



PERSPECTIVE

We aim to cure – but do we think of care?

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Abstract

In the context of demographic and epidemiological transition, the pattern of diseases and the type of interventions needed to control these diseases, their risk factors and complications have radically changed from the earlier era dominated by infectious diseases and maternal and child health issues. In addition, the ability to care (both self-care and care by families) faces significant challenges in the current scenario. I argue that as healthcare professionals, we need to focus not only on the science of disease and its treatment but also on the context in which caring occurs. If not, the science we practice will fail to make an impact equitably.



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Introduction

India, as well as most of the world, has seen a dramatically changing profile of diseases. This is also known as the epidemiologic transition. This transition happens almost simultaneously with a demographic transition, which refers to the changing age patterns in a society. In the state of Kerala especially, there is a significant ageing of the population. As part of these transitions, there is now more disease burden from the so-called non-communicable diseases than from communicable and maternal and child health-related issues, at least in most of the states of India and at the overall national level [1]. In addition to this general trend, there is increasing evidence from the study of what is termed “syndemics” that there is a concentration of disease and disability among the most marginalised communities across the world, which is happening precisely in the context of weak health systems [2]. In addition to these more extensive disease, demographic and health system levels changes, there is also a significant change in the socio-economic status of populations with increasing inequity, concentration of wealth, and more precarious living conditions [3].

Traditional public health programs and the design of health care systems have evolved in the era where communicable diseases like malaria and tuberculosis and maternal and child health issues have dominated. These have thus been the focus of public health interventions and public policy. While these were undoubtedly needed, the central argument of this paper is that to deal with the present epidemiological transition, we need to not only develop newer interventions for these diseases but focus equally on health system design to provide these services to the community in a relevant manner. Within this overall argument, I will focus on the concept of caring.

My argument is that the present trend in India (and most LMICs- (low and middle-income countries)) of the shifting to the burden of non-communicable diseases and their associated risk factors reflects this trend. Research has shown that while in the early 60s and 70s, Diabetes and hypertension were concentrated among the upper classes and urban populations, there has been a gradual shift in this, with individuals in the lower socio-economic groups now having the biggest burden [4]. Another sub-theme in this research is multi-morbidity, where the risk of having multiple non-communicable diseases is higher (and happens in a younger age group) for those from lower socio-economic groups [5].

One of the primary arguments in this context is that the present disease profile depends not only on care provided in healthcare institutions but also requires a massive effort from the patient and her or his family to continue the various therapeutic interventions at home and in the community settings. Thus, the importance of various types of physiotherapies, diet regimes, exercise regimes, regular follow-ups, and biochemical monitoring (to name a few illustrative sets of interventions) has become part and parcel of any therapeutic intervention. While in the hospital settings, many of the services are provided by clinical and para-clinical staff, outside the hospital and in community settings (where a significant amount of caring happens), these services are the family's responsibility – either to provide or to source from other public or private institutions. Thus, while for diseases like malaria, typhoid, and other communicable diseases, the patient must consume a few tablets and illness is episodic, in the new scenario, diseases are lifelong and require not only continuous consumption of medications but also a range of other interventions, health education and significant material investments.

One of the key aspects of these non-communicable diseases are that they require a much larger proportion of self-care. In other words, there are a large number of interventions as part of the treatment that is required to be done by the patient themselves, like diet restrictions, exercise, giving up tobacco and alcohol, regular medications, regular blood check-ups and follow-up visits, titrating the doses of various medications, screening for complications etc.

However, these changing requirements are taking place in a particular context - one in which the health systems are becoming more and more privatised and more and more market-driven and commodified and therefore, the ability of the health system to be flexible and patient-centric is reducing, given the limited funds available in the public sector and the profit motive of the private sector. In other words, disease care is becoming increasingly decentralised and family-based, precisely when there is less public investment in healthcare, and people are having greater difficulty to shoulder the additional financial burden.

I believe that a productive area of research would be to look at the “work” that is expected to be done by those with NCDs, complications of NCDs and other chronic conditions to “keep healthy”. This is especially relevant in a world where resources and wealth are becoming increasingly unevenly distributed, making self-care and management of these conditions more difficult for many.

Several Dimensions are Important

One is simply the time available for self-care and how this differs systematically among the different classes. Thus, people who are employed permanently in regular positions vs. people with temporary employment contracts or daily wages have very different experiences of illness and ability to care due to leave rules and security of employment. The critical question is how much “time” and “resources” are required for an individual to follow the available scientific evidence to prevent

and treat non-communicable diseases and their complications. What are the competing uses of time, and how does available time vary with class, caste, and gender?

The literature from the field of economics on human behaviour describes the effect of poverty and stress due to the socio-economic status on the ability to make so-called rational decisions [6]. The literature shows how people in financial difficulty cannot make decisions that may seem logical to us as health professionals. In other words, mere health education or improving communication with patients about what needs to be done is insufficient without contextual factors enabling such behaviour. This, of course, is traditionally considered outside the purview of the health care system. So, the question is how do low SES and the fact that you have a chronic and incurable disease with life-threatening complications lead to a reduction of available mental bandwidth, and alternatively, how does living in poverty reduce bandwidth for effective planning for and implementation of the necessary interventions in one's individual life?

People may not be fully health literate for various reasons. Therefore, the biomedical institutions' language, objectives, and aims of treatment may differ from what the people themselves are expecting and articulating. This gap is something that needs to be urgently explored. In the literature, it is referred to as the hermeneutic gap. Closely linked to this is the ability of patients to express themselves and their priorities in the health care encounter – given the shortage of time, training and resources that are usually at the disposal of doctors and nurses.

Although we have made significant advancements in the field of science and developed various interventions to control diseases, all players in the healthcare delivery system must take an equal interest in ensuring that our society can implement these scientific discoveries. With proper implementation, the science available can benefit society, and the benefits will be distributed fairly.

One of the critical aspects of this debate is the answer to the question - does health care produce health? To answer this, we must differentiate between the provision of health care, accessibility of health care services, and the utilisation of these services. While each of these are well-recognized concepts and, to some extent, measurable, what is neglected or ignored is the ability of the individual (and the population) to benefit from these interventions/services. This is expected to be automatic - but we know it is not.

The restoration of health, including the treatment and cure of disease, depends on much more than the mere consumption of services. At a minimum, it will include:

- Reducing the risk of disease (and the recurrence) or progressing to complications.
- Accurate diagnosis - and in the case of syndemics, a comprehensive assessment and accurate diagnoses of multiple morbidities (for which the system may or may not have the capacity).
- Prescription of the appropriate treatment - both medical and non-pharmacological.
- The ability of the individual (and family) to follow these instructions and benefit from them.
- Have access to resources that enable the preservation of health while undergoing treatment.
- The resources for long-term-rehabilitation care and care required to get back to normal or prevent recurrence or enable full benefit from the intervention consumed (which includes the ability for full follow-up and rehab process).

Towards Conceptualising Caring as an Ethical Imperative

While much of the work in medical and public health care focuses on therapeutic, preventive, and promotive interventions, one area often neglected due to its relative invisibility is caring. Caring as a concept involves self-care and care provided by others to patients. Caring is essential to support patients with timely medications, the performance of various physical interventions, travel for follow-up, and sometimes even cognitive work of understanding the disease process and therapeutic regimens, as well as the emotional work of coming to terms with one's mortality and morbidity. In addition, as healers and professionals, we need to care for ourselves (and, of course, our families). Hence, the act of caring is ubiquitous yet sorely neglected. In this paper, I delineate some of the main aspects of caring, the impact of caring on health and disease outcomes, and some of the constraints. Health professionals need to acknowledge the importance of caring, raise our voices, and advocate for steps to facilitate the caring process. If not, I argue that all our efforts at therapy and prevention will remain sub-optimal and inefficient.

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