

# Need to Bring Family to the Heart of Healthcare as it is Home, not a Hospital, Where Healthcare Begins and Ends

Sanjiv Kumar, Pankaj Bhardwaj<sup>1</sup>, Neeta Kumar<sup>2</sup>

Chairperson, Three Domain Health Leadership Foundation, New Delhi, <sup>1</sup>Department of Community and Family Medicine and School of Public Health, All India Institute of Medical Sciences, Jodhpur, Rajasthan, <sup>2</sup>Faculty of Dentistry, Jamia Milia Islamia, Jamia Nagar, New Delhi, India

## Abstract

Today the patients and their families are ‘powerless’ recipients of healthcare services. The healthcare services are siloed and fragmented and getting worse with an increasing array of specialists and subspecialists who “patch up” patients and send them back home. It is important for healthcare providers to become involved in the process of health promotion, prevention, and recovery. For successful implementation of this family-level care needs to be recognized and integrated into all policies, guidelines of the government, and healthcare providers reoriented through in-service and basic training.

**Keywords:** Family care, government, healthcare providers

## INTRODUCTION

Modern healthcare suffers from an elite and colonial mindset. It considers healthcare as a “service” that can only be “delivered” to patients as “passive recipients” by experts. The patients and their families are powerless recipients of healthcare services. Their expected role is to carry out instructions given to them by “know all” healthcare providers. The healthcare services are siloed and getting worse with an increasing array of specialists and subspecialists. They “patch up” patients and send them back home.<sup>[1]</sup> The current mindset is to look at healthcare from the windows of health facilities, where all expertise exists. It ignores the reality that it is home, not a hospital, where health is produced and promoted, the disease is detected, is initially addressed with home remedies, and a decision is taken when and which facility to go to for treatment. Family members also arrange the funds for treatment. Even those who are entitled to “free medical care” through social insurance schemes such as Ayushman Bharat incur opportunistic expenditure which includes boarding and lodging of accompanying family caregivers, making alternative arrangements to look after the family members who stay behind, and taking care of assets left behind and the wages lost while on treatment. It is family members who

watch over their own health and that of their loved ones. It is important for family healthcare givers to become involved in the process of health promotion, prevention, and recovery. It will empower actors that are not experts but genuinely interested to provide loving healthcare at home and also as caregivers in health facilities.<sup>[1]</sup> This will not only improve health outcomes but also reduce the burden on the healthcare system. In the agriculture sector, food is produced in the farms by farmers. To increase agricultural production, the government empowers farmers. Similarly, health is produced at home, in the family, and by family members. Family-level health care is imperative to transform the current paradigm of sick care into true health care.<sup>[1]</sup> So, to improve health, we must recognize the role of the family and empower families as it is home where healthcare begins and ends.

## Even primary healthcare stops at the doorsteps of the family

The mindset of healthcare providers has also infiltrated

**Address for correspondence:** Prof. Sanjiv Kumar, Chairperson, Three Domain Health Leadership Foundation, New Delhi, India.  
E-mail: drsanjivkumardixit@gmail.com

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**How to cite this article:** Kumar S, Bhardwaj P, Kumar N. Need to bring family to the heart of healthcare as it is home, not a hospital, where healthcare begins and ends. Indian J Community Med 2023;48:209-13.

**Received:** 17-02-23, **Accepted:** 20-02-23, **Published:** 07-04-23

### Access this article online

Quick Response Code:



Website:  
www.ijcm.org.in

DOI:  
10.4103/ijcm.ijcm\_95\_23

into comprehensive primary healthcare which has received increasing attention after the Alma Ata Declaration of 1978<sup>[2]</sup> and national documents and missions such as the National Rural Health Mission 2005 and National Health Mission 2013, Report of the Task Force on Comprehensive Primary Healthcare, and current National Health Policy 2017. It aims at providing healthcare to the community at their doorsteps and not at home. The Alma Ata declaration defines it as “primary healthcare is essential healthcare based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation.”<sup>[2]</sup> The elite mindset is reinforced when Alma Ata Declaration says that the community is expected by the service providers to “fully participate” in what is decided for them. This is how the health system reaches out to people through primary health care.

Health institutions are the key players, and family is at the fringe of healthcare. People have the right and the duty to participate individually and collectively in the planning and implementation of their healthcare.<sup>[2]</sup> This thinking is also deeply ingrained in the national health programs, flagship health missions, and policy documents of the government. There is a need for a power shift in healthcare empowering and motivating individuals and their families to take complete charge of their health and make decisions regarding their health. This has a multiplier effect with the right information being passed around from family to family and across generations within the families.<sup>[1]</sup>

## FAMILY AND ITS IMPORTANCE IN HEALTH AND SICKNESS

Every individual is dependent on the family for remaining healthy and getting care during sickness. The family has been and will continue to be the most important social institution within which bonds of care and love are woven between the members. The family is the focus of all those interested in development including society, governments at the local, state, and national levels, international organizations, development agencies, academia, social welfare organizations, and civil society organizations. In recognition of the importance of family, the United Nations General Assembly proclaimed 1994 as the International Year of the Family. The theme of the year was, “Family: Resources and Responsibilities in a Changing World”.<sup>[3]</sup> This theme is very true for health as a family, and its members who are the most important resource in healthcare in the society. It influences the adoption of health behavior and provides care for both health and illness. The family through its members helps individuals to remain healthy through prevention and health promotion interventions, provides care to family members who fall sick, manages minor ailments, fever, cough, cold, and diarrhea etc. at home, and decide and take those who need medical care to health care providers for outpatient consultation. and support healthcare for those who are at home during illness, hospitalized, and convalescing after discharge.

Family plays an important role in keeping family members healthy, preventing disease, and adopting health promotion behaviors. Family’s role is also vital to support family members when they fall sick, seek timely consultation from appropriate healthcare providers, and nurture them back to health during the period of illness and convalescence. Health care is a team work with family being the most important team player. The COVID-19 pandemic gave a boost to family-level care to those who had mild disease. Even a large proportion of moderately sick received care at home.

The concept and scope of family keeps evolving. Today with the advent of technology, the family has expanded with the availability of mobile phones and the internet to connect with extended family members and relatives. In addition to the family members residing together, the family members in distant places are “virtually” present at home. They are available for support, consultation, and guidance on various social issues including health. The technology has also expanded the availability of health experts in the “expanded” family or social circle for advice to help decision-making at home.

To effectively improve health, curative care must extend from hospital settings to home. This will not only reduce hospital-acquired infections, iatrogenic complications, improve outcomes, maximize the benefits of care<sup>1</sup>, minimize family disruption caused by hospitalization, and reduce the burden on healthcare system and also bring down the escalating cost of medical care.

An analysis of data from 32 countries, estimated that globally women contribute \$ 3 trillion (~Rs 24.5 lakh crores) annually. In India families’ contribution to healthcare at home is estimated to be Rs 213,000 crores, with women contributing a major share of Rs 175,000 crores and men contributing Rs 38,000 crores.<sup>[4]</sup> This is more than the total government expenditure of Rs 169,312 crores, which includes the central government expenditure of Rs 63,256 crores and the expenditure of all state governments of Rs 106,056 crores on health in 2018–19,<sup>[5]</sup> as estimated in India’s National Health Accounts in 2022. This is a huge contribution to health care even in financial terms. This needs to be recognized and family members empowered to do more through capacity building including task shifting where appropriate.

## CONCEPTUAL FRAMEWORK OF FAMILY IN HEALTHCARE

The broad role of family in health and disease can be broadly divided into the following five groups:

1. Healthy individuals – Keep them healthy through health promotion and specific protection
2. Those who fall sick – Early diagnosis prompt home treatment and timely referral
3. Treatment/care of the sick at home under ambulatory care: Treatment compliance, early detection of danger signs, and seeking medical care at a health facility
4. Convalescence and rehabilitation to resume normal

- family, social and professional activities
5. Healthy individuals or those with controlled long-term communicable and NCDs – Maintain control of diseases. Keep them healthy through health promotion and specific protection. Prevent and monitor complications of the existing NCDs and prevent other diseases.

### ROLE OF FAMILY IN HEALTH AND ILLNESS

A large number of home care agencies have become available, which can provide even intensive care at home with specialist nurses available round the clock and specialist doctors on call, virtually or physically when needed. Table 1 gives a summary of family’s role in health and illness:

Easy availability of technology, its miniaturization, and availability from anywhere seamlessly, such as smartphones, has further empowered families to access credible sources of health-related information at home both in health and illness. More and more diagnostics and treatments will be carried out at home. <sup>1</sup> It also empowers to access information on where to go and whom to contact. They are more aware and ask which treatment option is suitable for them and why. Telemedicine for consultations online received a boost during the COVID-19 pandemic and this is going to continue.

#### What needs to be done to strengthen family capacity?

As family plays a vital role in care during health and illness, recognition of this fact and capacity building of the family needs more attention. It is important to understand the role of family in caring for family members with various health conditions. Figure 1 is an example of maternal and child survival interventions. In the first category, a large proportion of interventions are carried out exclusively at home where healthcare providers have very little role. The second category is interventions delivered by the system on fixed days at institutions or in the community. It is family members who take the decision to avail of these services. The third category

is individualized care in sickness or medical emergencies that cannot be scheduled. The health system must empower families to carry out interventions in the first category and take timely action for interventions in the second and third categories by educating the caregivers and decision-makers in the family [Figure 1].

At the family level, eating habits, health-seeking behavior, and physical activity are practiced. After treatment at a health facility, treatment compliance, early identification of complications, and timely self-referral are also implemented by the family. Studies suggest that the level of family involvement within health care also has a strong association with the use of health services.<sup>[6,7]</sup> Table 2 below summarizes what families can do in the healthcare of hypertension and what can be done at the community, primary, secondary, and tertiary levels.

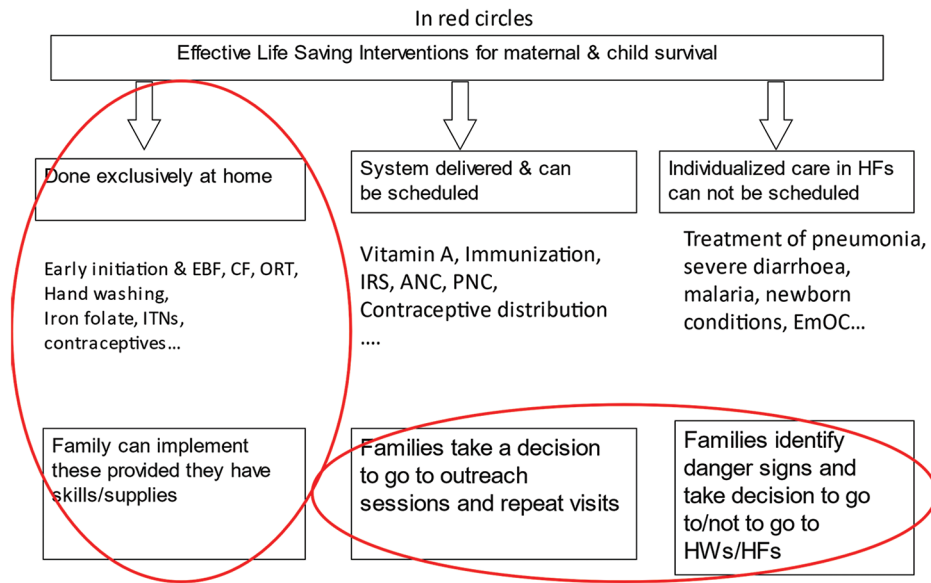
The role of family in life-saving interventions for maternal child health and in hypertension are given as two examples. Similarly, family’s role can be identified in all health problems This needs to be explained to family members. The treatment protocols for the management of health conditions should include family-level care. Healthcare providers need to become health coaches to build family capacity as well. The following need to be done:

**Revise national policies and standard treatment protocols and guidelines (STPGs)** to include the role of family: The existing policies, STPGs, and guidelines need to be restructured to emphasize the role of the family in promoting the health and care of the sick. The role of the family should be included in every health condition as is done for maternal and child survival interventions [Figure 1] and hypertension [Table 2]. The in-service health care providers need to be reoriented to include the role of family caregivers through in-service training.

**Restructure basic training of doctors, nurses, and all other healthcare providers to provide family-focused healthcare.** During posting in the Department of Community and Family Medicine, the students should be assigned families to take

**Table 1: Summary of the role of the family in health and illness**

| Healthcare components                 | Role of family in  |   |
|---------------------------------------|--|---|
|                                       | Health   | Disease   |
| Health Promotion                      | Diet: Food, type, quantity, quality, frequency, cooking, and storage; physical activity: what exercise, how frequently and Alcohol, tobacco, and drug use<br>Primordial prevention of risk factors | Maintaining the desirable behaviors as a nonpharmaceutical intervention in illness<br>Compliance to treatment<br>Prevention and early detection of complications and other diseases |
| Life course and inter-generation care | Desirable behavior and practices during pre-pregnancy, pregnancy, childhood, adolescence, youth, middle age, and healthy aging<br>Prevention of conditions such as LBW, risk factors               | Managing risk factors in those with diseases  |
| Traditional and sociocultural         | Dietary and other practices usually originating from Ayurveda  | Managing these practices in illness   |
| Early Detection of                    | Diseases and seeking prompt treatment  | Complications and prompt appropriate referral in various diseases such as Diabetes, Hypertension, infections, etc.  |
| Compliance to                         | Desirable health behaviors   | Treatment: Both nonpharmaceutical and pharmaceutical interventions  |
| Support to Care Givers                | Care of Caregivers and other family members  | Engage in hospital and post-hospital care including palliative care   |



**Figure 1:** Homecare for Life-saving Maternal Child Health interventions (in Red Circles)

**Table 2: Role of family, community, and health facilities in hypertension**

| Family level (1)  | Community level (2)   | Primary care level (3)   | Secondary and Tertiary care level (4)              |
|---|---|--|--|
| Promote Physical activities, healthy food, No tobacco use, alcohol intake, treatment compliance, Early Identification of complications and timely self-referral | 1 Plus<br>Educate the community about prevention and home care<br>Follow-up of patients | 2 Plus<br>Diagnose, Prescribe treatment<br>Identify and refer complications and Counseling.<br>Monitor cases at the family level through home visits by ASHAs and ANMs | 3 Plus<br>Appropriate management of referred cases |

care of and follow up till the end of their term. They should maintain family folders for keeping records of all families in urban and rural field practice areas.

**Restructuring Undergraduate and Post Graduate Medical Training** to empower and engage families in providing care to the sick. To achieve this, Community Medicine/Family Medicine/Preventive Social Medicine needs to include this in Undergraduate and Postgraduate training. In addition, postgraduates of all clinical specialties need to have a rotation/orientation in Community and Family Medicine (Preventive Social Medicine) Department. The government should consider restructuring MD in Community and Family Medicine rather than starting a new MD program in Family Medicine. For medical practitioners to be effective, they must be trained to become coaches who build family capacity in taking care of the health of their members to keep them healthy and recognize conditions early to seek appropriate care and become an important stakeholder in taking care during health, illness and convalescence. This can be done only if these practitioners have in-depth training in preventive and social medicine as applied to various health conditions at the family level. The foundation of clinical training by various clinical departments must be built on rigorous training in social determinants of health, prevention, and health promotions;

otherwise, the community disease burden will continue to increase.

MD (Family Medicine) is envisaged to be rolled out as a mix of clinical practice of pediatrics, medicine, surgery, orthopedics, gynecology and obstetrics, ENT, ophthalmology, etc., and it runs the risk of turning a family practitioner into a “jack of all clinical specialties, and master of none,” delivering these services at a clinic, outside a hospital, aping the western unaffordable healthcare model may not be appropriate for India.

All medical practitioners should address the needs of all phases of human life course to remain healthy through health promotion such as pre-pregnancy, pregnancy, early childhood development, child health and nutrition, health of school children, adolescents, youth, and middle-aged people, and healthy aging with a focus on maintaining good health rather than just detecting and treating diseases in these stages of human life.

**CONCLUSION**

Family, being the basic unit of society, plays an important role in the care of its members in promoting health and care when they become sick. If we want to reduce the burden of diseases

in India and improve the care of the sick, we must bring family from the fringes of the health system to the heart of healthcare. For successful implementation of this approach family level care needs to be recognized and integrated into all the policies, guidelines of the government, and health care providers reoriented through in-service and basic training. The new initiative of family medicine should build on a strong component of engaging family in health promotion and care of the sick.

### Financial support and sponsorship

Nil.

### Conflicts of interest

There are no conflicts of interest.

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