Better Mental Health Care for Older People in India

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ABSTRACT

Demographic aging will soon lead to a sudden increase in the number of older people with dementia and depression in India. We need to develop services to meet the mental health needs of the aged in the population. Geriatric Psychiatry section of IPS has initiated a process of consultations to address this emerging public health issue. Health professionals involved in the care of older people with mental health problems took part in focus group discussions. Their opinion and suggestions regarding development of psychogeriatric services and research were gathered. Urgent action is needed to improve the existing low levels of public awareness about mental health problems of older people. Home based care needs to be supported through formal services in the community. If sensitised properly clinicians, can be more effective in managing depression and dementia at primary care level. Research initiatives can be facilitated by networking of researchers and active efforts at dissemination of important research findings. Community health workers could be trained to identify and provide help to older people with mental health problems and their carers. Community outreach programmes for elderly could be particularly relevant in the rural areas where development of clinic based psycho-geriatric services may be feasible in urban settings. Good research can influence and shape policies which in turn can result in better mental health care for older people.

Introduction

Demographic aging will increase the prevalence of neuropsychiatric disorders and consequently the need for services, oriented to long-term care. Among the neuropsychiatric conditions, dementia and major depression will be the two leading contributors accounting respectively for one quarter and one sixth of all DALYs in this group (Murray & Lopez 1996). If the age-specific prevalence of dementia in developing countries matches that observed in developed countries, then by 2025 nearly three quarters of all cases would be living in the developing world, a total of 24 million people out of the estimated 32 million living with dementia worldwide (Prince, 1997).

Since infections and other acute medical problems continue to be major public health problems even now, health care services in our country, continue to be oriented towards the needs of acute episodic health care than that of long term care. This double burden of communicable and non-communicable diseases are going to make huge demands on the inadequate health care infrastructure in low income countries like India. Proactive policies and action plans are needed to tackle this challenging healthcare scenario.

Geriatric Psychiatry Section of Indian Psychiatric Society (GPS-IPS) has taken the initiative to start a process of consultations among the IPS membership to consider various strategies for improving the mental health of older people in our country. This paper describes an attempt to understand the opinions of mental health professionals involved in the care of older people. A qualitative method using focus group discussions (FGD) was used in this study to collect the views of these experts.

Method

A pre-conference workshop was organised along with the national conference of Geriatric Psychiatry Section of Indian Psychiatric Society (GPS-IPS) on the 13th of Dec 2003 at Thrissur. FGD was conducted on three topics namely “Mental health needs of older People”, “Development of Psycho-geriatric Services”, “Psychogeriatric Research in India”. The topics chosen were interrelated and it was hoped that the first FGD on “Mental health needs of Older People” will enable the participants to review the current as well as the emerging scenario in India and facilitate discussion on service development and research. Key themes were chosen for each topic at the beginning of the

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FGD and the discussions were held around those themes (See Table-1). There were twenty one participants. The list and details of participants are given at the end of the paper. Each FGD took about 90 minutes. Immediately after completion of the FGDs the notes were briefly analysed and the main findings were summarised. Main findings of the FGDs were briefly presented to a larger gathering of mental health professionals on the same evening for further comments and discussions. Prof. Venkoba Rao and many others who could not take part in the FGDs took part in the discussions and shared their views. The opinions thus generated were also documented. Detailed analysis of the notes were then made by SKS and AK, who conducted the FGD.

Table –1

| THEMES FOR THREE FOCUS GROUP DISCUSSIONS |
|-----------------------------------------|
| **FGD –1** “MENTAL HEALTH CARE FOR OLDER PEOPLE” | **FGD –2** “DEVELOPMENT OF PSYCHOGERIATRIC SERVICES” | **FGD –3** “RESEARCH IN GERIATRIC PSYCHIATRY” |
| Demographic Transition | Goal of Services | The need |
| Need for Psycho-geriatric Services | Identifying those in need. | Current status |
| Public awareness | Financial Aspects | Service Development & Research |
| Health Care Services | Services in rural & remote areas | Research Agenda |
| Importance of Home based care | Role of GPS – IPS | Role of GPS – IPS |

Results

All the participants of the FGD were health professionals working in different states of India. Out of the twenty one participants, there were twelve psychiatrists and seven post graduate students in psychiatry. One participant was a neurologist and the other a nursing professional with post graduate qualification in psychiatric nursing. Both of them are active members of the Thrissur Centre of the 10/66 Dementia Research Group. Two participants (SKS and AK) conducted the FGD; one facilitating the group while the other recording the proceedings, noting key themes and monitoring verbal and non-verbal interactions.

The first FGD on “Mental Health Care for Older People”

This topic was chosen to generate discussions on the current scenario in India. The main themes were (1) Demographic transition and increasing need for mental health services (2) Awareness about mental health needs of older people (3) Current care arrangements (4) Health care services (5) Home based care

According to the group, sudden increase in the number of older people India in the near future will translate into a growing need and demand for more services especially for long term care. However, regional differences are expected and the need will be more pronounced in states like Kerala & Goa which are ahead in demographic aging.

Though there are occasional campaigns by Non Governmental Organizations (NGOs) about dementia care and social issues like elder abuse, the public awareness about mental health problems of older people remains low. People are unable to differentiate mental health conditions from normal aging. The level of public awareness varies within the country and within various sections of the society. There could be rural urban differences as well as differences between northern and southern states. Within the country wide variations in the level of public awareness might affect the demand for services and be a barrier for service development.

Though dementia is a major public health problem, dementia care cannot be equated with psycho-geriatric care. The real task is to develop a range of psychiatric services than focusing on dementia care alone. Issues like stigma, non-compliance and caregiving needs special attention while deciding the ingredients of any intervention plan.

The group acknowledged the enormous and irreplaceable role of the families in providing care for older people with mental health problems in India. Home based care is the norm in our country and is remarkable that it meets the socio-cultural expectations of the people. Institutional care is neither affordable nor accessible to most people. This makes it clear that supporting and strengthening home based care should be the goal of community based psycho-geriatric services. At present, these families receive little or no help from the existing health services. Moreover, there are no special services for the older people in the public run health services in India.
The second FGD on “Development of Psychogeriatric Services”

The main themes were (1) Goal of Services (2) Identifying the people in need (3) Financial Aspects (4) Services in rural & remote areas (5) Role of GPS – IPS.

All participants were of the view that improving quality of life of older people with mental health problems and their carers should be the goal of psycho-geriatric services. Delivering interventions aimed at relief or reduction in symptoms will be crucial in attaining that goal. Provision for community based services is of crucial importance as otherwise services may remain inaccessible to those who need it most.

Strengthening and supporting home based care was agreed upon as a useful strategy. Development of clinic based services may not be of immediate relevance to rural settings where constraints of poor infra-structure had made general health care itself inadequate. Instead, development of Community outreach facilities for geriatric care will have to be considered. Geriatric care could be integrated to the existing community outreach services as well as the primary care services. Training health workers to identify disabling conditions like dementia and to provide simple home based interventions is a strategy which might be useful in resource limited settings especially in the rural and remote areas. Doctors working in the government run Primary Health Centres need to be sensitised, so that they identify older people with depression and dementia. This can be done as part of general training programmes aimed at improving their skills to handle health problems of the elderly.

Another strategy may be given priority in urban or semi-urban settings. Larger number of health care providers are available there and many old people tend to seek help. Attempts can be made to educate and equip these health care providers. We could consider giving them a brief training in order to help them to identify and manage common conditions like depression and dementia.

Everyone in the group felt the need to integrate psycho-geriatric services to the general health services. The training needs of the health care personal will have to be taken into consideration, while developing modules for such training. Financial commitment is needed to sustain services. Where will the money come from? Financial support will have to be ensured by getting proportionate budgetary allocation for care of the older sections in the population. Concerted effort by the families, NGOs and care providers at lobbying with the government may be required to get funds allocated for service development. Relevant information from research can be used to convince the policy makers about the need and cost effectiveness of such services. Private sector too, can play an important role especially in providing services to those who can afford to make out of pocket payment. We need to constantly explore the prospect of finding other sources of funding to sustain these services. According to the group it will be very hard to develop psycho-geriatric services in regions where general health care facilities do not exist and in remote areas which are not even covered by community outreach services.

The Group deliberated on the potential role of the Indian Psychiatric Society (IPS) in the development of psycho-geriatric services in the country. According to the group, the Geriatric Psychiatry Section of IPS (GPS-IPS) can take the initiative in identifying and networking clinicians interested in providing mental health services for older people. A status paper on mental health care of the elderly could be brought out by IPS after due deliberations. IPS could also consider bringing out documents like Guidelines / Fact sheets about management of common psychogeriatric conditions. IPS should take necessary steps to ensure that due importance is given to geriatric psychiatry in undergraduate and post graduate medical curriculum. IPS should be the advisor to central as well as the state governments on health care issues of the older people. It can act as a pressure group along with NGOs and other advocacy groups for the development services for older people. As an organisation which represents the clinicians involved in care of older people, IPS has an important role in the formulation of policies & programmes for older people, both at the national and state level.

The third FGD on Research in Geriatric Psychiatry.

The main themes were (1) The need for research (2) Current status (3) Service Development & Research (4) Research Agenda (5) Role of GPS – IPS

The group acknowledged its concern about certain limitations in research in geriatric psychiatry. Many participants noted the paucity of published research from India, especially on biological aspects. Quality research, apart from upgrading our knowledge, can also provide data which can be used in service development. This can also be used to build a strong case for development of services.
The group felt that there is an urgent need to strengthen the research capability in the country to generate better research output in geriatric psychiatry. More research in biological aspects of aging, mild cognitive disorder and dementia was proposed. It is important to generate good research questions by organizing workshops for people motivated to do research. Such workshops should also aim at equipping participants with research skills. It is hoped that these initiatives will be able to set a research agenda for the future.

Many centers could work together using common protocols to collect useful information from the clinical setting. Addition of research component to routine clinical work may enable centers to collect useful data that might inform and assist in development of better services. Such collaborations may prove, to be cost effective and need to be pursued.

Limitations in accessing published research is a problem which needs to be addressed. Access to research papers varies from centre to centre. It is even more difficult to have access to unpublished research data. It was pointed out that Geriatric Psychiatry Section of IPS can play a role in making relevant research papers available to members who need it. Similar assistance may be possible in getting rating scales and other relevant research tools. IPS could also assume an active role in dissemination of findings of relevant research in geriatric psychiatry in the country.

The group felt that large multi-centred collaborative studies on the epidemiology, course and outcome of geriatric psychiatric disorders should be given high priority in the research agenda. Proposals for such projects may be submitted to The Indian Council of Medical Research (ICMR) and World Health Organisation (WHO) for funding. Such studies will be able to generate data from nationally representative samples which then can be used as research evidence to formulate better policies. Well informed policies can lead to better services.

Discussion

This study used focus group discussions, a qualitative method for collecting the opinions of health professionals. Qualitative research has its drawbacks, notably limited generalisability due to the recruitment of small, convenience samples (Khan & Manderson, 1992). However this method of investigation can be of help in eliciting the opinion of various stakeholders while formulating policies and planning for new services. This attempt is only a beginning and will have to be followed up by wider consultations. Issues related to mental health of older people, needs to be deliberated upon by all those who are involved in their care. Potential users as well as providers of services need to take part in the process of service development and IPS had taken up similar initiatives in the past (Shaji et al., 2001). Geriatric Psychiatry Section of IPS has now initiated a process of consultations within the membership of IPS regarding psycho-geriatric service development and research. The opinions generated by the FGDs are reported here with the hope of facilitating further discussions.

Raise Awareness

The group recommended immediate action to improve the existing low levels of public awareness about mental disorders in late-life. Insufficient media attention compounded by lack of priority accorded to the health care needs of the elderly seems to perpetuate the current low level of awareness (The 10/66 Dementia Research Group 2000). This general lack of awareness has important consequences. Caregivers often do not receive the help and understanding that they require from family members and others in the community, and indeed are sometimes unjustifiably criticised for perceived shortcomings in the care that they provide. As long as the current low levels of public awareness prevail, even conditions like dementia would remain “hidden problems” (Shaji et al 2002) The demand for services will not become noticeable unless the awareness increases. In the absence of public demand, there will be no constituency to place pressure on the government or policy makers to start psycho-geriatric services. So there is an urgent need to raise awareness about mental disorders of late-life in the community and amongst health professionals.

Support Home-based Care

The family, obviously, takes on the responsibility of providing care for its older members. Co-resident carers are the key to long-term care. However, given certain circumstances, the care can be extremely demanding and can produce negative effects on the carer and other family members. (Shaji et al., 2003, The 10/66 Dementia Research Group 2004). Though most families are supportive, there is concern that both respect for older people and the caring traditions of the extended family are changing, rapidly. Narratives of conflict over finances and property, and reports of neglect and abuse of older persons are sadly commonplace.
& Prince 2001). The notion of the Indian family as endlessly supportive is not true, especially when faced with the huge demand of caring for behaviourally disturbed demented people at home (Shaji et al., 2003, The 10/66 Dementia Research Group 2004). Though these families need support and assistance in the form of formal health and social services, there is no provision for such help now. It is in this context that we need to consider development of psycho-geriatric services in India.

The pioneering work from Goa (Patel & Prince 2001) had shown that community health workers frequently recognized individuals with dementia, even when the primary health physicians rarely saw this condition in their clinical work. The Thrissur centre of 10/66 Dementia Research Group (Shaji et al 2002) had later validated a community case finding method in which the Anganwadi Workers were trained to identify cases of dementia. The prospect of health workers being able to identify cases of dementia and deliver simple interventions at home following suitable training is being actively pursued by the 10/66 dementia research group in their ongoing studies at Goa, Chennai & Vellore. We need to consider the development of a brief training programme for community health workers which will enable them to identify older people with mental health needs and facilitate their access to appropriate health care. Following this training these workers should be in a position to support and guide the families engaged in home-based care.

**Policy Initiatives**

There is a clear expectation that GPS-IPS can play a proactive role in facilitating both service development and research. A clear cut policy needs to be formulated and plans and programmes based on such a policy needs to be implemented. The National mental health programme will have to be suitably modified to meet the mental health needs of our aging population.

Development of user friendly services for the older people is a social need which will be increasingly felt in all developing countries in the years to come. Development of such services will require participation of all stake holders. Older people and their families need to take part in matters like service development. So it is important for GPS-IPS to initiate interactions between various stake holders like administrators, health care providers and the users of services etc.

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**Research Initiatives**

Psychiatrist will be increasingly called upon to provide care for older people in the future. More research is needed to strengthen our knowledge base. Findings from research can also guide service development. GPS-IPS should try to help by encouraging networking among researchers and by facilitating their access to published papers and research tools. People motivated to do research should be given training opportunities to improve their research skills. Wider dissemination of important research findings is another activity which demands immediate attention. Large multi-centred collaborative studies on the epidemiology, course and outcome of geriatric psychiatric disorders should be given high priority in the research agenda. Research evidence can be used as powerful tools to influence policies and to develop better services.

**List of Participants in the Focus Group Discussions:**

J.K.Trivedi, Lucknow; James.T.A Antony, Thrissur; E. Mohandas, Thrissur; Charles Pinto, Mumbai; Prof. K. Praveen Lal, Thrissur; P.Sivasankaran, Thrissur; A.G. Viswanathan (Retd Deputy Director of Health Services, Thrissur; K.R.Anandan, Thrissur; Mukundan, Thrissur; Shailaja, Thrissur; Alby Elias, Bangalore; V.N. Vasudevan, Bangalore; Smitha Patankar, Pune; Sachin Jindal, Bangalore; Mohit Trivedi, Mangalore; Uday Shankar, Naveen Kumar, Bangalore; Thomas Iype, Thrissur; Roy K. George, Kottayam; Arun Kishore, Thrissur; K.S. Shaji, Thrissur.

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K.S. Shaji et al

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