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Ageing in place together: Older parents and ageing offspring with intellectual disability

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Abstract

Limited research has been conducted about ageing in place among older parents who cohabit with their ageing offspring with intellectual disability (ID). This study aims to explore which older parents would choose ageing in place together with their ageing offspring with ID instead of moving and what factors are associated with this choice. A face-to-face interview was conducted using the 'housing pathways' framework with older parents (≥ 60 years) cohabiting with their ageing offspring with ID (≥ 40 years) from two local authorities in Taiwan. In total 237 families completed our census survey between June and September 2015. The results showed that 61.6 per cent of the participants would choose ageing in place with their ageing offspring with ID, while 38.4 per cent of the participants would stay in their previous place without their disabled children, move in with their other children or move to a nursing home. Logistic regression analyses revealed that parents who preferred ageing in place together with their offspring with ID were more likely to own a house ('personal control'), have higher levels of life satisfaction ('self-esteem') and satisfaction with their current community ('self-identity'), and have a lower level of social support than parents who chose another option. To meet the needs of older parents and their ageing offspring with ID, care and housing transitions should be considered as part of long-term care policy.

Keywords: intellectual disability, older parents, ageing in place, long-term care, Housing Pathways, Taiwan

Introduction

Moving in old age, relocation and housing transition have become significant issues in debates about ‘ageing in place’, as they relate not only to research but also to policies on health, social and residential care in an ageing society (Golant 2003; Jolanki and Vilkkio 2015; Means 2007; Moore 2000). People with intellectual disability (ID) live much longer than they did in the past, resulting in an expanding population of parents who are continuing to care for a son or daughter into old age (Emerson and Hatton 2004). Despite the policies that exist and the research that has been conducted to date, both health and social service providers typically lack an in-depth understanding of the needs of these older parents and their ageing offspring with ID (Baumbusch *et al.* 2017; Hubert and Hollins 2000).

The choice between moving in old age and ageing in place can be more complex for older parents caring for an ageing son/daughter with ID than for older people who have no offspring with disability, because these older parents need to manage not just their own but also their offspring’s ageing matters, such as transition plans for their offspring’s housing and care needs. With regard to older parents who still live with their offspring with ID, previous studies have mostly focused on these parents’ future care plans of their disabled children (Jokinen and Brown 2005; Walker and Hutchinson 2019). Care and housing transitions among these older parents and their ageing offspring with ID are rarely seen as parts of a whole, taking into account the needs of both generations, older parents and their disabled offspring.

In Taiwan, similar to many other countries, the percentage of individuals aged 65 years and over has risen dramatically in recent years, and ageing issues have become key health

and social care concerns in society (Chou, Kröger and Pu 2015). Since 2000, ‘ageing in place’ has been a central goal of the long-term care (LTC) policy for older people in Taiwan (Wu and Chuang 2001). However, similar to other countries, older people with ageing sons/daughters with ID are overlooked by Taiwan’s LTC policies, although, as in many countries (Braddock *et al.* 2001; Weeks *et al.* 2009), the overwhelming majority (93%) of Taiwanese citizens with ID live with their family in the community (Ministry of Health and Welfare, Taiwan 2018). Nevertheless, while national surveys of people aged 55+ years are conducted regularly in Taiwan, there is no empirical data available concerning ageing issues and living arrangements for ageing adults with ID and their older parents.

For the general population of older people, several Western and Taiwanese studies have discussed ageing in place and residential options. Based on Western studies (Means and Evans 2012; Robison and Moen 2000; Schmertmann *et al.* 2000), variables that are related to older people’s choices in housing transitions (ageing in place, coresidence with children or relocating) include the following: age, gender, presence of a spouse in the household, education level, living environment (urban vs. rural), ownership of housing, community participation, health and culture. In Taiwan, despite the ongoing decline in coresidence with children among older people, over half of older people still prefer living with their children later in life, which is a higher proportion than seen in Europe, Japan and South Korea (Directorate-General of Budget, Accounting and Statistics, Executive Yuan, Taiwan 2006). In addition to the variables identified in Western studies, financial condition is another strong predictor of housing transitions among older Taiwanese people (Chang and Chang 2010; Chen and Lin 2010; Tseng, Chang and Chen 2006).

For people with ID in old age, the following moving alternatives exist: moving to a nursing home for older people (Thompson, Ryrie and Wright 2004; Bower and Bigby 2014), moving to a residential setting for people with ID, moving to a siblings’ home, moving to

somewhere else or ageing in place and staying with their parents. Care and housing transitions for ageing adults with ID and their older parents need to be considered as a whole, meaning as a transition for an ‘older two-generation family’, in order to meet the needs of both the older parents and their ageing offspring with ID.

Recently, the needs of older parents with ageing offspring with ID have received attention from parental groups concerned with limited housing options for both parents and their ageing offspring with ID in Taiwan. Terms such as ‘older two-generation apartments’ (Wang 2011) or ‘same institutions for people with ID and the elderly’ (Cheng, Chen and Yen 2004) have been raised in this discussion. A qualitative study (Chou, Lee and Wang 2018), which interviewed older parents cohabiting with an ageing son/daughter with ID in Taiwan, found that these older parents’ preferences to either age in place or move were connected to the family and cultural contexts. However, quantitative data on these connections has been lacking in Taiwan, as in many other countries.

To analyse the decision-making process regarding moving or not moving, Clapham (2005) developed the concept of ‘housing pathways’, which includes the following four domains: personal control, identity and self-esteem, social support and inequality. According to Clapham (2002, 2010), personal control can be defined as ‘feeling in control of one’s housing circumstances and the process of achieving one’s goals’ (p. 260). The meaning of home for people is linked to their individual experiences of security, positive identity and self-esteem, which are associated with a sense of the ability to cope and a sense of ownership; identity comprises both self-identity and social identity. Social support can be provided by family and close friends but also by health and social care professionals. In the framework, inequality is seen as social exclusion and a lack of resources, which have an effect on the chance to be in control of one’s life and self-esteem.

In this study, the ‘housing pathways’ framework (Clapham 2002, 2010) is employed to explore which older parents would choose ageing in place together with their ageing offspring with ID instead of other options and what factors are associated with this choice. We hypothesise that older parents’ choice of ageing in place together with their ageing offspring with ID is associated with the four domains of the housing pathways framework.

Methods

A survey was completed through a face-to-face interview in this study, and all potential participants were invited to take part.

Data collection and Participants

The participants in this survey study were older parents from older two-generation families that included parents aged ≥ 60 years and their ageing offspring with ID aged ≥ 40 years who were cohabiting in the same household. The families were recruited from two local authorities, H City and W County, which are located in the northwestern and northeastern parts of Taiwan, respectively. In general, H City is a wealthy city with a relatively younger population and better welfare system than the rest of Taiwan. In contrast, W County is a more remote area and has a higher proportion of ageing population than other local authorities in Taiwan.

In Taiwan, disability welfare benefits are available only to those who are assessed by the local government, determined to have a disability and provided with a disability certificate. From the two local governments, based on their disability assessments, we received a list of people with ID, including information on their age, sex, address, telephone number, level of ID, whether they used residential service and whether they had multiple disabilities (MD) in addition to their ID. However, we were not told which of them were cohabiting with older parents.

Because of this limitation, we screened all those citizens in the two local authorities who were listed as having ID or MD + ID, being aged ≥ 40 years and not using residential service. In order to attain the participants' trust, first, the principal researcher's university and the city/county government posted a notification and invitation letter to all these families. The screening involved making a telephone call to each individual with ID (or MD + ID) aged ≥ 40 years. Through the phone conversation, we confirmed whether the individual with ID (or MD + ID) was living with at least one parent aged ≥ 60 years. If this was the case, the family fit the criteria and was invited to join our study and asked whether they would allow us to interview them at home. In those families where both the father and the mother were aged ≥ 60 years and cohabitating with their offspring with ID, only the mother was invited to participate in our survey as most often mothers were primary family carers in these families.

Structured interviews were then conducted at the participants' home by one of the trained interviewers (15 working in H City and 13 working in W County) who read through the questionnaire and recorded the answer to each question. All of the interviewers had completed six hours of interviewer training prior to beginning the survey interviews. During the data collection, three senior social workers working with people with ID were employed to supervise the interviewers, review the data, check for missed questions or answers, and make corrections to the questionnaires that the interviewers completed.

Ethical approval for the study was obtained from the Research Ethics Board at the National Yang-Ming University (IRB: YM103016F); all participants were informed of the study's details and signed an informed consent form.

In H City, there were 589 individuals listed with ID (517 with ID and 72 with MD + ID) aged ≥ 40 , and of those, 195 fit the criteria of our study; 161 (45 fathers and 117 mothers) of them completed the study (response rate 82.6%). In W County, 795 individuals were listed, and 102 met the sampling criteria; 76 (13 fathers and 63 mothers) completed our study

(response rate 74.5%). Overall, 237 older parents of ageing people with ID took part in this survey between June and December 2015 (response rate 79.8%) (for details, see Figure 1).

Among the participants, 45.6 per cent were married, the family having both the father and the mother alive. 75.9 per cent of the interviewees were mothers and 24.1 per cent were fathers. The mean age of their offspring with ID was 48.6 years ($SD = 6.5$, range: 40-74), and 62.0 per cent were male. The mean age of the parents who were interviewed was 75.4 years ($SD=8.0$, range: 60-99), and 84.4 per cent had received no formal education or attended only primary school. Among the families, 73.8 per cent lived in an urban area, 11.4 per cent hired a live-in migrant care worker, and 83.5 per cent owned the house/flat where they lived. A very small proportion of the older parents (4.6%) and their ageing offspring with ID (14.8%) were using any social services (e.g. daycare, home care). Most (82.7%) of these older parents reported that they did not have any formal or informal social support or that if they did, it was not helpful. Half of the older parents (50.2%) reported that they had a poor or very poor health condition. Over half (56.9%) of the families had a monthly income of less than US\$700. In general, the participants were satisfied with their living community (74.0%) but not with their life (11.0%) (see Table 1).

<Please insert Table 1 about here>

Dependent Variable

Ageing in place together was measured by two questions. The first question was, ‘*What will be your future living arrangement when you are disabled?*’ (1 = *not moving*, 2 = *move in with a sibling* (of the offspring with ID), 3 = *move in with more than one sibling*, 4 = *move to a place close to siblings*, 5 = *move to residential setting*, 6 = *never thought about it*, and 7 = *have thought about it but have no idea*). The participants who replied 1 (not moving) to the first question were then asked the following question, ‘*You have replied that you will not*

move when you are disabled. What about your son/daughter with ID? Will she/he continue to stay with you here when she/he gets old?' (1= yes, 2= no). If the parent replied 'yes', the answer was coded as 'ageing in place together'. All the other answers to the above questions were coded as 'other'.

Explanatory Variables

The explanatory variables include the four domains of Clapham's (2010) housing pathways framework as discussed above.

Personal control was defined by the following questionnaire item: 'Does the house/apartment belong to your family (i.e. the participants or their children)?', and the answer was coded as 'yes' and 'no' (the latter includes 'It is rented' and 'It belongs to other relatives or an employer').

Positive self-identity was measured by the following question: 'Are you satisfied with your current living community, e.g. the area and the image of it?' and was rated by five ordinal categories from *very dissatisfied* (1) to *very satisfied* (5). *Positive social identity* was defined by a question that asked, 'Are you willing to tell people where you live?' and was rated by five ordinal categories from *very unwilling* (1) to *very willing* (5). The participants' *self-esteem* was measured by the following question: 'In general, are you satisfied with your current life?' and was rated by five ordinal categories from *very dissatisfied* (1) to *very satisfied* (5).

Social support, including formal and informal support, was measured using a translated local version of the *Family Support Scale* (Dunst, Jenkins and Trivette 1984). A higher score indicates greater support ($\alpha = .71$ in this study).

Inequality was defined based on the participants' demographic and socioeconomic variables including *the level of disability of the offspring with ID* (based on the assessment

data shown in the disability certificate and categorised into four levels: mild, moderate, severe and profound), the participants' *age* (coded as an interval variable), *gender*, *level of education* (determined by the question, '*What is your highest level of education?*'), *health* (determined by the question, '*How is your health in general?*'), *family income* (determined by the question, '*How much is your monthly family income, including wages, governmental subsidies and pensions?*') and *housing geography* (determined by the question, '*What is your home address, including name of county and municipality?*', coded as urban or rural area based on the municipality). The participants' *level of education*, *health* and *family income* were rated as ordinal categories, with a higher rank indicating higher education, better health and higher family income.

Statistical Analysis

We analysed the results using the Statistical Package for Social Sciences (SPSS), Version 20.0. A descriptive analysis was used for the characteristic data, and a cross-table analysis and F-test were used to determine if there were significant differences between the two groups 'ageing in place together' and 'others' in terms of the participants' characteristics. Pearson's correlation coefficient was used to measure the associations between 12 independent variables. Logistic regression analyses were used to identify the factors associated with ageing in place together with ageing offspring with ID.

Results

Comparison between the two Groups: 'ageing in place together' vs. 'others'

Most (61.6%) older parents who were interviewed replied that they would not move when they were disabled and that their ageing sons/daughters with ID would continue to live with them, so they would be 'ageing in place together' (G1). The rest of the older parents, that is,

those who were not planning to age in place together with their ageing offspring with ID, were labelled as ‘others’ (G2).

A comparison between these two groups (G1 and G2) found that there were significant differences between them in terms of housing geography ($P < 0.05$), parents’ education ($P < 0.05$), house ownership ($P < 0.001$), parents’ satisfaction with living community ($P < 0.05$) and life satisfaction ($P < 0.05$). The findings suggest that when compared with the parents from G2, the parents from G1 were more likely to live in a rural area, have a lower level of education, have a higher proportion of home ownership, have a higher level of life satisfaction and satisfaction with the living community. However, a statistical comparison revealed no significant differences between the two groups concerning gender, age, level of disability, or social service use among offspring with ID or in terms of parents’ age, gender, health, living with other children without disability, social support, social service use, family income or whether the family hired a live-in migrant care worker or not (Table 2).

<Please insert Table 2 about here>

Correlations between the Indicators of the Four Domains of Housing Pathways

The correlations between the 12 variables that were defined based on the housing pathways framework in this study are shown in Table 3. The findings show that the indicators of parents’ personal housing identity (satisfaction with community), social housing identity (willingness to tell people where one lives) and self-esteem (life satisfaction) were strongly related with one another ($P < 0.01$); in addition, self-esteem was strongly associated with parents’ health ($p < 0.01$) and family income ($P < 0.001$).

Compared with fathers, mothers were more likely to be younger ($P < 0.01$), have a lower level of education ($P < 0.001$), have poorer health ($P < 0.01$) and live in a rural area ($P < 0.05$). Parents’ age was negatively correlated with education ($P < 0.05$), and parents’

education was positively related to their health ($P < 0.05$). Parents who had obtained a higher level of education were more likely to live in an urban area ($P < 0.05$) than parents with a lower level of education. Level of disability among offspring with ID was not significantly correlated with any of the other 12 variables.

The correlation results suggest that these older parents were mostly mothers and that they were more likely to be satisfied with their living community and have family ownership of their housing than other parents. However, these parents also had a lower level of education, health, and family income than other parents.

<Please insert Table 3 about here>

Factors Associated with Ageing in Place Together with Offspring with ID

Table 4 shows that the logistic regression model on ‘ageing in place together’ was statistically significant ($P < 0.01$) based on chi-square tests. Based on the ‘housing pathways’ framework, the significant positive factors associated with ‘ageing in place together’ included ‘personal control’ (housing ownership) ($P < 0.05$), ‘positive housing self-identity’ (satisfaction with the living community) ($P < 0.05$) and ‘self-esteem’ (life satisfaction) ($P < 0.05$), as well as social support, which was negatively related ($P < 0.05$). All the variables reflecting ‘inequality’, such as the participants’ demographic and socioeconomic variables, which included the participants’ resources, were not significantly related to ‘ageing in place together’ among the participants.

The findings indicate that older parents’ ability to control their housing and whether or not they have a strong housing identity and self-esteem are important factors in decision making about relocation and ageing in place together with their ageing offspring with ID. Surprisingly, the findings show that those older parents who have a lower level of social support are more likely to be ‘ageing in place together’ than older parents with a higher level

of social support. Overall, the results suggest that on the one hand, older parents may choose ageing in place together with their offspring with ID because they live in owner-occupied housing and are happy with their life and living community. On the other hand, their choice may be due to the lack of social support for moving.

<Please insert Table 4 about here>

Discussion

In general, the older parents in this study were 75+ years old, and had cared for their offspring with ID for almost five decades. Most of them were mothers. This study confirmed what was found in previous Western as well as Taiwanese studies that have compared young and older parents (Aldwin *et al.* 1996; Hayden and Heller 1997; Chou *et al.* 2009): that this generation and group of older parents, even those living in rural areas, have been doing caregiving work for a very long time. Consistent with previous studies conducted for older family caregivers (Chou *et al.* 2011), these older parents generally had low levels of social support, health, family income, and education and only a very small proportion of them used social services.

Among these older parents, over 60 per cent did not want to move but wanted to age in place together with their ageing offspring with ID, regardless of whether the household had two parents (60.7%) or one parent present (62.3%). Echoing previous Western and Taiwanese studies (Carroll and Qualls 2014; Chen and Chang 2004; Litwak and Longino 1987), these parents are not only similar to the majority of older people who do not have children with ID and do not want to move, but after several years, they have adjusted to their situation, including taking care of their offspring with ID regardless of their sociodemographic context (Chou *et al.* 2011).

Compared with parents who had other options, older parents who would choose not to move but instead age in place with their ageing offspring with ID were more likely to have

lower education, live in a rural area, own their house/flat and have a higher level of life satisfaction and satisfaction with the living community (as shown in Table 2). This is consistent with a previous qualitative study (Chou, Lee and Wang 2018) that found that parents living in their own house had rarely thought about moving and appreciated the environment where they lived (e.g. good air quality in a rural area) and had grown accustomed to the neighborhood that they had known for years.

Concerning the housing pathways framework (Clapham 2002, 2010), based on the regression analyses in this study, we found that the domains of personal control (family owned the house/flat), self-identity (satisfied with the community) and self-esteem (life satisfaction) were positively significantly related to 'ageing in place together'; in contrast, social support was negatively related. The demographic and socioeconomic factors included in the domain of inequality were not related to the choice of whether the older parents planned to age in place with their ageing offspring with ID. These findings imply that the hypothesis of this study was only partly supported.

These results are inconsistent with those of other studies that focused on older people who do not have offspring with ID and whose housing pathways are strongly related to care needs and service use (Bradley 2011; Faulkner 2007). This study found that older parents' age, gender, education, living geography, family income, care needs of children with ID (e.g. level of disability) and personal health, namely, all factors of the 'inequality' domain, were not determining factors in the parents' decision regarding ageing in place together with their offspring with ID.

Previous Taiwanese studies (Chou *et al.* 2009; Chou *et al.* 2011) have suggested that families that have a higher level of education and income are more likely to also have a higher level of formal and informal social support. Under the current familistic and market-oriented care policy regime in Taiwan, only older parents who have a higher level of social

support and income would be likely to be able to afford a nursing home of good quality. In terms of social support, it can also be said that parents choose ageing in place together with their disabled children because they lack the support and resources to move. Additionally, this group of parents who have a lower level of individual capital (e.g. education and family income), mostly mothers, are more likely than other parents to follow traditional values, which stipulate that caring for family is a responsibility (Chou, Lee and Wang 2018).

Moving to a nursing home still carries a stigma in Taiwanese society. If parents move to a nursing home, they often feel that they have been abandoned by their children (Chen 2011; Wu and Chen 2014); parents also feel guilty if their children with ID move to an institution (Chou, Lee and Wang 2018). In addition, the family is responsible to pay the cost of residential care services; in particular, moving to a better quality care home costs more (Yang 2005). Hiring a live-in migrant care worker is a better economic choice for some families (Chou, Kröger and Pu 2015); the findings of this study indicated that 11 per cent of the participants hired a live-in migrant care worker.

In conclusion, the findings suggest that older parents choose ageing in place with their ageing offspring with ID because the family owns their house/flat (having 'personal control') and because they like the community ('positive self - identity') and are happy with their current life ('self-esteem'); however, these parents have a low level of social support for moving.

Some limitations of this study should be noted. First, even though all of the parents who were cohabiting with their ageing offspring with ID were invited to participate from two local authorities, representing urban and rural areas in Taiwan, the population from only these two areas of Taiwan was included, so one needs to be cautious when making generalizations. Second, the number of parents who were investigated was rather small due to the small overall target group population. Therefore, there might not have been sufficient power to

detect certain effects, for example, correlations between the explanatory variables and ageing in place together with ageing offspring with ID. Third, this study was cross-sectional and is unable to reveal cause-and-effect relationships; therefore, the results cannot show the direction of the association between the explanatory variables and the dependent variable. A longitudinal study is desirable in the future. Last, the definitions of the four domains of housing pathways in this study could be discussed in future studies, in particular by studies conducted in other countries with different cultural contexts.

Despite the above limitations, the findings of this study contribute to knowledge related to moving or ageing in place among the group of older people who cohabit with their ageing offspring with ID. Furthermore, these findings extend beyond the housing pathways approach, which focuses on individual older persons' decision making about moving or ageing in place and suggest that older parents cohabiting with their ageing offspring with ID should be viewed as a whole in terms of both policies and research on ageing. Consequently, LTC policy should pay special attention to those older two-generation families that cannot afford formal care or the cost of a migrant care worker and who are now ageing in place together. For these families, ageing in place may not be the best choice but rather the only available choice.

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Author contribution

Y-CC designed the study, collected and analyzed the data and wrote the paper; TK assisted in designing the study, discussing, writing and revising the paper.

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Conflict of Interest

The authors declare no conflicts of interest.

Ethical standards

Ethical approval for the study was obtained from the Research Ethics Board at National Yang-Ming University (IRB: YM103016F).

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