (January 21, 2014a). Demand for transitional care service at Khoo Teck Puat Hospital on the rise. *Today Online*. Retrieved from https://www.todayonline.com/singapore/demand-transitional-care-service-khoo-teck-puat-hospital-rise, dated 23 November 2018.

- 17. Mohandas, V. (January 22, 2014b). More hospitals to launch transitional care services. *Today Online*. Retrieved from https://www.todayonline.com/singapore/more-hospitals-launch-transitional-care-services, dated 23 November 2018.
- 18. Mokhtar, F. (Mar 21, 2016). From hospital to home: More patients making use of transitional care. *Channel News Asia*. https://www.todayonline.com/singapore/demand-transitional-care-service-khoo-teck-puat-hospital-rise Retrieved from https://www.channelnewsasia.com/news/singapore/from-hospital-to-home-more-patients-making-use-of-transitional-c-8118938, dated 23 November 2018.
- 19. Robinson, B. (1983). Validation of a Caregiver Strain Index. Journal of Gerontology. 38:344-348.
- 20. Shah, S., Vanclay, F., & Cooper, B. (1989a). Improving the sensitivity of the Barthel Index for stroke rehabilitation. Journal of Clinical Epidemiology, 42, 703 709.
- 21. Sheikh, JI and Yesavage, JA. (1986) Geriatric Depression Scale (GDS) Recent Evidence of Development of a Shorter Version. Clinical Gerontologist. 5(1/2) 165-173.
- 22. Tsuchiya A, Ikeda S, Ikegami N, Nishimura S, Sakai I, Fukuda T, et al. (2002). Estimating an EQ-5D population value set: the case of Japan. Health Econ, 11:341-353.
- 23. Tyagi, S., Ong, P.H., Ho, V., Hoenig, H., Hong, S.I., Matchar, D. B., Luo, N., Yoong, J., Chan, A., Finkelstein, E.A., Lee, K. E., Venketasubramanian, N., Menon, E., Chan, K.M., Silva, D.D., Yap, P., Tan, B.Y., Chew, E., Young, S.H., Ng, Y.S., Tu, T.M., Ang, Y.H., Kong, K.H., Do, Y.K., Guo, E., Singh, R., Merchant, R.A., Chang, H.M., Yeo, T.T., Ning, C., Cheong, A., Koh, G.C.H. (unpublished manuscript). A prospective cohort study on the health, social and financial effects of care-giving among caregivers of elderly stroke patients in the first post-stroke year in a multi-ethnic Asian country: A study methodology paper.
- 24. Wee, S.L., Vrijhoef, H.J.M. (2015). A conceptual framework for evaluating the conceptualization, implementation and performance of transitional care programmes. JOuranl of Evaluation in Clinical Practice, 21:221-228.
- 25. World Health Organisation (2018). WHOQOL: Measuring quality of life. Retrieved from http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/, dated 18 Mary 2018.

Exploratory Study on Care Transition of Older Persons