Decision Making on Institutionalization Based on Resources, Cultural Differences and Personal Preferences

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Abstract

Singapore is ageing at a much faster rate compared to other countries, yet, little is known about Advance Care Planning (ACP) in the elderly. This discussion is based on a review of Singapore's long term elder care services, informal caregiving, advance care planning and related discussion. The survey was also conducted on 69 Singaporean respondents and suggested that filial piety might not be diminished in younger generations of Singaporean respondents. Changes to the demographics pose a challenge to the sustainability of filial piety. High age-dependent ratio translates to higher caregiver burden. With less siblings to shoulder caregiving responsibilities, Singaporeans' expression of filial piety may be altered and this is evident in the reliance on paid informal care such as foreign domestic workers (FDWs). With the support from FDWs and other professional home care services, institutionalization may then be a last resort. There are several unique factors which shape the elder care landscape through the government's "many helping hands" policy, cultural differences among the races, and the heavy reliance on FDWs to provide paid stay-in elder care. Using the case of Singapore, we argue that the decision for institutionalization cannot be easily made by rational reasons but are constrained by unique cultural factors. The decision on institutionalization should also be based on individual preferences and articulated through ACP. This paper explores the use of ACP in factoring the healthcare preferences of the elder and proposes a model of decision making regarding institutionalization should ACP be absent. (245 words)

Keywords: Caregiving, Institutionalization, Advance Care Planning, Filial Piety, Foreign Domestic Workers.

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1. Introduction

The World Health Organisation (WHO) defines Long Term Care (LTC) as the provision of care services to help chronically ill and functionally disabled people maintain a good quality of life with the highest degree of independence, personal fulfilment and dignity by combining medical, nursing and social services.

Singapore is aging rapidly. The percentage of citizens aged 65+ is estimated to double from 12.4% in 2014 to 24.0% in 2030, rising to more than 30% in 2050 and at a much faster rate compared to Japan or the U.S. Singapore will take only 27 years to transition from an 'ageing society' in 1999 (7% seniors) to a 'super-aged society' (20% seniors) in 2026,(Tan Teck Boon, 2015) much faster than Japan, China, Germany and the United States, which took or will take 36, 32, 76 and 86 years to make that transition respectively.(East Asia Forum, 2015). As such, the large multi-generation families in Singapore with intrinsic elder care support has declined rapidly. There is now an increasing presence of dual income working couples, singles, divorcees, childless married couples and small nuclear families in Singapore, means that greater support services is needed when adult children are unavailable.

In addition, the number of semi-ambulant or non-ambulant elders in Singapore is projected to triple from 44,600 in 2010 to 132,000 in 2030¹. These elders would require assistance in their activities of daily living (ADL). Furthermore, the number of Singapore elders aged 65 and above who live alone has nearly tripled from 14,500 in 2000, to 42,100 in 2014². These factors mean that the demand for long-term care will be met by non-familial means, even though the Singapore government is aware that many seniors prefer to live at home³. The Singapore government adopts the "many helping hands" approach, which comprises three tiers of assistance (self, community, state) and relies heavily on the Asian concept of filial piety to support seniors. In line with Singapore's "many helping hands" approach, the government funds Voluntary Welfare Organisations (usually set up by religious organisations or by charity groups) to provide services for long term care of elders, rather than the government being the direct provider. Elders needing long-term care services can be broadly classified under residential or nonresidential services. Institutionalization of elders can be considered as residential services that cater to seniors who are unable to care for themselves or cannot be cared for in their own homes.

Non-institutionalised and non-residential long-term care services for elders consist of:

- a. Home-based services and
- b. Center based services.

Home-based services include nursing care, personal care, home therapy, meals services and escort services.

² Tai, J., 2015 Old and home alone in Singapore, Straits Times, published on 17 Aug 2015

¹ Source: Department of Statistics Consensus 2010

³ Aging Planning office, Ministry of Health, Write up on Singapore's long-term care system, The 12 ASEAN and Japan High level officials meeting on caring societies, 21 – 23 Oct 2014

Centre-based care services cater to elders who require care services in the day while their caregivers are at work. These centers are mostly located within the community and close to the elder's home. Centre-based services include rehabilitation services, dementia care services and day care services.

Residential or institutionalized care services include nursing homes, community hospitals, chronic sick hospitals and inpatient hospice care.

The government is ramping up long term care by increasing beds in nursing homes from 10,968 in 2014 to 13,022 in 2016. Non-residential care support has also increased from 14 home care providers and 5 home palliative care providers in 2014 to 21 home care providers and 7 home palliative care providers in 2016.⁴

The government is focusing on strengthening home and community care support to help elders avoid institutionalization. This is evident in the planned 195% increase in community care places from 3,500 a day in 2011 to 6,2000 per day in 2020 and another 163% planned increase of home care places from 6,900 home care places in 2015 to 10,000 home care places in 2020.

2. <u>Literature review</u>

2.1 Institutionalization of elders appear to go against the grain of filial piety

Often, when families decide on institutionalization, there are many practical factors to consider. While upholding the individuals' values of dignity, personal fulfilment and independence are ideal, availability of resources is an important factor, and possibly an overriding factor to consider in the decision-making process leading to institutionalization.

However, in the case of Singapore, decision-making on institutionalization is not straightforward and there seems to be a tension between pragmatic considerations of costs and available resources, against the traditional Asian value of filial piety. Filial piety is a strongly internalized concept based on social expectations. It can be broadly defined as a value which seeks to honor parents, particularly in the form of showing them gratitude by taking care of them in old age.

According to a national survey conducted in Singapore in 2011, majority of the elderly population expected their children to support them and rely on the notion of filial piety as a form of tacit "social contract". In another survey conducted by the Institute of Policy Studies for Singapore Perspectives in 2018, it was found that "family" was ranked as first in line to take care of the elders, while "government" was ranked as second in line to take care of elders. There seems to be a disconnect between Singaporeans' expectations and

⁴ Chan, A., Ostbye, T., Malhotra, R. and Hu, J. (2012). Survey on Informal Caregiving: Summary Report for the Ministry of Community Development, Youth and Sports. Singapore: MCYS. Available from https://www.msf.gov.sg/publications/Pages/The-Survey-on-Informal-Caregiving.aspx

the government's concept of the multi-helping hands approach which advocates family, community, and finally, the government as the last in line for social welfare.

2.2 Changing demographics of Singapore

While institutionalization may be against the notion of filial piety and frowned upon by society, the changing demographics of Singapore may not allow familial caregivers to continue upholding the value of filial piety in the same manner as what earlier generations did in providing home-care for elderly parents by themselves.

Statistics from a report by the Social Development Division (SDD) on Long-term care of older persons in Singapore (2015) revealed that Singapore's old age dependent ratio was 4.9 in 2015, and is projected to decrease to 2.1 in 2030. There is also less intergeneration support, as three-generation households⁵ decreased from 32.6% of total households in 2000 to 23.1% in 2014. On the other hand, one-person households increased from 7.5% in 2000 to 11.9% in 2014 and nuclear families increased from 9.2% in 2000 to 17.7% in 2014.

The shift in family structure means that the caregiving burden of elders in each family will increase. The available pool of informal caregivers is set to shrink, particularly as, a substantial number of women, who forms the bulk of the informal caregivers, are in the workforce.

According to Chan et al. 2012, 60% of family caregivers are female, out of which daughters constitute a large portion of family caregivers. It is foreseeable that this pool of female caregiver will either diminish or face greater caregiver burden in juggling between caregiving and work as women become better educated and have increased participation in the work force.

Complicating matters are ethnic and cultural differences. According to the 2011 national survey of senior citizens in Singapore, 62.6% of Chinese elders (age 65 years and older), 79.6% of Malay elders and 72.9% of Indian elder are in contact with family members every day. The ethnic differences perhaps point to the differences in family living arrangements, with Malay families relatively preferring to live in intergenerational households. The survey also found that more Malays required physical assistance or were bedridden (4%) compared to Chinese and Indians. The lifestyles and diets of various ethnic groups may present different sets of caregiving challenges. These ethnic differences suggest we need to take into account ethnic differences, when designing a model for decision making on institutionalization,

2.3 Caregiver stress and burden

Ang & Maholtra 2017 found that interruptions to caregiver's work added more stress to caregivers and may worsen relationship between care recipient and caregiver due to

⁵ Three generations households are households where grandparents, adult children and grandchildren live together

feelings of "sacrificing" one's career for the care recipient. The same study also found that caregivers who are employed experience more mental stress than non-caregivers, due to the strain of juggling caregiver and work duties.

According to Chan et al 2013, if caregivers lack a conviction in filial piety, the execution of filial piety (rather than internalizing the value with conviction) due to societal expectations will result in higher caregiver stress, particularly when resources are tight. This internal conflict between what the caregiver truly desires and what the caregiver does so as not to be judged for lack of filial piety, cause breakdown of the caregiver if she grudgingly make sacrifices for caregiving.

3. Methods

3.1 Survey

The survey was conducted from February to April 2018 through convenience sampling using an online survey platform to understand how younger generations value filial piety. The data consists of 69 Singaporean respondents to understand how younger generations value filial piety. All respondents completed the online survey that measured the attitudes that encouraged filial piety.

3.2 Measures

Attitudes measured were caregiving preferences of elderly or chronically sick parents, in terms of familial support, outsourcing of caregiving support to FDW, institutionalization, and co-residing with elderly or sick parents.

3.3 Analysis

Univariate statistics (simple frequencies) was used to generate a profile of respondents and overall scores for variables of interest. The preference for familial caregiving, coresiding, employment of an FDW and institutionalization of elderly loved ones was ranked. An independent t-test was performed on variables with a normal distribution to test for differences in means and across two groups. An analysis of variance (ANOVA) was performed on data to test for differences between three or more groups.

The linear regression model was used to determine the univariate relationship between covariates and continuous behaviour outcome after adjusting for confounders (gender, marital status, occupation, income, education, housing, chronic conditions, and attitudes). Skewness was determined graphically using a histogram with a superimposed normal plot. The selection process begins with a univariate regression analysis of each variable. Any variables that have a significant univariate test at p-value cut-off point of 0.20 was selected as a candidate for the multivariate analysis (Bursac et al., 2008). The STATA v15 (StataCorp LP, USA) software was used for the statistical analysis, with the significance level set at P<0.05. The survey results were used to predict the sustaining power of filial piety in compelling family members to look after their elderly parents.

3.4 Results

The survey results suggest that filial piety is still a strong notion in Singapore as institutionalization of elderly parents was last in ranking of caregiving preferences. When asked if respondents would co-reside with parents if one of them were chronically ill and require caregiving, 94.2% of the respondents would. Amongst the top three most cited words for looking after their elder parents were "duty", "responsibility" and "love". These three words echoed the concept of filial piety and gratitude, reflecting the idea of "returning to our parents what they have given to us".

When asked to rank respondent's preference for caregiving, co-residing was the top choice (score of 4.23), followed by staying near parents (score of 4.17) and employing an FDW (score of 4.15). The marginal differences between the three top preferences suggests that FDW holds an almost equal ranking of caregiving preference, as compared to the other direct expressions of filial piety.

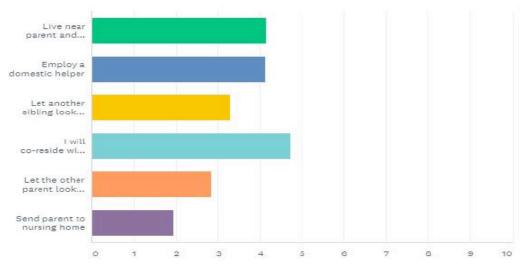


Figure 1. Caregiving preferences

However, in view of the changing demographics, increasing caregiver's burden, and the increasing employment of FDWs, it is likely that the notion of filial piety might evolve as younger generations view FDWs to be a more filial form of caregiving than institutionalizing elderly parents.

Even though Singaporeans have a globalized outlook and are exposed to western influences, Singaporeans still retain traditional views of familism and filial piety. Singaporeans are also receptive to usage of FDWs as paid stay-at-home caregiver of their elderly parents rather than to institutionalize their elderly parents. (Tamyah, S., K., and Tan S., J., 2013).

Huang, Yeoh & Toyota (2012) described Singapore's solution to its eldercare predicament as predicated on 'othering' caregiving, where caregiving is conveniently

outsourced to the FDW. In fact, Yeoh & Huang 2010 concluded in their study that FDWs are becoming the de factor caregiver of the elderly in Singapore.

4. Discussion

4.1 Paid informal care - Foreign Domestic Workers (FDWs) as an alternative to institutionalization of elders

In Singapore, FDWs are mainly employed from neighboring countries (Indonesia, Philippines, Sri Lanka and Myanmar) to provide paid stay-in elder care. The survey of informal caregiving (Chan et al 2012) found that 49 percent of Singaporean families hired FDWs to provide care for their elders. Among those who required help for more than one ADL, a higher percentage of families (71%) employed an FDW. In fact, a Singapore national survey in 2011 revealed that FDWs were the third largest pool of caregivers, after spouses and adult children. The results of this study are consistent with the survey results, which reflected respondents' preferences for familial caregiving and reliance on FDW, above institutionalization.

FWDs' indispensability to the families makes them closer to the family in both emotional and pragmatic aspects. Tantzi & Skinner 2009 described FDWs as a form of "deinstitutionalization of eldercare" and a "cost containment strategy". Hiring FDWs transfers caregiving from skilled healthcare professionals to paid caregivers. FDWs should be empowered with formal caregiver training.

The benefits of hiring an FDW are multi-fold. For the government, FDWs reduces the pressure to provide institutional support. FDWs provide both instrumental and emotional support to caregivers They reduce disruptions to the normal routines of caregivers and reduce the financial strain (Chan et al. 2013) on caregivers. A mutual-support relationship can be built between caregivers and domestic helpers through trust and interdependence. FDWs are available most of the time as they are live-in helpers. They help families save cost and allow the elder to age at home, which sustains the deep-rooted Asian ideology of filial piety, albeit superficially.

In addition, there is a nursing home bed crunch and elders may have to wait for several months for a subsidized bed at a nursing home. (Tai and Chan, 2015). In Singapore, nursing home charges range between \$1200 to \$3500, while a private two-bedder in Malaysia's nursing home costs around \$900 a month. In fact, a nursing home in Johor (nearest Malaysian state to Singapore) has 40% of his residents from Singapore. Nursing home shortage and cost considerations make FDWs a more attractive option.

In 2010, there were 150,000 foreign domestic workers in Singapore (Tew and et al. 2011). This number had risen to 246,800 by December 2017. (Ministry of manpower http://www.mom.gov.sg/documents-and-publications/foreign-workforce-numbers).

Singapore's reliance on FDWs is increasing. In view of the increased demand, the government will need to review legislatures to protect FDWs and to also screen FDWs

and ensure that they are mentally sound. These measures are necessary as there are cases of FDWs being ill-treated by employees and also those (FDWs) who abused the elderly care recipients.

4.2 Individual preferences vis-à-vis family member's preferences in decision making on institutionalization

Even though the support of FDWs is an alternative to institutionalizing the or at least serve as another tier of support, before resorting to institutionalization, the decision to institutionalize an elderly loved one need not be shouldered by family members. In fact, family members may not always make decisions that are reflective of the desires of the care recipients.

A cross-sectional survey (Maholtra et al. 2015) using a discrete choice experiment on 211 patients and their informal caregivers found that caregivers are more willing than patients to pay to extend life and improve end-of-life experience. A summary of the key findings is as follow.

- a. Patients are willing to pay SGD 18,570 to extend their life by one year
- b. Patients are willing to pay SGD 22, 199 to avoid severe pain
- c. Patients are willing to pay SGD 31,256 to die at home
- d. Patients are willing to pay SGD 4051 to avoid being a burden to family and friends
- e. Patients are willing to pay SGD 16,191 to receive high quality health care to extend life
- f. (HOW about caregivers?)

The study showed that caregivers had a greater preference for life-sustaining treatments than patients themselves. This discrepancy suggests that clinicians should consult and respect patient's preferences as long as they have the mental capacity to do so. The results showed that advanced cancer patients prioritize pain management and home deaths highly. Instead of extending life and providing more institutionalized care, it is perhaps more important to focus on pain management, supporting home deaths and providing end-of life care at home. Institutionalization may in fact be more for reducing caregiver's burden than an execution of patient's wishes. Improving capacity for home hospice services can facilitate home deaths.

Differences in willingness to pay suggest that caregivers have to take into consideration patient preferences to age and receive treatment at home than to rely on caregiver's belief about what is best for the patient. Clinicians will usually acquiesce to caregivers who are the decision makers in many instances, however their decisions may not represent the preferences of patients.

With reference to the survey results, we learned that family members tend to support caregiving decisions that are more representative of filial piety, however not all care giving preferences of the elders are in alignment with this value. For example, caregivers

may opt to have more aggressive treatment or treatment to prolong life, because such "perseverance" in treating the patient may be deemed as being filial and not wanting to let the person go. It is also socially and ethically desirably to be seen by others that the caregivers are doing their best to seek treatment and care for the elders. It is therefore pertinent to take into account care recipient's preferences and ease the burden of decision-making via advance care planning.

4.3 Advance care planning

Advanced Care Planning (ACP) refers to a voluntary, non-legally binding discussion about future care plans between an individual, his healthcare providers and close family members, in the event that the individual becomes incapacitated and unable to make decisions. ACP may also include clarifications about the individual's wishes, values and healthcare objectives. ACP does not just deal with end-of-life, but also applies to long-term care.

ACP also includes the Advanced Medical Directive (AMD) and Lasting Power of Attorney (LPA). Under the Mental Capacity Act 2008, an individual aged 21 and above in Singapore can make advance preparation by applying for a statutory document known as the Lasting Power of Attorney (LPA). The document allows the individual (donor) to appoint a proxy (donee) or multiple proxies to make representation on behalf of the donor in the event of loss of mental capacity to make decisions pertaining to personal welfare and financial matters

However, it seemed that social-cultural factors revolving around the family remain the biggest challenges to take-up of ACP. Locally, the Asian emphasis on collective decision-making leads to the propensity by patients to leave decision-making about end-of-life issues to their children. According to a study by Tay SY, issues pertaining to the Asian culture of collective family decision-making were the greatest barriers to ACP engagement. Lo TJ's study on patients with early cognitive impairment showed that unmarried patients were more likely to actualize ACP plans.

Another major Asian cultural factor was the aversion towards talking about death for fear that it would bring bad luck (Lo, T.J., et al 2016 & Ng, R., et al.2013). A study by (Cheong K et al 2015) broke down this lack of support into the following: patient's lack of trust in the family, family agreeing with patient that ACP was irrelevant, and family members' dismissive attitude towards patients' end-of-life plans.

Ethnicity was mentioned as a challenge in a pilot study conducted on local patients (Sim, D., et al, 2013). This study showed that Malays were less likely to discuss ACP compared to other ethnic groups. We can compare this finding against that from an earlier Malaysian study which revealed that race, ethnicity and cultural values were important factors in ACP. The majority of the Malaysian subjects, especially those with Islamic faith, believed that their views were influenced by religion (Htut, Y., K. Shahrul, and P.J. Poi, 2007).

It appears that even in advance care planning, cultural and ethnic differences influence the take up rate. As compared to western societies, death and dying is a taboo topic in many Asian cultures, which then acts as an obstacle for conversations on ACP. Factoring the culture specific challenges and unique societal contexts, we propose the following model on decision-making for institutionalization that may be suitable for Singapore.

Decision making model for long-term care of elders

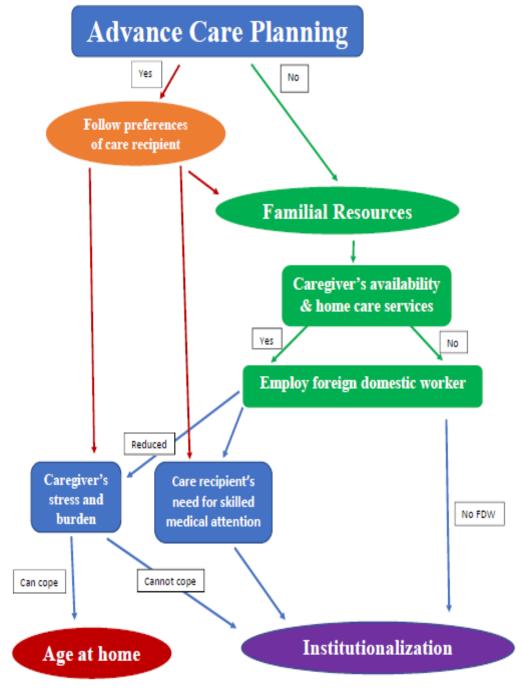


Figure 2. Proposed decision-making model for institutionalization of chronically sick elders

5. Conclusion

In Singapore, the government provides acute care and establishes funding frameworks for eldercare in the community. Singapore's policies place the responsibility of eldercare on the family as the primary caregiving unit while institutional care is seen as a last resort. Unique to Singapore are the availability of FDWs and home-care services, as attractive caregiving alternatives to the two extremes of i) full familial caregiving and ii) institutionalization.

As there is no universal model for decision making on the institutionalization of elders. Various countries should factor in unique cultural values and societal norms in proposing a decision-making model that is state-specific. Ideally ACP should be more commonly used to mitigate some of the dilemma that caregivers face in decision-making on institutionalization, and to ensure that the wishes of the care recipient are respected. Sensitivity to unique cultural factors and individual preferences will then help to shape a more robust and reflective model that is more appropriate for the respective care and social landscapes.

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