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Care and support for care givers In Indonesia *

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Introduction.

This paper is a case study of voluntary care givers providing Home Care for frail, lonely, bedridden and poor older persons in Tegal Alur, a very poor sub-district of West Jakarta.

The Home Care program developed as a community volunteer-based pilot project Home Care model adapted to the social, cultural and socio-economic situation in Indonesia.

The Home Care program by volunteers is a reach out program for family care givers to avoid care giver burn-out as well as support family care givers in caring for their loved ones.

The goal of the Home Care program is to develop a community-based and community-run model of home care services for vulnerable older persons in Indonesia, and to promote the inclusion of home care services in government policy on ageing.

With other words, community based Home Care is one of many ways to care and support family care givers.

Demographic Aging trends in Indonesia

Indonesia is an Archipelago consisting of more than 17.000 islands, a very complex and diversified developing country in terms of geography, ethnic, social and cultural conditions

The Indonesian population is the fourth largest in the world, with a population of 220 million in 2005.

Java represents 7% of the territory of Indonesia but 2/3 of the total population.

Following reform and decentralization, there are now 33 provinces

Five (5) provinces (West Sumatera, Central Java, East Java, Yogyakarta and Bali) have an aged population structure (>7%), of which Yogyakarta has the highest proportion of older population (13.6 %). (BPS 2005)

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For the past three decades, Indonesia has made significant progress in the economic and human development. This resulted in better health conditions for Indonesians and longer life expectancy. The country's life expectancy has increased dramatically, from 45 in 1970 to 69, 2 in 2005 (BPS 2006).

Indonesia has also successfully implemented the family planning program. In the early 1950s, the average Indonesian family consisted of six children and their parents, in the 1990s it consisted of approximately 2.5 children and their parents (UN, 1999).

At the same time that the birth rate declined, the number of older population has increased at a rapid rate. It is estimated that by the year 2020, aging population in Indonesia will reach 11.34% of total population.

As a consequence of demographic transition during recent decades, the Indonesian population is experiencing the impact of this swift demographic change. The steady increase of older age groups, both in absolute numbers and in relation to the working-age group, have a direct bearing on relationship within families, equity across generations, and the family solidarity that is the foundation of the society.

The ability of families to care for their older members is under threat as a result of rural-urban migration and or economic and internal family pressures. Although families remain the primary care givers of the vast majority of older persons, the number of older persons at higher risk of dependency and disability are increasing at the same time as the ability of families to provide care is decreasing.

With an increasing older age structure, Indonesia's biggest challenge lies in providing support to these older persons, especially the needy. The economic crisis in the 90's and the recent National Disasters most seriously threatens the livelihood of vulnerable groups, to which many of the older persons belong.

On the other hand, it is also common practice in rural areas that the elderly are given the responsibility of caring for the grandchildren or of taking care of and supervising the household. These tasks, keeps them occupied and provide them with a sense of usefulness which in turn result in feeling of happiness and zest of life.

If the family is no longer in the position to provide support to the aged as traditionally expected, and the government is not yet in a position to ensure comprehensive care for those in need, the best hope for support seems to be the community. Community

involvement in handling the social and economic problems of its members has strong cultural roots in Indonesia, especially in relation to the elderly.

Recognizing its limitation and acknowledging the important role of the community in social development, the Government encouraged the involvement of civil society through NGOs and social organization in providing support for older persons, community-based support was also seen as a component of good governance in terms of popular participation in social development and self-reliance.

The reform era and democratization also saw a paradigm shift in development programs for the older persons, toward increase community and civil society participation in governance in which the government would act as a facilitator while implementation will be done by the community and civil society.

There is a growing sense in civil society to support the elderly, as reflected in active participation of the community in programs for the elderly during the economic crisis, during emergencies and during national disasters. The role and contribution of community-based care to support the elderly has been recognized and appreciated by the Government. Indeed, traditional forms of assistance provided support to the frail and poor elderly even before government programs were initiated.

More than 400 social organizations dealing with the elderly have been registered in Indonesia. Most are run by Non-Government Organizations (NGOs) or social organizations. Their missions are varied; some target the better-off elderly, others are professional organizations, some cover the disadvantaged elderly, some are associations of retired public servants, army retirees etc.

Although the role of community based care has been recognized by the Government, there is no policy or legislation yet to render direct care and support to care givers. It is noted that in the Region there is a policy vacuum on care and support for the care givers.

Where policy for support for care givers exist, the active implementation, supported by appropriate budgetary allocations will require political will, strong commitment in the bureaucracy and powerful local support in the community.

Care givers in Indonesia.

Care givers are people who provide informal care to others in need of assistance due to disability, chronic illness or old age. Most carers are family members, friends or neighbors of the person receiving care. There is no data available, to examine the amount of informal care being provided in Indonesia. Placing a monetary value on the work of informal carers is the first step in evaluating whether the current usage of informal care and formal care models is socially optimal, in terms of both efficiency and equity.

The demand and supply of informal care will increase in the future, most notably, and in accordance with the Aging Population projections:

- Many chronic and disabling conditions are highly age-related
- There will be a smaller number of younger people
- Changing work and family conditions, which reduces the ability of family members to provide care

Most family care givers struggle to balance care for an aging parent or relative with other major responsibilities, including jobs and caring for children. In most cases, the family care giver is a spouse, the eldest daughter or other family member needing care.

While family care giving is often very rewarding, it can also be stressful and causes tension within families, especially when the care recipient requires around the clock assistance.

Community involvement in handling the social and economic problems of its members has strong cultural roots in Indonesia, especially in relation to the elderly. Volunteering has always been an integral part of every aspect of Indonesian life. Indonesia's tradition of voluntary action can be credited to religious and spiritual values, but is it also a matter of mutual dependence and mutual assistance (gotong-royong).

With the high number of disadvantaged older persons, living alone, frail or neglected, in 2003 a community volunteer based home care pilot project was implemented in Tegal Alur, a poor sub-district of West Jakarta. This program serves frail disadvantaged older persons living in a low-income community.

Volunteers / care givers were recruited from the community and trained in basic care-giving skills. Direct beneficiaries of this program are the elderly who are in need of care. Indirect beneficiaries are family members, community in promoting volunteerism and the Government (cost effective care).

In general care givers:

- Are mostly women (grandmothers, mothers or daughters)
- work on a voluntary basis
- their caring expertise is not easily replicated in substitute care arrangements
- in general, self-reliant
- provide respite care
- potentially struggling with their own health issues and frailty
- Limit their services to a day activity (they do not take over the role of family members).

CARE AND SUPPORT FOR CARE GIVERS.

An evaluation of the impact of providing voluntary home care services to the disadvantaged older persons has been conducted in 2006 (3 years after the program

started), whether it met a need in the community including the need of care givers, and to use data to make changes in the program.

The study assessed impact in five specific areas:

1. Community familiarity of the program
2. Acceptability of the services from a cultural point of view
3. Favorability of the services
4. Importance attached to meeting the needs in a low-income community
5. Influence the program had on promoting community involvement in the caring efforts

This study employed a qualitative approach, and the data was collected through interviews, observation and documentation.

1. Sources of data consisted of:
 - a) Primary data, collected from interviews with older people, family care givers, volunteers, community and related government officials.
 - b) Secondary data, gathered through available documents
2. Sources of information were
 - a) older people
 - b) family care givers
 - c) volunteers
 - d) community
 - e) related government officials
 - f) field coordinator
3. Sampling techniques employed in this study were purposive sampling and in each category the sample was randomly selected as follows:
 - a). Older people, 30 persons
 - b) Family care givers, 30 persons
 - c) Volunteers, 10 persons
 - d) Community (including informal leaders) 10 persons
 - e) Related government officials 10 persons.
4. Data collection:
 - a) Interviews using a set of questionnaires with close ended questions, and discussions with the interviewers to review the information.
 - b) Observation to complement data collected and observe the conditions of

older people's living conditions, volunteer's interaction with the older persons, family care givers and community as well as interaction among volunteers.

- c) Documentation, study relevant documentation such as TOR of the project, magazines produced by YEL, articles, government policies on ageing.

6. Data analysis.

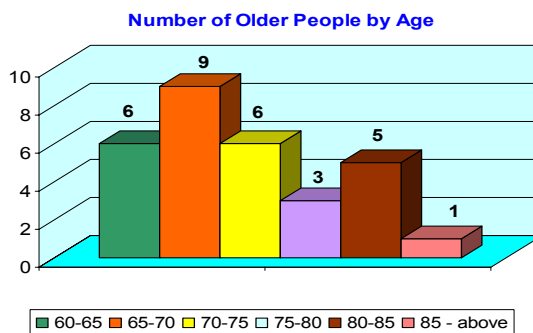
Data collected was analyzed qualitatively complemented by quantitative data to ensure accuracy. The presentation and analysis of data focused on five main areas: (1) familiarity measures how much each cohort knows about the program; (2) acceptability measures whether a home care program for older people is a service that is consistent with Indonesian values; (3) favorability measures the degree of satisfaction with volunteerism and the service; (4) importance measures the degree to which home care program is needed for the poor and frail elderly to remain independent in the community; and (5) influence measures the impact of the home care program on each group.

Results

Respondents were randomly selected and consisted of 30 older people and 30 family caregivers from all resident units, 10 volunteers, 10 community people and 10 government officials from municipality office, sub-district, community health centre, chief of resident and neighborhood units.

Characteristic of Older People

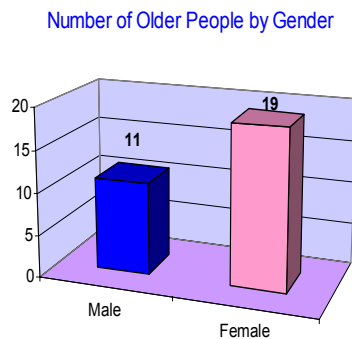
1. Older People by Age



The age of respondents ranges from 60 to above 85 years, the majority of which are in the 65-70 age group.

2. Older People by Gender

The graph below shows the number of Older People by Gender:

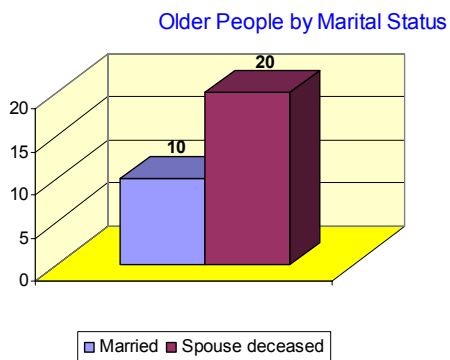


By gender, the numbers of female are more than male older people.

In the community in general there are more female than male elderly. In Tegal Alur sub-district, the majority of disadvantaged older persons are women.

3. Older People by Marital Status

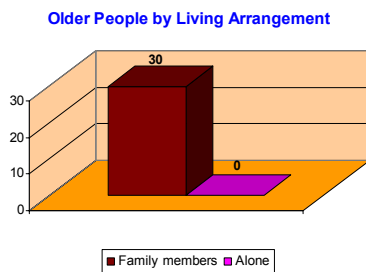
The number of older people by marital status is shown below:



In terms of marital status of the older people respondents, the highest percentage are those whose spouses are deceased (66.7 percent) while only 33.3 percent are still married. More older people served by the Home Care Program are those whose spouses are deceased and in need of care including companionship.

4. Older People by Living Arrangement

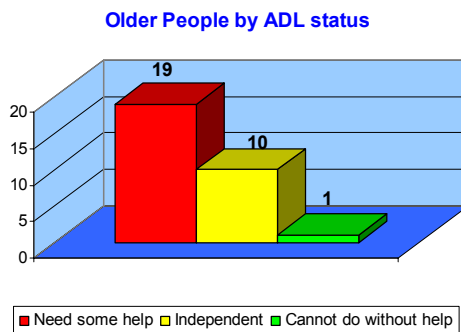
The number of Older People by Living Arrangement is shown in the graph below:



By living arrangement, all older people respondents are living with family members consisting mostly of children and grandchildren. This shows that there is a genuine concern to care for the elderly even among poor families.

5. Older People by Activities in Daily Living Status

The number of Older People by Living Arrangement is shown in the graph below:



The majority of older people in this study needed some help from others in their activities in daily living and interestingly enough only one respondent was totally dependent on home care.

Data Analysis

Analysis of data was focused on the impact of five areas, i.e. familiarity, acceptability, favorability, importance and influence on each category of respondents and the overall impact of Home Care Project. The ranking of score ranges from 1 to 4 (very much disagree to very much agree).

1. Impact of Home Care Services

The average mean score of the Home Care Project in all categories of respondents and areas of evaluation, 3.85, indicates that the services provided were perceived as very satisfactory. (Table 1). With a rating from 1 to 4, the general score is above average

The average mean score for all areas of this evaluation in the category of volunteers is 4, and indicates bias that could not be prevented due to the fact that they administered the questionnaire and also were the service providers.

Table 1: Impact of Home Care Project

Target group Areas Of Evaluation	Older People	Volunteer	Family caregiver	Community People	Government officials	Average of Total score
Familiarity	3.71	4	3.78	3.67	3.97	3.82
Acceptability	3.81	4	3.82	3.77	3.93	3.87
Favorability	3.89	4	3.89	3.8	4	3.92
Importance	3.64	4	3.71	3.67	3.93	3.79
Influence	3.72	4	3.8	3.73	3.93	3.84
Average of total score	3.76	4	3.8	3.73	4	3.85

The impact of this volunteer-based Home Care Project on Government Officials in all areas of evaluation shown in Table 1 is way above average. This could indicate that government officials are in support of and satisfied with the services provided by community volunteers to older people.

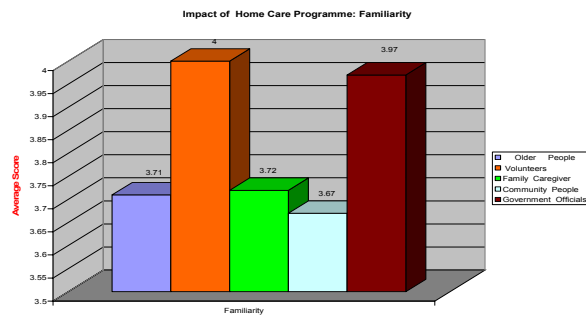
2. *Acceptability.* The data shows that the government officials are in favor of home care services provided by the volunteers as this is appropriate in their tradition and culture which highly values and respects older members of the community. Since this program filled a need that was unmet prior to its inception, officials appear to be in full agreement about community participation in taking care of those elderly people who are in need. .

3. *Favorability.* The area of favorability shows the highest score. This is an indication of a positive attitude toward home care services in meeting the older people’s needs and also shows efforts to promote more attention to older people’s issues in the community. It is interesting to note however, community people responded with more ambivalence concerning the general need for home care for older people who required help. Although the sample is very small and the degree of variation on the scale is very slight, 40 percent

of community rated ‘agree’, 60 percent ‘very much agree’ to the question concerning perception of need. The older people and family caregivers cohorts rated 16.7 percent ‘agree’, 83.3 percent ‘very much agree’ and Government officials 100 percent at the highest rating.

4. *Familiarity.* Familiarity among the government officials scores the highest, which could indicate that they are very much aware of the program a volunteer-based service in the community to take care of the older people who need care at home. This home care program evidently effectively disseminated program information to those who impact on policy for the elderly. Other cohorts also responded positively about their knowledge of the program.

Although there was some degree of variation among the different cohorts, it seems it is due to the ambiguity of the question.



5. *Importance.* All respondents, particularly government officials perceive this service as an important undertaking to assist older people in maintaining independent living for the poor and frail elderly. Again, given limitation of this data, there was, however, a difference in ratings around perceived need for home care. Interestingly enough, only 43 percent of older people very much agreed that there was a need for home care services, compared to 67 percent of the family care givers, 70 percent of community people and 100 percent of the government officials who rated very much agree. This difference suggest that older people may have some feelings about receiving help from outside the family. In addition, the responses of all four cohorts showed consistently more variation about the importance of this project in assisting older people with mental and emotional issues.

Their responses could indicate that in general people perceive home care as meeting the daily living needs of the elderly due to physical deterioration as opposed to mental deterioration.

6. Influence. Data indicate that older people highly appreciated the services delivered in daily activities, particularly in providing friendship, considering that the majority of respondents are living with family members who are caught in their busy daily lives. However, only 57 percent strongly agreed that the program helped them with their daily activities. This could mean that older people need more services than already provided. It certainly brings some emotional comfort to the elderly as well as family care-givers.

From interview with families, they perceived home care service is helpful in reducing their burden as most of them are preoccupied with their own families and work. It also educated them in proper caring for older people.

Home care service motivated the community to help older people, particularly those who are poor. As such services are new, the influence this project potentially has on the government is that they are encouraged to develop welfare policies pertaining to older people in a cost effective manner. In addition this program stands as a good model for providing community based program for vulnerable older people.

Conclusion

Home Care Pilot Project in Tegal Alur Sub-District, West Jakarta is satisfactory for older people and related significant others covering family caregivers, volunteers, community people and government officials. The study clearly demonstrated that all people involved in the services share the same interest in the welfare of older people in the community and are supportive to the activity. It is an organized effort from, by and for the community with an active role of the local government.

Families as primary caregivers are appreciative of the service provided by the volunteers. It also shows that the community sustains family life and is the primary channel for providing care at home for older people. Traditions of mutual help at the community level in Indonesia continue to provide essential social assistance mechanisms for many of the older people of the poorest families.

Government plays a significant role in advocating a shared responsibility for providing services to the frail and vulnerable older people at home. As revealed by the study, they are in support of such services provided by the community and recognized the need to address older people issues particularly among the poor families.

Recommendations

1. The study suggested that the home care pilot project in Tegal Alur Sub-District for frail and poor older people with active participation of volunteers and other service providers in the community was a success and met a defined need. Because of the evident positive perception of all cohorts, this community-based service should be offered to more older people in the community as well as be replicated to other regions in Indonesia.
2. The government at local and regional levels should coordinate and make use of existing networks to ensure sustainability of the service. This support includes advocating for the needs of the older people in policy and in mobilization of resources.
3. The data on favorability, importance and influence shows there may be a need for continuing to educate the community on older people issues. This effort could strengthen the community's perception of the service as consistent with the Indonesian values. It could also facilitate the elderly's acceptance of help from outsiders.
4. Volunteers need more training in psychosocial issues so that they could be more helpful to the elderly in accepting and dealing with the process of ageing.
5. Instruments for data collection in future studies should limit the use of abstract questions in questionnaires to ensure better insights and measurements.
6. In order to further use volunteers for providing services, a more objective in-depth study of the volunteers' experience need to be conducted. This knowledge will help in designing training volunteers, providing support to volunteers and motivating community to volunteer in caring for the elderly.

7. Raising awareness of care givers in the general community programs.

Outreach to Home Care, community based care and Community health centers will assist care givers to access support and assistance they require.

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Raising awareness of care givers in the general community programs.

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