

# Psychological Health of the Primary Caregivers of home-based adults with dementia: India and Taiwan

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## ABSTRACT

**Objective:** Currently 30 million people are affected by dementia in the world, and the majority of them are cared for by their families. Caregiving is a challenging task; the impacts of caregiving have been identified as financial, physical, and psychological stress. The purpose of the study was to identify psychological health of caregivers of home-based adults with dementia in India and Taiwan. They are Asian countries with similar laws but are in different economic development stages.

**Data:** Fifty Indian and 67 Taiwanese primary caregivers were interviewed by a native occupational therapist. Data are quantitative and qualitative.

**Methods:** Psychological health was assessed using culturally validated instruments: the Zarit Burden Interview, the Center for Epidemiological Studies-Depression, and the University of California Los Angeles Loneliness scale. Reward for caregiving was also assessed. ANCOVA and correlation were used for the analyses.

**Results:** Although caregivers in India and Taiwan provided similar amount of care giving tasks, Indian caregivers exhibited significantly better psychological health than Taiwanese caregivers. Indian caregivers expressed strong needs for raising awareness of the illness and more day care centers. Taiwanese caregivers expressed needs for improved services for caregivers from the government. Both countries' caregivers also expressed needs for increased numbers of trained formal caregivers. While families and friends were perceived as the most helpful, they were reported as the most unhelpful support.

**Recommendations:** In general, raising awareness of the disease among public is needed. More support from governments are necessary in order to help caregivers continue providing in-home care. Specific needs should be addressed in each country.

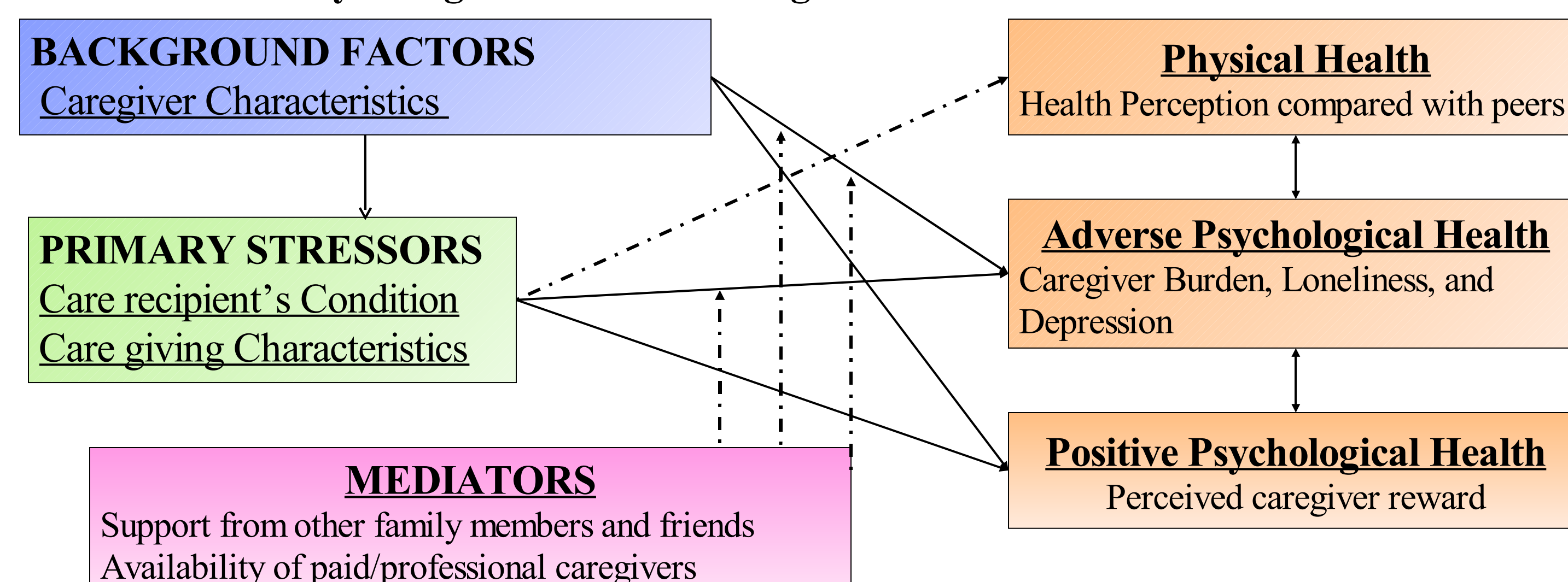
## BACKGROUND

### Social differences related to caregiving

	India	Taiwan
Economic Development	Developing country	Developed country
Proportion of older adults in the total population	5.2%	10.5%
Number of people with dementia	1.5 million or 1-3% of older adults (underestimated)	146,000 or 6% of older adults
Healthcare system	Private health insurance	Universal Health Care
Laws to protect older adults	Mandates family members' care for older parents	Mandates care for older parents
Type of support for caregivers	paid "housekeeper"	paid aide Day care center
Tradition	Familism, Hindu philosophy	Familism, Confucian influence
Responsible person for the care recipient based on tradition	Son	Eldest son
Actual caregiver	Daughter-in-law	Daughter or Daughter-in-law
Residency	Extended family	Nuclear family with other family members living nearby

### Conceptual Model:

#### Framework for Psychological Health of Caregivers of Adults with dementia



## Research Questions

1. What are differences in the psychological health of Taiwanese and Indian primary caregivers of home-based adults with dementia in terms of rewards, burden, loneliness, and depression?
2. What are differences and similarities in caregivers' perceptions about social support between Taiwan and India?

## METHOD

### Study Design

Cross-sectional design.

India: person-to-person interviews

Taiwan: Person-to-person, phone interviews, and mail survey

### Participants

Inclusions criteria: (1) age 18 years or over, (2) being a self-elected primary caregiver of a person who is diagnosed with dementia, (3) providing care for at least three months, (4) the care recipient living at home .

Indian participants (n=50) were recruited from a mental hospital, a day care center, and private psychiatric clinics in Mumbai, the largest city in India (population of 11.9 million), Taiwanese participants (n=67) were recruited among people who responded to the notification of this study through the Taiwan Alzheimer's Disease Association's website and lived in Taipei city and surrounding counties. (population of 6.4 million)

### Instruments

Survey for caregivers of persons with Alzheimer's disease and other dementias includes demographic information, Zarit Burden Interview, the Center for Epidemiological Studies-Depression (CES-D), the University of California Los Angeles Loneliness scale and the Picot's Role Reward Scale.

## RESULTS

### Demographic and Care giving Characteristics of Primary Caregivers and Care Recipients

Variables	India (n=50)	Taiwan (n=67)	Differences
<b>CG Age</b>	49.4 (13.0)	54.5 (10.6)	$t = -2.327$ (.022)
<b>CG Education</b>			
<12 years	16 (32.0%)	8 (11.9%)	$\chi^2 = 27.088$ (<.001)
High School	5 (10.0%)	14 (20.9%)	
Some college, BS/BA	19 (38.0%)	42 (62.7%)	
> MA/MS	10 (20.0%)	3 (4.5%)	
<b>CG Housing Status</b>			
Own	11 (22.0%)	60 (89.6%)	$\chi^2 = 64.960$ (<.001)
Does not own	39 (78.0%)	7 (10.4%)	
<b>Paid/professional aide</b>			
Hours/week	26.5 (45.6)	56.4 (76.5)	$t = -2.454$ (.016)
<b>CG Health care coverage</b>			
Very sufficient to Sufficient	23 (46.0%)	50 (74.6%)	$\chi^2 = 36.839$ (<.001)
Not sufficient to Not at all sufficient	5 (10.0%)	17 (25.4%)	
No coverage	22 (44.0%)	0	
<b>CR Age</b>	74.0 (9.6)	82.2 (7.8)	$t = -5.121$ (<.001)
<b>CG Global deterioration scale</b>			
Very mild to mild cognitive decline	8 (16.0%)	0	$\chi^2 = 14.460$ (.013)
Moderate to moderately severe cognitive decline	26 (52.0%)	38 (56.8%)	
Severe to very severe cognitive decline	16 (32.0%)	29 (43.2%)	



India

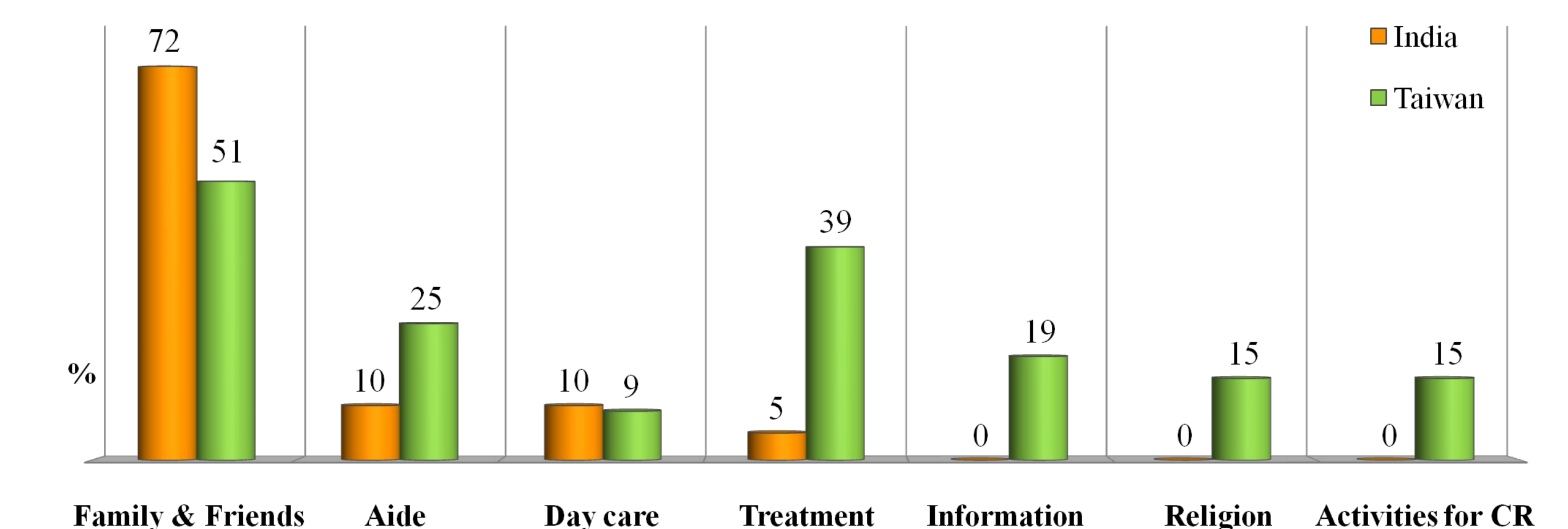


Taiwan

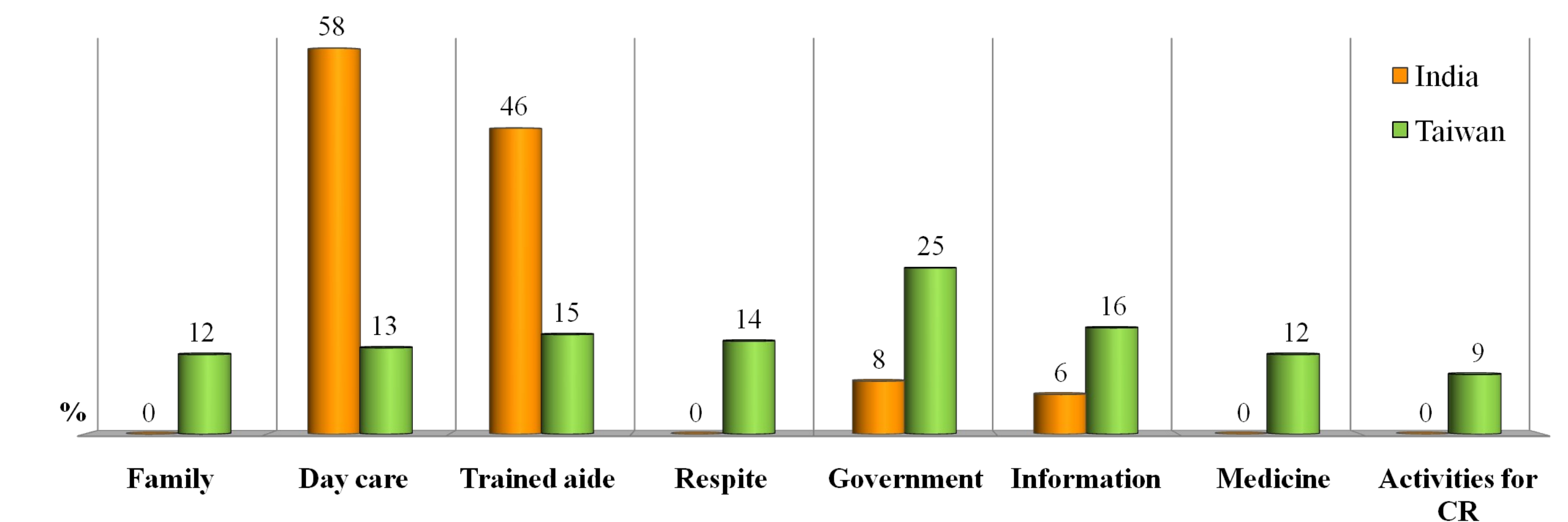
**Research Question 1:** Taiwanese caregivers perceived higher levels of rewards from caregiving experiences but exhibited the worse psychological health than Indian caregivers.

Variables	India (n=50)	Taiwan (n=67)	Differences
Perceived Rewards	28.153 (1.37)	38.721 (1.14)	$F = 28.115$ (<.001)
Caregiver Burden	30.634 (2.10)	40.497 (1.74)	$F = 10.289$ (.002)
Depression	5.607 (.88)	11.517 (.72)	$F = -20.794$ (<.001)
Loneliness	27.265 (1.45)	33.548 (1.20)	$F = 8.805$ (.004)

**Research Question 2-1:** The most helpful support



**Research Question 2-2:** The most wanted support



## CONCLUSION

Indian caregivers have sufficient family support but there is a need to raise awareness of treatment and resources for dementia. Compared with Indian caregivers, Taiwanese caregivers are more aware of the diversity of available support. However, they suffered financially and psychologically to care for their care recipients in a dilemma between new lifestyles and old traditions. Further large-scale cross-national studies are warranted to assess the generalizability of these findings.

In spite of the economic development and more available resources in Taiwan, Taiwanese caregivers experienced more psychological reactions, either rewards or stress, from the caregiving process than Indian caregivers.

Caregivers in both countries emphasized the help received from their family and friends. Caregivers also expressed the importance of raising awareness about dementia and receiving greater governmental support.