

## **Introduction:**

In poor settings characterized by norms prescribing family care of older adults and underdeveloped public systems of geriatric care, policy makers often believe that younger generations will continue to provide care for frail older family members. In this paper, we compare data from caregivers of institutionalized older adults with that from caregivers of older adults who remained at home to explore the process that leads family caretakers in Cairo, Egypt to place frail older relatives into formal long-term care. Several factors influenced this process: older adult's health status, availability of kin, filial obligation and ideals of reciprocity, characteristics of family caregivers and the quality of caregiver-older relative relationships, religious conviction, and a desire to do what is "best" for the older relative. The knowledge produced in this paper is an important first step to provide adequate services to Egypt's growing older population.

## **Background:**

Declines in fertility and increases in longevity in Egypt have led to increases in the proportion of Egyptians that are old and frail. The development of services to provide care for these older adults has lagged behind demographic change, and as a result, the family continues to be the major source of support for growing numbers of frail older adults. My own observations in Cairo support the idea that noninstitutionalized older adults who required extra care live with relatives, generally their offspring.

However, traditional family structures in Egypt are changing due to dramatic social and economic changes at the community and societal levels.<sup>1</sup> Although these changes do not assume dissolution of kinship ties, they reflect new, competing demands on the time of adult caregivers and the types of care that frail older adults require.<sup>2</sup> A study on intergenerational living arrangements in Turkey found that urbanization and economic development on the aggregate level, and modernity and secularism at the individual level resulted in a decline in co-residing and living in close proximity to older family members.<sup>3</sup> A study in Egypt investigated growth in the populations in homes for the aged. While the study concluded that the growth did not indicate widespread rejection of family responsibilities, in some cases it did reflect changing conditions and attitudes toward family life.<sup>4</sup>

As populations age, the need for formal and informal support structures increase as older people tend to no longer be economically active. Adult family members often face being responsible for their aging relative while also providing for their children leaving adult families with the economic burden of two generations of dependents.<sup>5</sup> In addition to financial issues, adult family members must deal with the health concerns of their older relative. The risks for both chronic disease and disability are strongly related to age, so as the population continues to age, there will

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<sup>1</sup> Nawar et al. "Autonomy and Gender in Egyptian Families." 1994. *Middle East Report* 0(190): 18.

<sup>2</sup> Nassehi-Behnam. 1995. "Change in the Iranian Family," *Current Anthropology* 26(5): 571-574.

<sup>3</sup> Aytac, Isik A. 1998. "Intergenerational Living Arrangements in Turkey," *Journal of Cross-Cultural Gerontology* 13(3): 241-264.

<sup>4</sup> Rugh, Andrea B. 1981. "Orphanages and Homes for the Aged in Egypt: Contradiction or Affirmation in a Family Oriented Society," *International Journal of Sociology of the Family* 11(2): 203-233.

<sup>5</sup> Uhlenberg, Peter. 1992. "Population Aging and Social Policy," *Annual Review of Sociology* 18: 449-474.

be an associated increase in the demand for all types of health care.<sup>6</sup> In the United States, there has been an increase in the placement of frail older adults in abundantly available long-term care facilities.<sup>7</sup> Although such facilities are less readily available in the Middle East, the rate of institutionalization is difficult to determine.<sup>8</sup>

### **Setting:**

The setting for this research – urban Cairo – is one in which economic and social changes have created dramatic changes in the daily circumstances of Egyptian families. Although this study was qualitative and based on interviews with a relatively small sample, the stories of informants to some extent reflect the societal changes and their impact on decision-making processes that have been observed in representative sample-surveys conducted in other settings.

### **Data and Methods:**

The study method consisted of open-ended, semi-structured interviews with “cases” and “matched controls.” The case group consisted of a sample of the adult caretakers who placed their older relatives into the long-term care center at Palestine Hospital in Cairo, Egypt since its establishment in 1994. The control group consisted of family caretakers who provided for their older relatives in their homes in Cairo. For cases and controls, we sought to interview both the older adult’s primary caretaker and financial provider, however in almost every case, the older person was his or her own financial provider or the family caretaker also acted as the financial provider. In situations where caretaking duties were shared between family members, we tried to interview the primary caretaker if he or she was available. In two instances we were able to interview more than one caretaker of an older person and in two instances we interviewed secondary caretakers.

The 17 cases were found through admission records at the long-term care center in Palestine Hospital. Because of the imperfect availability of telephones and the high costs of other randomized methods of identifying controls, we sought to identify the control group through the cases. In the end, only one of the 14 controls was found through a case. Seven controls were known to Dr. Nadia El-Afifi, the center director, three were found through other controls, and two were identified through the Egyptian Alzheimer Society.

We attempted to match the cases and controls on four points 1) age of the caretaker plus or minus ten years, 2) health status of the older relative, 3) relations status of the caretaker to the older relative, and 4) sex of the older relative. We were able to create six pairs that matched on all four points, seven pairs that matched on three of the four, one pair that matched on two of the four, and two cases remained unmatched as cases outnumbered controls.

Between June and August of 2003, 17 case caretakers, 14 control caretakers, and one control-financial provider were interviewed. A total of 32 interviews were conducted. Nineteen of the interviews were conducted in English and 13 were conducted in Egyptian Colloquial Arabic. All

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<sup>6</sup> Soldo, Beth J. and Vicki A. Freedman. 1994. “Care of the Elderly: Division of Labor Among the Family, Market, and State,” in L. Martin and S. Preston (eds) *Demography of Aging*. Washington DC: National Academy Press.

<sup>7</sup> Nazarchuk, Sharon Agnes. 2001. “The Care and Cost of Elderly in Long-Term Care Facilities in the United States,” *Dissertation Abstracts International* 62(3): 1217-A.

<sup>8</sup> Margolis, S.A., Reed, R.L. 2001. “Institutionalized older adults in a health district in the United Arab Emirates: health status and utilization rate” *Gerontology* 47(3):161-167, 2001.

of the case interviews were conducted in Palestine Hospital and six of the 15 control interviews (including the financial provider) were conducted in the informant's homes.

Study participants completed a short sociodemographic questionnaire and open-ended, semi-structured interviews that covered topics related to family dynamics, decision processes, expectations, and perceptions. The qualitative format of the interviews allowed the informants to share their personal stories about how and why they made certain caretaking decisions for their older relatives. All interviews were transcribed and entered into NUDIST Vivo and were analyzed for decision triggers.

### **Results:**

Most decisions to place or not place older relatives into long-term care were not hinged on single events, but rather were processes related to six major themes that emerged from the data. These themes were: older adult's health status, availability of kin, filial obligation and ideals of reciprocity, characteristics of family caregivers and the quality of caregiver-older relative relationships, religious conviction, and a desire to do what is "best" for the older relative.

*Older adult's health status:* Issues surrounding health comprised the only true decision events. Five of the 17 cases were admitted to the long-term care center after having an acute illness and then remained at the center for treatment and care. An additional case was admitted after an acute incident that involved problems with his dementia. Another case was admitted after the caretaker wife suffered an acute illness brought on from the stress of caretaking. Ten of the 17 cases (58.8%) listed their older relative's physical health as "poor" or "very poor" compared to six of 14 (42.9%) of controls. Eleven of the 17 cases (64.7%) reported that their older relative suffers from dementia compared to eight of the 14 (57.1%) controls.

*Availability of kin:* For both cases and controls the majority of the family caretakers were the older person's son or daughter. Often, the adult children would share caretaking responsibilities for their parents with their siblings. While cases and controls had roughly the same number of living siblings, controls had significantly more siblings living in their neighborhood (26) as compared to cases (7). These available kin perhaps led them to be more flexible in traditional informal care structures. For the cases, the eight non-child caretakers consisted of four brothers, three wives, and one daughter-in-law. For the controls, the two non-child caretakers were one wife and one daughter-in-law.

*Filial obligation and ideals of reciprocity:* The sense of duty to care for older relatives, especially parents, remains strong among cases and controls sampled in Cairo. Controls viewed the decision to put parents into long-term care as "shameful," and cases tended to feel guilty about their decision. However, both cases and controls considered long-term care to be a good option for an older person with no spouse or children living nearby. Both cases and controls generally felt it was the duty of children to care for their older parents – though they did not all agree on what "caring" entails. Many mentioned that they feel adult children must provide daily care for their parents to reciprocate for the care that parents provided them in their childhood.

*Characteristics of family caregivers and the quality of caregiver-older relative relationships:* Many informants discussed how personal circumstances affect the ability of a person to care for an older relative. One repeated example was if the daughter's husband will not allow her to

spend time away from her household duties or bring her parent into his home, she cannot care for her parents. However, there was often a disconnect between expressed cultural ideals and behavioral practices. Time constraints of work in general and women's work in particular and the ability to care for parents at home were often discussed. Another issue of circumstance was the sex of the caretaker and the sex of the older relative. It was frequently mentioned that certain duties (like showering the older person) were inappropriate for a person of the opposite sex, even if the person was their offspring. Many cases and controls had initially tried or were currently using hired caretakers to tend to their older relative's needs. Hired caretakers were often uneducated youths from the country. Almost all of the informants complained that these caretakers were dishonest, unsympathetic, or provided inadequate care. When informants were asked, in general who *should* be responsible for taking care of older adults, most answered that it should be the older person's children. Norms dictate that sons should be the financial providers of their parents while daughters more often are responsible for daily hands-on care. However, when probed further many believed that "personality" superceded the sex of the child. Regardless of sex, those who were more disposed to care for the parents should be the primary caretaker.

*Religious conviction:* Almost every case and control discussed the influence of religious ideology in decisions to care for their older relatives. All but two of the informants were Sunni Muslim. The non-Muslims were a Christian case and a Christian control. The Muslim informants described how the Qur'an tells them they must care for their aged parents on earth to earn a reward in paradise.

*Desire to do what is "best" for their relative:* The controls felt that placing their relative into a long-term care facility to be cared for by strangers was a dereliction of duty. Several cases said that though they knew their older relative would not want to be in a long-term care center, their health and safety required it. The caretakers of older adults suffering from severe dementia were especially concerned about their relatives hurting themselves. These older adults required constant supervision so the caretakers believed long-term care placement was the best way to keep their relatives safe.

### **Conclusion:**

To the extent that the Egyptian population continues to experience further declines in fertility and increases in longevity, emerging challenges regarding the care of older adults will become more pronounced. Thus far the government has relied on the expectation that children and families should care for the financial and physical needs of their older relatives. The few care facilities for frail older adults are housed in private institutions, private hospitals, or are run by religious organizations. Assisted living facilities require residents to be ambulatory. Limited facilities, decreased familial ability to care for adults at home, and increased longevity (adding years associated with chronic disease) all add to an increasing demand for long-term care centers despite the lingering negative attitudes towards such facilities. The decision process of the family caretakers hinged on six major themes: older adult's health status, availability of kin, filial obligation and ideals of reciprocity, characteristics of family caregivers and the quality of caregiver-older relative relationships, religious conviction, and a desire to do what is "best" for the older relative. Understanding how these themes affect the individual decision of family caretakers is vital to meeting the needs of both the older adults and those who care for them.