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Fewer women receive tertiary care for epilepsy in Kerala State, India

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ABSTRACT – *Purpose.* The stigma attached to epilepsy often restricts early diagnosis and optimal care, particularly among the underprivileged. We aimed to ascertain any gender bias in the utilization of services for epilepsy in a tertiary and community care facility in Kerala State, India. *Methods.* The R. Madhavan Nayar Center for Comprehensive Epilepsy Care (RMNC) is a leading tertiary care facility in South India. The District Mental Health Program (DMHP) is a community-based care facility that provides medical consultation and anti-epileptic drugs (AED) free of charge. We analyzed the sex ratio (SR) – number of women per one thousand men – of all registrations in these centers according to year of registration, age, religion, income, distance from domicile to the center, and religion. *Results.* The SR in the RMNC (1976-2004, n = 12354) was 729. At RMNC, age-specific SR increased up to the 3rd decade (864), and progressively declined beyond 50 years. The SR was lower for those domiciliated at more than 200 km from the center when compared to others. The SR at the DMHP (1999-2004, n = 221) was high (1125). The age-specific SR at DMHP showed two peaks at 21-30 years (1368) and 51-60 years (2333). *Conclusion.* Fewer women with epilepsy (particularly in lower socioeconomic groups) receive tertiary care in this state, in spite of a higher SR in the community (907 for epilepsy and 1058 for all population). The tertiary treatment gap is wider for women over 30 years (particularly over 50 years), when their longer life expectancy is also taken into consideration.

Key words: epilepsy care, gender bias, treatment gap, tertiary care, women, India

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There are about forty million people with epilepsy in the world. The stigma of epilepsy is likely to have greater impact on the social life of women than men, particularly in India and other similar countries. Adverse effects of AEDs may have more impact on women. Women belonging to socially and economically backward sectors and to certain religious groups tend to be more vulnerable with regard to utilization of health care facilities (Fikree and Pasha 2004). There are meager data available on the gender-specific utilization of epilepsy care services in India or other countries. We aimed to ascertain the gender bias in the utilization of epilepsy care at community and tertiary levels in a developing country.

Table 1. General information about Kerala State and Trivandrum District*.

Characteristic	Details
Population	29.1 million
Population density no. of persons/km^2	749
Religion	
– Hindus (%)	57.3
– Muslims (%)	23.3
– Christians (%)	19.3
Population aged 60 years or more (%)	8.8
Children in the age group (0-6) % (Trivandrum District)	11.4
Children in the age group (0-6) % (Kerala State)	11.9
Mean age (yrs) at marriage (females/males)	21.9/27.7
Literacy rate overall/female	89.8/87.9
GNI per capita (PPP) USD for India	2570
Households with electricity, safe drinking water and toilet (%)	9
SR Kerala State	1058
SR (Trivandrum District) *	1060
Average household size (Trivandrum District) *	4.3
Average household size (Kerala State)	4.7
Literacy rate of males/females (%) (Trivandrum) *	92.6/86.1
Literacy rate of males/females (%) (Kerala)	94.2/87.7

* Data pertain to the Trivandrum District in Kerala State where the study was carried out. Trivandrum is the Capital District of Kerala State. GNI = gross national income; PPP = purchasing power parity; SR = females/ 1000 males (2001);USD = US Dollar.

Methods

This study was carried out at the R. Madhavan Nayar Center for Comprehensive Epilepsy Care (RMNC) in Sree Chitra Tirunal Institute for Medical Sciences and Technology in the Trivandrum District of Kerala State. This center has all the advanced facilities for the medical and surgical treatment of epilepsy, and accepts patients on referral by any practitioner of modern medicine, or alternative systems of medicine. It also maintains a registry of epilepsy and pregnancy for the preceding eight years. The District Mental Health Program (DMHP) is a pilot program operating in Trivandrum district, Kerala State for the past five years. A team, under the leadership of a psychiatrist who is trained in the basic aspects of epilepsy care, executes the program. The team visits the community health centers every month according to a schedule, and evaluates patients with mental disorders and epilepsy, upon referral from local practitioners, physicians, and community health workers. They provide medication (phenobarbitone, phenytoin, sodium valproate and carbamazepine) free of charge and also refer selected patients to specialised centers whenever further evaluation is required.

We extracted the demographic data for all patients attending the RMNC for the period 1976-2004 from the computerized medical records of the Institute. The distance from the Institute to respective provincial (district) headquarters for each patient was taken as the distance to the place of domicile. Data from the DMHP were gathered from the registers of that program for the period 2000-2004.

Sex ratio was defined as the number of women per 1000 men attending the service. We also compared the SR for different sub-groups within those attending the tertiary center according to age, domicile, and other socioeconomic factors. Socio-demographic data for Kerala State was gathered from the all-India census (2001) (Registrar General, India 2001) and Sample Registration System (SRS) for the year 2001 (Registrar General, India 2002). The SR for those attending the tertiary care center was compared with the average SR for the state and also with that of the community center. Some of the relevant socioeconomic and demographic characteristics for Kerala State are provided in *table 1*.

Results

There were 12 354 registrations of epilepsy at the RMNC during the period 1976 to 2004 and the SR was 729. The corresponding figures for all registrations under the department of Neurology were 72 012 and 631 respectively. The SR for people with epilepsy attending the RMNC according to the age group, period of enrollment, religion, place of domicile and family income are provided in *table 2*.

Table 2. Sex ratio (women per 1000 men) for persons with epilepsy attending the RMNC.

	Total number	Sex ratio	95% CI	p
All epilepsy	12354	729	703, 756	
Period of registration				< 0.001
1976-79	30	765	342, 1672	
1980-84	119	608	410, 893	
1985-89	297	547	427, 697	
1990-94	1804	700	637, 770	
1995-99	4391	679	639, 722	
2000-04	5711	794	753, 837	
Age group (years)				< 0.001
0-9	2059	727	666, 794	
10-19	3120	791	736, 849	
20-29	3043	865	804, 929	
30-39	1863	594	540, 653	
40-49	1102	650	574, 734	
50-59	638	575	488, 678	
60 and above	529	570	475, 682	
Religion				0.631
Christian	2820	747	693, 806	
Hindu	7772	731	699, 765	
Muslim	1739	689	625, 758	
Others	23	769	302, 1899	
Income (INR)*				<0.001
< 401	1259	635	566, 712	
401-700	2264	665	610, 724	
701-1300	1937	670	611, 734	
1301-2800	824	706	613, 813	
> 2800	6070	800	760, 842	
Domicile				< 0.001
< 60 km	6572	833	793, 875	
60-200 km	2598	646	597, 700	
> 200 km	2264	616	565, 671	
All neurology registrations	72012	631	622, 640	

INR = Indian Rupee (INR 45 = USD 1); RMNC = R. Madhavan Nayar Center for Comprehensive Epilepsy Care; SR = sex ratio.

There were 221 registrations for epilepsy care under the DMHP between 1999 and 2004. The age-specific SR for those attending the DMHP is provided in *table 3*. Other demographic details of those attending the DMHP were not available.

We observed that the SR was low (729) for those registered for epilepsy care in the RMNC when compared to the SR for Kerala State (1058) or the Trivandrum District (1060). At the RMNC, there was wide fluctuation in the SR between 1976 and 2004 (*table 2*). There was a statistically significant (p = 0.001) difference in the SR between different age groups. The SR was low (727) for those under ten years, but gradually increased to a maximum of (865) for the age group 20-29 years, and thereafter steadily declined to (570) for the age group 60 years and above. At the RMNC, the SR was lower for the Muslim community (689) when compared to Christian (747) or Hindu communities (731), but the difference was not statistically significant. The SR was statistically significantly (p = 0.00) lower for those with a lower monthly income (635), when compared to those with a higher income (800) (*table 2*). Distance from the place of domicile to the RMNC was another factor that had a significant correlation with a lower SR (*table 2*).

In contrast, the SR observed at the DMHP was higher (1125) than that observed at the RMNC, Kerala State or Trivandrum District *(table 3)*. Again, in contrast to those attending the DMHP, the SR had two peaks, one corresponding to the age group 20-29 years and a second peak (2333) between 50 and 59 years of age *(figure 1)*.

Table 3. Sex ratio for persons with epilepsy attending community centers under DMHP.

Age group (years)	Total	Sex ratio	95% CI
0-9	12	1000	267, 3742
10-19	70	1188	722, 1964
20-29	45	1368	729, 2615
30-39	52	926	515, 1657
40-49	27	800	342, 1830
50-59	10	2333	533, 13993
60 and above	5	1500	172, 17975
Total	**221**	**1125**	**856, 1480**

Discussion

The SR for utilization of a gender-neutral service is generally considered a sensitive indicator for the gender bias that exists in a community. We have examined the SR in two epilepsy care services (a tertiary care center – RMNC – and a community care center – DMHP). The majority of the patients attending the tertiary care center came from the catchment area of the community care center. These two models are not alternatives in epilepsy care but rather, are complementary to each other. There are differences between the two with regard to the services offered. The pathways to care are very similar, but are not precisely comparable. Hence, the results should be interpreted within these limitations and should not be generalized.

This study has shown that there is a distinct gender-based disparity in the utilization of epilepsy care services in the tertiary and community care centers. Fewer women were attending the tertiary care center, while the reverse was true for the community center. The SR for Kerala state is one of the highest in India (1058). The SR for epilepsy in Kerala State is 907 (Radhakrishnan *et al.* 2000). Nevertheless, there were only 729 women for every 1000 men with epilepsy attending the tertiary referral center. There are few data to indicate that men have more severe epilepsy necessitating attendance at tertiary centers. Assuming the absence of such gender bias, it appears that women with epilepsy experience a treatment gap with regard to tertiary care. At the tertiary care center the SR was low at extremes of age and was highest in the reproductively active age

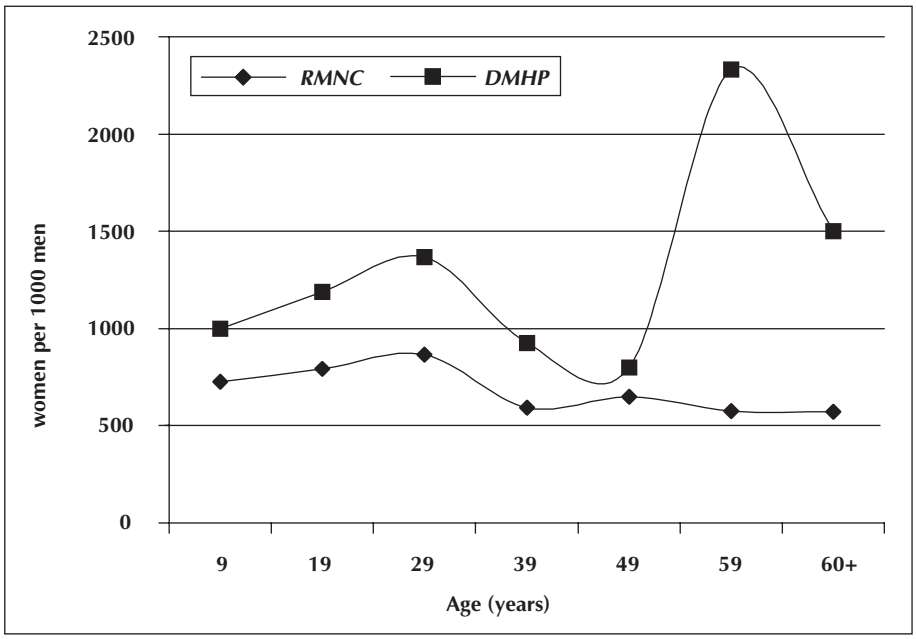

Figure 1. Age-specific sex ratio for women attending to tertiary (RMNC) and Community (DMHP) care services for epilepsy in Kerala State.

group (21-30 years). The mean age at marriage for women with epilepsy (22.0 years) is comparable to that for all women in Kerala State (21.9 years) (Thomas *et al.* 1999). Marriage and pregnancy-related concerns probably explain the higher SR for women in their third decade attending tertiary care facilities. In the tertiary care facility, the treatment gap widens further for the older women. One of the reasons could be their longer life expectancy (72.4 years) compared to men (67.3 years).

We identified three socio-economic factors that correlated strongly with a lower SR in the utilization of tertiary care for epilepsy: older age, lower economic status and greater distance between place of residence and the center. Proximity to the care center is likely to be an important determinant for utilization of services, especially for women. A survey in Australia has shown that use of community care services was higher among residents of highly accessible areas and public hospital use increased with increasing remoteness (Eckert *et al.* 2004). Patients' economic status was another significant determinant of SR in tertiary care utilization. Lower income groups had a lower SR at tertiary care centers. The majority of patients attending this center had to bear at least a part of the service charges and had to buy the medicines (Thomas *et al.*1996). Economic independence and social standing appear to have a profound influence on access to epilepsy care. Kerala State has the highest literacy rate for men and women in India, and women in general have a high social standing and economic independence (*table 1*). In spite of such favorable aspects, fewer women are attending the tertiary centre in this state.

There was only a marginal difference in the sex ratio for the Christian (742) and Hindu communities (736), but both were higher than that for the Muslim community (635). Christians and Hindus constitute 19.3 and 57.3% of the population in this state. Personal beliefs, trust and traditions influence the selection of health care facilities to a certain extent. In a study from Nigeria, Urban Igbo women preferred rural-based health services, probably because of belief in rural-based therapists' ability to cure conditions and affordability of the services (Izugbara and Afangideh, 2005).

A paradoxical situation existed in the community center where the SR was more in favor of women, especially the elderly. The community service was closer to the patients' domicile and provided services and AEDs free of charge. Low cost and easy access may be possible reasons for this second peak observed in the community center.

Women could go by themselves or with older women to these centers, while a male escort is often essential for traveling to distant tertiary care centers. Special community-based programs for women or elderly persons can indirectly influence the gender specific difference in utilization of epilepsy care. The late-life peak in women attending the community centers is again unlikely to be related ongoing programs, since there are no special programs targeting women of this age group. In contrast, women of childbearing age who are offered several special programs had a lower SR in the community centers.

There are few data on the gender-specific utilization of epilepsy care from India and other similar parts of the world. A survey in the UK has shown that people with epilepsy consulted health services twice as often, and were referred to secondary care three times more frequently than people without epilepsy irrespective of age, sex and social class (Gaitazis *et al.* 2002). Another long-term follow-up of a cohort of women with epilepsy (n = 59) revealed that significantly more mothers with epilepsy complained of physical infirmities, reduced body-related quality of life and more family stress events. They also tended to have lower education and employment (Titze *et al.* 2001).

This study has revealed a strong gender bias in the utilization of epilepsy care. More women with epilepsy tend to take advantage of community-based epilepsy services and fewer women attend tertiary care services. Few data are available on gender-specific differences in the etiology, natural history, and response to treatment of epilepsy. Further studies are necessary to ascertain the biological reasons for gender-specific differences in the utilization of epilepsy care. The treatment gap for women (at the tertiary level) is higher among the socially and economically underprivileged categories, and is worst among the elderly. Efforts to reduce gender-based treatment gaps need to attend to the socioeconomic aspects of the issue and should aim to provide the services closer to the place of domicile. Further, multicentric prospective studies are desirable to further explore the gender-specific differences in treatment preferences and service utilization for epilepsy. □

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